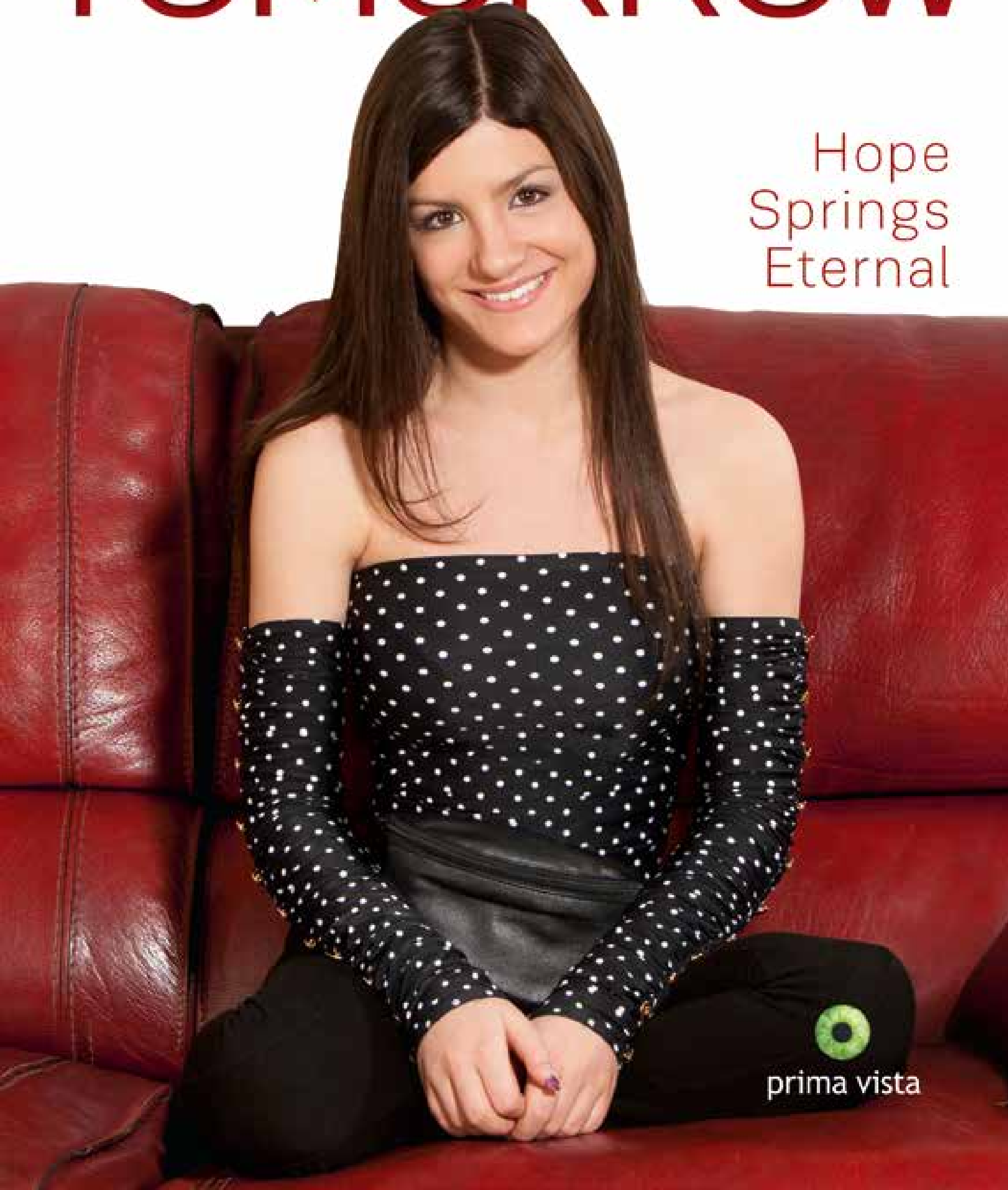
MALEEN FISCHER

AS IF THERE WERE NO TOMORROW



Hope Springs Eternal

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I DEDICATE THIS BOOK TO MY PARENTS,
MY HEROES:
MY MOTHER, WHO NEVER TOOK, BUT ALWAYS GAVE;
MY FATHER, WHO NEVER GAVE UP ON ME,
AND SAVED ME.
THEY TRULY ARE MY GUARDIAN ANGELS.

CHAPTER 1

Heaven can wait

So this is how dying feels. It is very still around me. Only the monotonous beeping of my heartbeat monitor conveys the assurance that I am not in another world. Oxygen is pumped into my lungs from the breathing mask strapped around my head. The elastic band is tight and constricts my chin. I have difficulty opening my eyes. My bed has been hydraulically positioned more upright to help me with my breathing. My upper body is in an almost upright position. It is a very strange feeling when strength is being continually sapped from your body. Somehow I manage to bring myself to open my eyes and look toward my mother. She is seated to the right of me on a chair. She is wearing a gray shirt and her hair is drawn back tightly, allowing me to see the glitter of her earrings. A good meter separates her hand from mine. A male nurse in a dark blue uniform is standing between us, pressing on a touchscreen. It regulates the amount of antibiotics being administered through the tubes that lead into my abdominal cavity.

Our gazes met for only a few fleeting moments, but they were enough for me to recognize the desperation in my mother's eyes. For the past 15 years we have spent day and night together. Every two to three hours she would come into my room and stand by my bed–every night, 365 days of the year. She wanted to be certain that the tube that led to my heart was still properly adjusted, that the pump that kept me alive was working correctly. Just one small mistake and my life would be over that very instant. She knows this. And that is why she always comes to my bed. Every night. From the very beginning we have fought this battle for my survival together. No task in the world can be more grueling than to try and keep one's child alive–year after year, 24/7. I know her expressions only too well and know when they are filled with hope, resignation, anger or fear. Desperation--this deep, sheer desperation, when hope seems to fade more and more–having to accept the inevitable, this expression I had never seen on her face before.

The room I am lying in is one of the three "terminal patients" rooms in the Health Park Medical Center in Fort Myers. Here patients are cared for when there is practically no hope of recovery. It provides them with a dignified framework to say their farewells to family and friends. Just the night before a critically ill seven-year-old girl died in an adjoining room. All the relatives were in the room next to her bed and were able to bid her goodbye.

I can only see a silhouette turning a knob on the tube leading to my tummy. The curtain is drawn back; the plastic blinds, with their terribly tacky serpentine pattern in grey, mint green and bright orange, which separated my bed from that of my boyfriend Dominik's and the chair that my mother spent most of last week on, are virtually no longer visible. The advantage of a "terminal room"–if one can actually speak of an "advantage" under such circumstances–is the fact that friends and relatives can spend the night with you. They can hold your hand and give you courage when life is continually seeping out of your body. To the left of my bed two large metal racks are standing on which dozens of tubes and bags with all kinds of medication fluids are hanging. All these things really have to go into my body? An adult has approximately six or seven liters of blood, and in these bags here there are three or four liters of fluid. Where is this all going to go? After all, I am only 1 meter 55 centimeters.

Since the age of three I have been fighting for my life and now, apparently, the end has finally come. When I was first diagnosed, doctors told my parents that I would have five years "at the most". The diagnosis: pulmonary hypertension, and there is no known cure. Too few people around the world are afflicted by this condition for the industry to be interested in research–well, at least that was the case back then. Our lungs normally function at a low pressure and a very low resistance. With pulmonary hypertension, when there is a great amount of stress, and later even in a relaxed state, a strong increase in pressure occurs. Thereby, the right side of the heart is continually pumping against a resistance–comparable to watering the lawn with a garden hose and holding the end of the hose closed. The heart continues to pump harder and harder. As a result, the right heart ventricle becomes larger and larger until the heart finally gives out and the patient dies.

Well, I am now 17 years old and have outlived the initial dire prognosis by many years. I have experienced a great deal in my life, wonderful moments as well as living everyday life in constant fear. But now, taking the last steps in my life, a time when the end is not only near, but also already palpable, I feel a kind of peace, a sense of tranquility and security taking away the fear.

It was on January 28, 2013 something happened that brought me to this desperate, final situation. My stomach suddenly started hurting so badly that I thought it was going to burst. My father Gerry was in Austria at the time, where he operates the Vienna "Schnapps" Museum, a small private museum on the outskirts of the city that is primarily visited by tourists and tour groups. While I am residing with my mother in Florida he has to make money in Vienna. In desperation I called him, crying and screaming, "Daddy, I am in such terrible pain, I'm going to die! Please believe me. Please help me!"

He tried to calm me down. "You will see, Mommy will get some pain medication from the drugstore; it will help and tomorrow you will be feeling much better."

My boyfriend Dominik was with me, holding my hand. We had only known each other for three months, but what we were to experience over the course of the next three connected us like an invisible bond that never can be severed.

After a few hours I had to throw up and vomited green bile. The seriousness of the situation was evident. My mother immediately took me to the hospital in Cape Coral. It was after midnight. The nurse on duty termed me "not an emergency", so we had to wait for a total of six hours before a doctor even examined me. I spent hours bent over in pain screaming, but no one wanted to help. "Stay calm," they said over and over again to my mother and me, even threatening to call the hospital security. The diagnosis provided by the examining doctor, Dr. Grey (name has been changed, but he was suspended a week later for a "not further disclosed" incident) was precise and considered my condition generally not very serious: I had a kidney infection, caused by a bacteria that affected the mucus membrane of the renal pelvis as well as the surrounding connecting kidney tissue. This is accompanied by fever and severe pain. What is already terribly painful for a "normal patient" can, in my condition, lead to a life-threatening situation.

Because of my serious illness my immune system has been badly weakened. That is the reason I am forced to have as little contact with strangers as possible. I did not see a classroom from the inside for the first 14 years of my life. I was home-schooled. The risk that a simple cold or the flu, something that occurs regularly in every school, could pose was just too high and according to my doctors, a very real threat to my life. Going to a playground to play with other children? I was never allowed. The threat of an infection through the implanted tube was just too high. Visit with girlfriends? Much too risky. Going to a pop concert like other girls my age do, swimming or going to a pool in the summer? No way. My entire life has been determined by rules, prohibitions and imminent dangers. But so what–I am alive! I should have been dead long ago. Therefore I want to savor every day. This is how I deal with my illness.

And now this: a kidney infection (pyelonephritis). The doctors, however, were upbeat and convinced they could get the problem under control with antibiotics. I kept telling them they should have a look at my appendix. My mother repeatedly told them the same thing. After an ultrasound test the doctor told us my appendix was "okay"–a serious misdiagnosis, because it was not even possible to see my appendix on the ultrasound. Later we found out that I had an anomaly, because my appendix was pointed upward toward the heart and not, as was usually the case, downwards. So being prescribed some antibiotics I was released and allowed to go home (home in this case being Paradise Cove, my parents' small, quaint house in Cape Coral in the vicinity of Fort Myers, Florida that they have rented for the past several years). This came about after doctors told my parents that the winters in Austria were much too dangerous for me–the risk of a simple cough endangering my life was just too high and so my mother and I have spent most of the winters in Florida. I love this little patch of land, which in the meantime has really become my paradise. With its west-facing location, one can spend many sunny hours on the terrace even in the "winter" wearing only a t-shirt. This is my idea of happiness.

The morphine shot that they gave me to ease my pain before releasing me only attained its full effect as we returned home. I was no longer in pain; however, it did nothing to alleviate the real cause of my illness. A few hours later I was again writhing in pain in my bed. I could not even get up and go to the bathroom by myself, because the pain was so intense. I twisted from side to side to try and find a position in which I felt less pain. Then something completely unforeseeable happened. The following night the pain suddenly subsided. I was relieved and finally was able to fall asleep. The antibiotics seemed to be taking effect.

That was, until I awoke early in the morning. The pain was even more intense than the evening before. It felt like my stomach was about to explode, like an invisible hand had entered my body and was trying to rip out my insides. I have become accustomed to pain but this was even too much for me. Dominik carried me from my bed into the living room. I was bent over, screaming with pain. My whole body was shaking. I looked at Dominik and said, "Darling, I am dying!"

My mother grabbed the telephone and called emergency, yelling into the receiver, "Come quickly, my daughter is dying!"

The emergency dispatcher immediately put her through to the paramedic driver, who already was on his way to our house, and over the next four or five minutes she explained the situation to him: pulmonary hypertension, first aid kit and tube cannot be removed under any circumstances–regardless of what happens. I continued to scream, because the pain was so intense. My mother was in panic and raced to open the front door so that paramedics could enter the house immediately. Dominik pressed himself tightly against me and prayed. With its siren wailing, the ambulance stopped in front of our house only eight minutes later. Three paramedics ran into our living room and immediately recognized my extremely critical condition. The youngest paramedic, probably in his early twenties, only uttered two words: "Oh shit!" He lifted me from the sofa, put me on the stretcher and just two minutes later we were racing off to the next hospital. It was the Health Park Medical Center of the Lee Memorial Hospital in Fort Myers, about 10 kilometers away. My boyfriend had to stay behind, because only one person was allowed to ride in the ambulance. He arrived with a friend a bit later. My mother had to sit on the passenger seat in the front of the ambulance, as the paramedics were afraid that they might have to do a tracheotomy during the ride.

I was gasping for air, my pulse was racing, my heart was beating much too fast. A paramedic put an oxygen mask over my face and pumped air into me. He told me, "Please calm down. Breathe very slowly. Think about something soothing; otherwise I will have to open you up to do a tracheotomy." That worked. I thought about my grandmother Tati, and how we made pancakes in the kitchen, as I tried to calm myself and breathe very slowly. In the meantime the second paramedic shoved ice packs under my back, as my body temperature had risen to over 40 degrees Celsius.

Fifteen minutes later the ambulance arrived at the hospital. A team of emergency doctors was already waiting. Around ten doctors, paramedics and nurses led by Dr. Joe Genaro Diaz, an emergency physician with over two decades of experience, quickly took charge of the proceedings. I was immediately taken to the trauma room. A young doctor quickly cut open my mother's pink-grey t-shirt that I was wearing. A vein catheter was immediately inserted into the crook of my left arm. A nurse, however, forgot to fasten it and simply set the cuff of the blood pressure monitor on the middle of the needle. In the meantime Dominik had arrived at the hospital and entered the room just at the moment another nurse pressed on the button of the blood pressure monitor. Immediately the needle stuck in my arm shot out into the room and a large stream of blood from the crook of my arm where the needle had been soaked his t-shirt. "Are you nuts?" screamed Dr. Diaz at the nurse. Dominik, whose t-shirt had been soaked by my blood, sat down calmly next to me and, without saying a word, pressed my stuffed frog into my hand–my lucky charm that has been my companion since my earliest childhood and has experienced every traumatic situation in my life with me. A few seconds later, my blood pressure sank dramatically. The EKG showed flickering waves, about 500 per minute. They brought me back with a defibrillator. This device shoots electricity through the body in order to stimulate all heart muscle cells simultaneously, and normal heart muscle activity is restored. I regained consciousness. Even if I was not in this world for a few moments, but on the way to another one, I did not experience any of the usual symptoms. No tunnel, no white light, no hovering above my body–nothing that I can recall today.

They continued to ventilate me and shortly thereafter they were able to determine that the original diagnosis–the one that had allowed me to go home just a day-and-a-half ago–was wrong: I never had a kidney infection. But what was it?

At this point it became apparent to the doctors that my survival chances were minimal. They called a clinic in Miami that specialized in pulmonary hypertension cases and wanted to transport me there via helicopter. Dr. Diaz was against this measure. "She will never survive the flight!" he said to a colleague in the room. My parents heard this, as did Dominik and I.

Dominik…I could never survive all this without him.

CHAPTER 2

Can you hear my heart beat?

I have known Dominik's mother Irene for four years. She attended an art opening for our pulmonary hypertension initiative at which prominent Austrian personalities such as Franziska Meinl, Fiona Swarovski and Irene donated their paintings for auction. She was wearing very unusual over-the-knee boots that I liked so much that I asked her about them. We talked for a very long time and immediately took to each other.

Irene and I have stayed in contact over the years, sometimes chatting via Facebook, until she moved to London and we lost sight of each other.

Then, one day I received an email inviting me to her daughter Mariella's fashion show. She is a 24-year-old designer who, in October 2102, was presenting her collection to a large audience for the first time. I agreed to come, not knowing that this evening would change my life. The show took place in a white tent in front of the Vienna Museum Quarter. My mother Benita and I received seats in the first row. Diagonally across from us, Irene sat next to a young, very handsome man. He smiled at me and I grinned back. He had steel blue eyes, a very masculine face, and was wearing a black sweater. His glistening bald head reflected the spotlights. The show lasted for almost half an hour. As the applause died down Irene came over to us. We exchanged hugs and she said, "I would like to introduce you to my son Dominik."

So this handsome young man was Irene's son. We chatted for a bit and then she said, "Later, you must come to Mariella's after-show party, because she also is celebrating her birthday today." I looked over to my mother and she nodded in approval, and so I said I would come.

Two hours later I was standing with my mother in front of an old Viennese palace where Mariella's party was just starting. About thirty close friends had gathered and music was cool–House and Soul. Dominik was waiting for me at the entrance. "I wasn't aware that you have known my mother for such a long time. She has told me a lot about you," he said and ordered a Coke. His best friend, also named Dominik, joined us. We didn't stay for long. Large groups of people don't appeal to me. After thirty minutes I walked toward the entrance with my mother. Dominik stopped me. "I'll write down my name for you, and you can add me to your friends on Facebook," he told me with a bright smile on his face. He pressed the piece of paper into my hand, gave me a hug and a soft kiss on my cheek, and then left.

This night I remained awake for a very long time. Somehow, he had touched my heart. It is not often in life that one meets a person to whom one feels close to from the very first moment–where one feels a sense of security that just cannot be explained. It's like two souls that meet in one life, and in the next one, as well.

First thing in the morning I went on Facebook and wondered, Should I make contact? Finally I decided to send a friend request. An hour later I received the confirmation. I wrote him via the chat option, a few friendly lines: "Let's meet up." Dominik responded quickly. A week later we went on our first date. We went to dinner and immediately connected. As I liked him a great deal, I wanted to tell him all about my illness. I have always been straightforward.

However Dominik immediately interrupted. "Everything I need to know my mother has already told me. There is nothing that bothers me, nothing at all."

Over the next three weeks we repeatedly saw each other. Each time we met, we grew closer. On our fourth date he invited me to his apartment. He has a very quaint old apartment in the third district of Vienna. I was surprised how tastefully it was furnished and how neat it was; after all, he is a bachelor. Dominik is a very meticulous, conscientious person. One can see this by the way he lives. In the living room there was a very large gray couch on which we sat down. We nestled comfortably into the red velvet pillows. Dominik asked me, "Should we give us a try?" I put my arms around him and we kissed.

These first weeks with Dominik were so wonderful, gradually getting to know each other, the first affectionate moments, but this all came at a very inopportune time. Only two weeks remained before I was to leave for the United States, not for a short time, but for six long months. I looked at Dominik and asked him, "How do you see this working? I will be in the USA for almost six months."

"Let that be my problem," he said "I will join you soon." We saw each other virtually every day before my pending departure. We dined together, went for walks and to movies, and spent almost every minute with each other.

The last two nights before I was to fly to the U.S., Dominik spent the night at my house. We got up early and he brought me to the hospital for my last check-up. He sat at my side throughout the examinations. Then, all of a sudden, it was the morning of my departure. We embraced affectionately. "I will see you very soon," he whispered in my ear. As my taxi turned the corner he was still standing on the street waving to me.

Two weeks after my arrival in the United States, Dominik was ready to come over. My father drove me the three hours from Cape Coral to the airport in Miami. I had butterflies in my stomach. Was he really on the plane? Had he changed his mind at the last moment? I waited. Never has an hour seemed longer. I was extremely nervous. I cannot describe my feelings the moment I saw Dominik exit from the baggage claim. We embraced for minutes, a blissful eternity. It was one of the most wonderful moments of my life.

Dominik stayed with me for three weeks. It was the first time he had been in the United States. We took walks along the beach in Fort Myers, ate fast food at the grill around the corner, shopped at the typical American malls, sat in the sand despite the cold and looked out at the ocean, silent but bonded. We even bought Christmas decorations together. My mother had the bright idea to give us two plastic Christmas trees, under the condition that we decorate them. She drove us to a Dollar Tree store. I was so embarrassed that I wanted to crawl under the car seat. However, Dominik has a great sense of humor and enthusiastically played along. He decorated his Christmas tree with a great deal of red and gold. Mine glistened in a noble blue.

That evening I showed Dominik my favorite restaurant in Cape Coral: Brew Babies. Every Friday they had live jazz music. The tables are made of thick wood, the tablecloths are a sparkling white and the glasses made of heavy lead crystal–very unusual for America. I introduced him to the owner and his children. We ate ossobuco with mashed potatoes and Chicken Marsala.

We spent most of our time at home. Because of the holidays, high school had not yet begun again; therefore I did not have to get up in the morning to go to class. It was a very carefree time–just him and me.

On December 23rd Dominik flew back to Vienna. “I will be back soon,” he promised me at the airport. He would keep his word.

Two weeks later he came to see me again. He wanted to stay for three weeks, but extended his stay. School starts at 7 a.m. in the U.S.; therefore I had to get up at 6 every morning. Even though I told Dominik to stay in bed, he got up with me every day. While I was in school he went running, did other sports activities and even signed up at the L.A. Fitness Center located close to our house. School was out at 2:30 p.m. every day. He often picked me up with my mother directly from school, which was situated only about 10 minutes from our house. We spent the afternoons together.

Dominik is an extremely altruistic person. Whenever someone needs something, he will try his best to help. I can rely on him 100%. He not only is very reliable, he is also a perfectionist who loves to read. He is interested in history and Greek mythology and knows a great deal about computers. As a child he was quite a rebel, dividing his time between his father in Steyr (Upper Austria) and his mother in Vienna, as his parents were divorced very early on. Dominik has two siblings, his sister Mariella, who is 24 and his older brother, Philip who is 26.

Two wonderful weeks remained before the horror scenario was to unfold. That only three months after our first meeting, Dominik would be sitting be sitting next to me, holding my hand and praying for me in a palliative care room in a American hospital was the last thing we would ever have envisioned.

CHAPTER 3

The harsh reality

An administrative staff member interrupted the doctors with a question about who would take responsibility for the costs. This is a determining factor for the treatment you will receive in a hospital in the United States. If you can pay, then they will do everything humanly possible to help you. If not, they will only stabilize you and let fate take its course. My mother dialed my father's cell number in Vienna and hastily explained the situation to him. She yelled into the phone, "Gerry, you have to do something!"

He replied in one sentence: "I will take care of it." My father immediately called the hotline of the Europäische Reiseversicherung (European Travel Insurance). Thank God we were covered by this travel insurance, because where else on a Saturday night can one, in a matter of minutes, get a cost guarantee? The insurance company immediately contacted the doctors in Florida. Thirty minutes later they directly contacted the hospital administration and confirmed via fax that all costs were covered. From this moment on everything was possible.

The company's medical consultant called my father back and informed him, "Your daughter is very, very ill. You have to be prepared for the worst and I would advise you to catch the next plane to the United States. You have to take care of your wife."

My father raced to the airport and boarded the first plane bound for Florida. "It turned out to be the longest 15 hours of my life," he later told me. "No telephone, no text messages, no email–and the indescribable worrying if I would ever see you alive again…"

The doctors needed the ensuing six hours to stabilize me enough to allow them to do a CAT scan. My condition was still life-threatening. After the CAT scan it was clearly evident what the doctors had overlooked only two days earlier. I had acute appendicitis. An infection of the appendix can lead to a rupture. Children are often affected by this condition, and generally it is a routine operation that barely takes 20 minutes and can take care of the problem; however, in my case it became life-threatening. My appendix had ruptured–the worst possible complication. The massively infected appendix ruptured during the night, and this was the reason the pain in my underbelly subsided for a short period of time. The built-up pus had spread throughout my underbelly which, for a short period, provides relief for the swollen colon, but can result in death. Because feces and dangerous bacteria entered my underbelly, it led to severe peritonitis. It worsened to such an extent that I went into septic shock.

All my other vital organs were starting to fail as a result of this, severely threatening my life. My skin turned very sallow and became moist; even though I still had fever, my systolic blood pressure–generally between 120 to 130mmHg–suddenly fell to below 70mmHg. Briefly it was even at 50/20. A circumstance that is life-threatening even for a healthy person looked like it was the beginning of the end for me.

The doctors reacted quickly and immediately started a dialysis and finally decided to do a blood transfusion in order to get the sepsis under control. Actually, an immediate operation was required, but my blood circulation was just not stable enough. The surgeon on duty refused to do it, as he thought I would not survive the operation.

They moved me from the trauma room to the "terminal room". Later the doctors told me that at this point they really did not believe I would survive the ordeal. They inserted a large catheter into a vein in my right leg. I received one blood bag after another–altogether they repeated this procedure seven times. This was very dangerous, however, because these transfusions washed the prostacyclin, Flolan, that was being injected into my heart every thirty seconds out of my body. This could lead to a heart attack that, in my current condition, most likely would have been fatal. Therefore the doctors decided, in accordance with my mother's suggestions– after almost 15 years she knows more about my illness than most physicians–to provide me with transfusions as well as Flolan at the same time, adding the pros-

tacyclin every 30 seconds to the fresh blood infusions.
Dr. Diaz took my mother under his wing, as her anguish over the situation was overwhelming. He told her that a friend of his was a good surgeon to whom he would entrust his children without hesitation and who also worked at the hospital. "Should I wake him up?" he asked her.

"Please do it–and whatever else it takes to save my daughter's life!"

Just a short time later–in the meantime it was 2 a.m.–Dr. Rodrigo A. Mon came into my room. He is a short, very handsome doctor in his mid-thirties, born in Puerto Rico, who has made a name for himself in Florida as one of the leading pediatric surgeons. Dr. Diaz and Dr. Mon retired to a conference room for a good half hour. Dr. Mon then came out and spoke to my mother. "I will do it, but only with my own team." She took his hand, squeezed it very hard and thanked him. One thing was certain: the operation was my only chance for survival. Dr. Mon, contacted his anesthetist and two operating room nurses. All were at the hospital twenty minutes later and introduced themselves to me.

"Don't worry, we will make sure everything will turn out for the best," the anesthetist soothingly told me.

It was shortly after 3 in the morning. My lips were dry, I was terribly thirsty, but the doctors refused to let me drink anything.

A nurse only wet my lips with an ice cube. Dominik continued to sit next to me, very calmly, and held my hand. Dr. Mon once again spoke to my mother. He explained to her that he needed a period of at least thirty minutes during which my blood pressure must be stable and the blood parameters must be close to normal levels in order to attempt an operation. He and his team would stay at the hospital and immediately be contacted the moment these prerequisites were achieved. Dr. Mon bid her good night and with his entire team went off to get some sleep in the clinic.

I was given a blood test every twenty minutes throughout the night until morning. I was extremely tired, but they kept me awake through various procedures. I was not allowed to fall asleep–a stipulation set by the doctors. This was due to the fact that in my precarious condition the probability that my lungs would collapse and I would die was just too great. Dominik told me soothing stories and repeatedly told me that he would stay with me, no matter what.

Finally at 10 in the morning it was time. The blood parameters appeared to stabilize and met the requirements. The station quickly became very busy. A few minutes later we were in the operating room. "There are two procedures to be considered," Dr. Mon explained to my mother and asked for her consent to operate. "One opens up the entire abdomen, something I really want to avoid with your daughter, because the danger is just too great that her cardiovascular system will collapse and she will die on the operating table." My mother took a deep breath. "What I will do is a micro-invasive operation. I will enter through the belly button and two other points and will attempt to remove the pus and the appendix. This operation should not take longer than 30 minutes in order not to unnecessarily burden her cardiovascular system." My mother signed the consent form, without reading a line of it. "Let's go," Dr. Mon said to her.

My mother–who has gone through so many low points with me, who has stood by me in numerous life-threatening situations, who worried and suffered with me during my darkest hours–was now virtually paralyzed by fear. She gave the operating nurse the back-up pump filled with fresh medicine for me.

As I was rolled toward the operating room my chances of survival were the worst imaginable. A seriously ill 17-year-old with a ruptured appendix, an inflammation of the abdominal cavity, a septic shock would generally be considered a fatal diagnosis for even a healthy person. However, when the young girl also is suffering from pulmonary hypertension and her life is dependent on a pump–how can such an operation be performed successfully? What really are her chances? Three percent? Five percent? Maybe ten?

They rolled me into the operating room. At the entrance stood the vice-principal of my school, Diana Breen, and the intensive-care nurse, Gina Fair. Both took my hand for a few moments and said that they would pray for me. My mother had called the school the day before and explained why I could not attend classes. Both had dropped by to give me courage and provide support for my mother should I not make it out of the operating room alive.

At the very instant I was put onto the operating table the principal of our school, John A. Cavell, asked everyone in our school to pause for a moment. He made an announcement to the entire school. All 370 students began to pray for me.

The emergency operation lasted for approximately two hours. Dr. Mon was able to remove the infection source in my stomach. He removed the ruptured appendix and cleaned up the peritoneum with a saline solution and antibiotics, paying particular attention to the infected areas, and inserted tubes into my stomach, before he stitched me back up. With the tubes it was possible to continue to irrigate and inject antibiotics for a few days after the operation.

Dr. Mon spoke to my mother and told her that the operation was a success, but that a new, serious problem had developed: "She is no longer breathing on her own. Only the respirator is providing her with air." Even though my blood pressure was stable, the first signs of a massive organ failure were being detected. The gastro-intestinal tract and the diaphragm were no longer functioning. My doctors were considering giving me an artificial bowel outlet. I don't know how, but somehow, even in my virtual delirium, I overheard them discussing this procedure.

A few moments later, my intestines started to work again.

During this perilous phase the “respiratory team” was called in–a fully independent unit operating in virtually all American clinics and specializing in the respiratory function of patients. A doctor from the team sat down between my bed and a very large machine that they had installed in the room. With his headphones and a computer screen he continually monitored my lung activity and checked to see if he could detect any resistance by my lungs to the machine-induced breathing. He sat next to me for eight hours before he was able to confirm a resistance. I was conscious; therefore I was able to hear everything. He said to my mother, “We will not get many chances to get her breathing on her own. If we cannot succeed, then she will need a respirator for the rest of her life.” I was receiving 100% oxygen. The doctor exactly explained to me what they intended to do. This procedure concerned the tube that had been inserted into my mouth and led down to my lungs and was providing me with air. It had to be ripped out at the right moment. Before this was done, he had to insert a feeding tube through my nose while I was fully conscious. This was necessary to insure that no stomach fluid could trickle into my lungs during the split second of the aforementioned extraction. This would most likely have fatal consequences.

Inserting the feeding tube was a relatively harmless. It certainly was very unpleasant, but nothing more. Before the respirator tubing was to be ripped out of my trachea, five members of the team were posted around my bed. Each one had a special task. The doctor was to pull the tubing out of my body. At the same moment a lung specialist would, from the back, place a helmet-shaped breathing mask over my entire head, while a second member of the "respiratory team" adjusted the pressure ratio on a monitor. As soon as the pressure was set–which would take two minutes–it was Dominik's task to get me upright in order to lift me out of the bed from the side, so that I could stand. Another nurse had to roll the metal racks containing the prostacyclin and the pump alongside me on the right, while to my left the respiratory machine on rollers was being moved. It was my mother's task during this multifaceted process to ensure that my leg catheter and the tubes from my stomach would not be ripped out. This was the plan. However, there was one catch. The doctor told us, if we were not able to reactivate my breathing within the first fifteen minutes the probability of me having to remain on a respirator for the rest of my life was very high. Therefore, it was absolutely essential to get me on my feet and force me to walk by myself, regardless of how much pain this would cause. Nothing could replace the kind of "shockwave" caused by my walking, which would jolt my lungs into functioning again. The simple fact was that fifteen minutes would decide the rest of my life. I did not doubt for a second that we would succeed.

I have known pain since my earliest childhood and, I guess you could say I have almost become accustomed to it. But the pain caused by the "ripping out" of the breathing tube from my trachea is something I had never experienced before and sincerely hope I will never have to experience again. I flailed about wildly and hit Dominik in the middle of his face. I tried to kick the doctor and tried to scream as loudly as possible, but the mask that had been pressed onto my head muted the screams coming out of my mouth. The lung specialist, who I almost kicked, yelled out, "Let her rampage, it's good for her lungs!"

With the last strength I had left, I was forced to drag myself through the hall. They dragged me through the lobby. The other doctors and nurses who were observing this wild spectacle started applauding and yelling, "Go girl, go!" So something like this does not only happen on "Grey's Anatomy"–this is really America. After two rounds it was over. Five minutes later I was back in my bed in the intensive care unit.

"Don't say anything," my mother whispered to me. "Everything will be all right."

After battling so long against that enemy in my lungs, I should die from a stomach infection? Not me. I want to live. Heaven can wait. I still have things to do.

CHAPTER 4

I can hear you

I am still here, or already somewhere else? I don't know. The hours and the days just seem to float by and disappear. I have aware moments and then I just think I am dreaming.

I hear my parents talking among themselves and with the doctors. I hear the nurses and hospital staff attempting to give my parents hope. I hear my father calling me "his little lioness." I hear all this but cannot respond. The breathing mask sits like a lead weight on my mouth and hinders even a syllable being uttered. I feel paralyzed, yet I am aware of everything around me. Is this what they mean by a near-death experience? Or is it just a light sleep and I can register everything around me? My parents and my boyfriend Dominik will tell me later that they were absolutely convinced I was in a deep sleep and was not able to hear anything. They only believed me after I reminded my father of his promise to me. He had promised to go shopping with me when I was healthy again and to buy me a Balenciaga bag. I had seen it in Vogue magazine many times and this truly beautiful cult object has always fascinated me. It is a fitting testament to the creative tradition of the haute-couture designer Christóbal Balenciaga, who passed away long before I was born. They are so terribly expensive that I never would have even dared to wish for one. But what all wouldn't a doting father promise when he is desperately worried about the welfare of his daughter?

It was the morning of February 4, 2013 when I awoke and finally felt whole again. I am still lying in the intensive care unit, but I finally feel a strong sense of hope inside me–things will get better. I am lying in a special bed that can be hydraulically adjusted in the front and the back up to 45 degrees. It gives one the feeling of swinging while lying down. The bed, the doctor explained, improves pulmonary gas exchange, as it simulates body movements in order to increase circulation and stimulate the lymph nodes, raise the oxygen levels in the tissue, loosen lung secretion and hinder an edema from forming. "George Michael had the same bed while he was a patient at the Vienna General Hospital (AKH)," my father told me and, from the way he said it, sounded as if he was quite proud of this fact.

I still have fever and can only remove the breathing mask for very short periods. Nothing is really possible without the right amount of oxygen after such a difficult operation. Despite a great deal of medication my stomach is still hurting–not nearly as excruciating as before the operation, but I know that I am not out of the woods yet. That alarming feeling that my life could end will not leave my thoughts. Just recently my blood pressure was 80/35 mmHg. When I received the blood transfusions they pumped a total of seven liters into my body. I felt like a bloated corpse that had been floating for days in an ocean. Despite receiving a 100% supply of oxygen my blood saturation and therefore the oxygen supply to my organs was still not at the proper level. The doctors asked my father to join them in their daily morning visits and asked for his opinion, even though he is not a health professional. It is wonderful way of dealing with concerned parents in an intensive care facility and greatly strengthens their trust.

My boyfriend Dominik is here. He is sitting next to me, holding my hand, and gently strokes my cheek. It certainly has not been easy for him. We have been together only two and a half months–exactly since November 15, 2012. He has known from the very beginning about my illness; however, it is a big difference to "know" about something and to be sitting in an American intensive care facility next to the girl that one had just met barely ten weeks ago and seeing her fight for her life. He is my anchor and an important reason for me to get well again. Well, at least in the sense it is possible for me…

2013 was an important year for me. I was able to pass the 8th grade of the Dominikanerinnen Gymnasium (equivalent to senior year in high school) in Vienna with the help of home tutoring and intend to take my final exams in the fall of 2013. Then my school years will finally be over and I can plan my life.

The Gymnasium of the Dominikanerinnen, located in Vienna's 13th district (Hietzing), is a private Catholic school that not only wants to convey knowledge and provide a solid education, but also to promote social engagement, mutual respect, teamwork and an orientation for values. The old building in the Schlossberggasse 17 originally was a monastery. In 1874 a school was added and in 1933 the high school. I only visit the school to take my exams. Nonetheless, I feel very much at home there.

First, however, I want to finish high school in the United States. During the winter months for the past four years I have been attending the Bishop Verot Catholic High School, located on Sunrise Drive in Fort Myers, Florida. It is run according to the tradition of the Salesian Order. When I say "attending", I mean just that. In Austria, as a precaution, I was not allowed to attend classes in school; however, the Bishop Verot High School has its own infirmary where the nurses were specially trained to be able to assist me in an emergency.

In order to survive I need prostacyclin. This can only be administered intravenously and takes effect within a span of 30 to 60 seconds. In emergency care it is used for treating a cardiac arrest and has the ability of opening up all blood vessels in the body immediately. To give you an idea, it's like a scene often depicted in Hollywood movies: an actor collapses from a heart attack, someone rushes over and injects a needle into his heart and immediately the life-giving muscle begins beating again. In Quentin Tarantino's cult classic "Pulp Fiction", John Travolta frantically rams a needle filled with adrenalin into Uma Thurman's chest after she collapses from a drug overdose. And presto, she opens her eyes again–pure drama–and the action-packed movie can continue with its main protagonists.

This situation in way resembles mine. I need the prostacyclin to survive. Because its effects diminish after about one minute, it has to be pumped into my body every thirty seconds–and right into the middle of my heart. This is done by a small pump that I carry in a black bag hanging at my hips and from which a small white tube leads to my chest. It makes its way through an opening between my ribs directly to my heart. This tube is my connection to life. If it rips and cannot be re-inserted within a matter of minutes, the consequences for me will be fatal. If the pump has a defect and cannot be quickly replaced by the extra one that I always carry with me, this also means that I will die.

This is also the main reason why I could not attend any school as a child–apart from the infections and other health risks involved. If any of my classmates during playing or frolicking about had inadvertently run into, or got tangled up in, my tube and ripped it out, I most likely would not have survived such an incident.

Now at eighteen, most of us no longer run around the schoolyard in playful abandon, and the danger of anything happening has greatly diminished. Still, the pump can malfunction at any time. If a clear emergency plan is not implemented immediately, my life is in jeopardy. At the Bishop Verot School every nurse knows exactly what to do should anything happen. Every movement, every lifesaving measure has been extensively practiced. Everyone in school knows me and understands the reason for the black bag always hanging at my hips–it is life preserving. I feel safe here.

Flu epidemics are not an issue in Florida. It's predominantly warm or hot throughout the year; one only has to be wary of air conditioners adjusted too strongly, but not of infections that are rampant in Vienna during the winter.

This year I want to catch up on the material I missed last semester, because I always spend half a year in Vienna, so I can graduate from high school in the United States. The graduation ceremonies take place before summer and then there is the senior prom. It is a very big deal here and all the students really dress up and dance the night away.

For me this is quite a quite a challenge, because I am not allowed to participate in any sport. I am not even allowed to jog. Never in my life have I played volleyball, tennis, or handball. The last time I went swimming I was a little girl. I had to wear a special neoprene suit, but going in and out of the water with the pump and the tubing was such an ordeal that I forever lost interest in a water sport activities.

When the summer is at its peak and the weather the most beautiful, when all my friends are at the beach swimming and the boys surf the waves, I can only watch. I have never swum in an ocean in my life. I have never been diving in the sea, never been able to do refreshing laps in a pool. None of this is possible for me. This was particularly hard for me as a child. I often was sad and just did not understand why I had to be so sick. Everyone was having fun, and the best I could do was wading in the shallow water and getting my feet wet.

Not being able to go swimming is acceptable compared to other more major problems: like taking a normal bath or shower. No water can be allowed to enter my body through the tube in my chest. But it's a sad fact that I have a hole in my upper body–an opening through which an elastic white tube is sticking and is connected to my heart.

Just try to graphically visualize this: a tube that is in the middle of your chest and is attached to your heart.

My illness has changed me a great deal. Anyone who has gone through something like I have must be similarly affected. It makes you more composed, calmer–even a bit stoic. What are my girl friends fighting about again today? What is my father's friend so upset about? What is making our neighbor so angry? Why does the taxi driver jump out of his car at the light and yell at the woman who, after three failed attempts, still cannot manage to park her Toyota in a tank-sized parking space? Damn it, what is wrong with you all? Are you all crazy? What are these problems compared to the hole in my chest? I wish you could spend a day in my body and perhaps then you would understand what humility means.

I am lying in the intensive care unit and a great many thoughts are going through my head. Will I be able to finish high school? Will I be able to get my diploma in Austria? What must my parents be feeling now–not only in these fateful moments, but also throughout all these years? Will I make it through the next week?

CHAPTER 5

Hanging by a thread

“I USED TO ALWAYS ASK MYSELF: WHAT HAVE
I DONE TO DESERVE THIS FATE?
TODAY I KNOW: WHY NOT ME?”

It was pure coincidence that I did not die the day I was born. I guess it was a kind of a premonition on this May 24, 1995 that startled my mother awake at 2 a.m.–an intuitive feeling of fear. She was lying quietly in her bed and noticed that the child in her belly was no longer moving. Up to that point I had been a very lively baby that certainly made its presence felt. All of a sudden I was still…

At 4 a.m. my mother’s water broke prematurely and my father, Gerry, raced with my mother to the Lainz hospital in Vienna. The doctors also discovered another anomaly in the ultrasound, but no one could or would explain to my parents what their concern actually was. I was born at six o'clock in the morning.

After the delivery the gynecologist told my father that I had been lying in a "skewed position" and that we were "lucky that everything turned out all right." My father was still in his street clothes standing in the maternity ward, but they handed me over to him and he affectionately hugged me very carefully. I could almost feel his thoughts: Everything will be all right. My mother was lying there in a weary daze, half asleep.

It was a day of great joy for my father. In the morning I was born, his only daughter, and in the evening of the 24th he had a complimentary VIP ticket for the UEFA Championship soccer match at the Ernst-Happel Stadium in Vienna given to him by his friends: Ajax Amsterdam vs. AC Milan–a highly anticipated matchup of two world-class teams. He got on his motorcycle and rode to the Prater (the famous Viennese amusement park), and the sky seemed to glisten in a blue shade that he had never seen before. "I felt like I was in seventh heaven," he would tell me years later. What happened only shortly after would turn the most joyful day of his life into probably the bitterest. Just as he arrived at the crowded stadium, his cell phone rang.

"You have to come back right away," my mother screamed into the phone, hysterical and filled with fear. "They have taken Maleen away!"

A coincidence would save my life, virtually before it had even begun. And as it has turned out, it would not be the only time that my life was hanging by a thread. A doctor from the Preyersche Children's Hospital had been contacted by the Lainz Hospital to look after another baby that had developed problems and, as fate would have it, he happened to walk by my bed. The experienced pediatrician needed only one look to recognize my life-threating condition: I had blue lips and my face was blue as well. He immediately sounded the alarm and a few minutes after initial emergency attention, I was transferred by ambulance to the Preyersche Children's Hospital.

After the frantic call, my father had immediately turned around and raced from the Prater stadium to the hospital. When he arrived at the hospital I was already intubated. I had bilateral pneumothorax–both of my lungs had collapsed–a life-threatening condition and, if left untreated, absolutely fatal. Throughout the night I was given 100% oxygen to breathe, but my blood saturation levels just would not exceed 90%. "If we don't reach 95% by tomorrow, her brain will not receive enough oxygen and her chances for survival will dwindle" was the horrifying news the doctor on duty delivered to my father. Severe brain damage was probably the least of their worries at the moment. I was given strong antibiotics. The next morning the saturation levels were back to normal.

That signaled the beginning of a battle that has continued to this day, and most likely will go on for as long as I live. I contracted pneumonia and for two months had to lie in an incubator into which a tube was placed directly next to my head. The doctors affectionately called it "fresh forest and meadow air." Thereby I was able breathe in a higher concentration of oxygen than normal air contained. I was told later that I cried a great deal the first two months of my life. My mother Benita was not able to console me. "It was a terrible feeling not knowing what was wrong with her" is how she recalls the first dramatic moments of my life today.

She breast fed me and quickly noticed that I was not getting enough air while sucking on her nipple. "She can hardly breathe," she warned the doctors and nurses every day. "Please do something, Maleen is having such difficulty getting air." The lung specialist, Dr. Dilch, a very competent, affable physician, explained to my father that after a bilateral pneumothorax and pneumonia, the lungs of a baby simply needed some time to regenerate.

It was not easy for my parents for many reasons. At the time my father was running a travel agency that had just moved to a new location in the Wipplingerstrasse in Vienna's first district, while at the same time operating the Viennese Schnapps Museum. My mother, in the meantime, was taking care of me around the clock in the hospital. This was possible through a mother/child insurance (called MuKi in Austria), which allows a mother to always be with her child.

"I became a believer during this time" is how my father reflects on those very stressful months today. "Prayer gave me strength." He remains a spiritual person to this day. "I placed my hands on Maleen's back and tried to transfer all my positive energy." My serious illness really changed my father. He was a well-liked staple of the Viennese scene, because many prominent Austrian personalities booked their vacations through him. Some of his customers became his friends, such as the popular Austrian singer/songwriter, Rainhard Fendrich, who would come to play an important role in my life.

After two months I was finally allowed to leave the hospital. But hardly home, I contracted pneumonia again and I had to be brought back to the hospital. I had to go back to the sterile atmosphere of a cold, strange world that as baby I probably was not really aware of, but was so very different from the warm, soft and pleasant environs of my home, where the comforting heartbeat of my mother when I lay on her chest provided me with such soothing sanctuary. This situation often repeated itself: released from the hospital, back home, serious complications, back to the hospital.

"The Preyersche Children's Hospital was an absolute horror for me" is how my father describes my time there. "It was terrible; the primary physician and the cardiologist were dreadful" is how he explains the reason for his mistrust, something that both my parents generally felt toward all doctors after all the complications that I (and they) had to endure.

It took three years before I was correctly diagnosed. The first pediatrician even called my mother “hysterical” and told her, “There is nothing wrong with your child.” Sadly, this is how some doctors deal with the very real fears of concerned parents. They only trusted Dr. Dilch, the lung specialist. He diagnosed a kidney infection and double-sided reflux, a return flow of the urine from the kidney, which was causing my body to slowly poison itself. In order to make this diagnosis, doctors had to insert a catheter. It must have caused me excruciating pain, my parents later recalled, as my heart-wrenching wail filled the room, startling everyone. I received very strong antibiotics. After a while the infection subsided and I was allowed to go home–until the recurrence of pneumonia.

I, Maleen Fischer, barely three months old, was subjected to one life-threatening condition after another. However, according to all those who knew me, cared for me and worried about me, my will to live was apparently immeasurably strong. I was born into this world and did not want to leave it so quickly. Not now, not here, not so fast.

The doctor in the Preyersche Children’s Hospital stumbled from one diagnosis to another. “Cystic fibrosis” was her last attempt to give a cause to what was endangering my life. It would have been a final, fatal diagnosis had it been right. Cystic fibrosis is an inherited metabolic disorder caused by a genetic defect, leading to chronic infections of the respiratory tract resulting from bacteria as well as digestive disorders from pancreatic insufficiency. At the time anyone receiving such a diagnosis had a life expectancy of no more than thirty years. Today the prognosis is somewhat better.

Today it is possible to “Google” a term and within a matter of seconds one has a fill of information regarding it. In 1995, however, it was much more difficult. For two days my parents were in a crazed, hysterical state, worried about my future, my survival. Then, on the third day came the unexpected relief: “It’s not cystic fibrosis.”

But what was really wrong with me?

CHAPTER 6

The bitter truth

“YOUR DAUGHTER HAS PULMONARY HYPERTENSION—SHE WILL NOT REACH THE SECOND DECADE OF HER LIFE.”

Professor Albrecht Beitzke, my attending physician in 1998

There are many good hospitals in Vienna, but there are some that are better than others. The Vienna General Hospital (AKH), the university clinic of the Vienna municipality, can be justly proud of its 300-year tradition. In the meantime, it has evolved into one of the largest and most renowned hospitals in Europe, with some of the most respected doctors in the world working there. In the eighteen years of life I have seen so many hospitals from the inside, have been examined and treated by so many doctors, that I believe I can make a somewhat objective judgment regarding the above.

Saluti et solatio aegrorum, for the “well-being and comfort of the sick", reads the Latin inscription on the entrance to the hospital complex that has been located there since the times of the monarchy and Emperor Franz Joseph II. It was here that Karl Landsteiner discovered the different blood types, Ignaz Semmelweis made his observations regarding hygiene during childbirth, Theodor Billroth pioneered new surgery techniques and Julius Wagner-Jauregg received the Nobel Prize in Medicine for discovering the therapeutic importance of the malaria immunization in the treatment of progressive paralysis. The facility itself is really very impressive: 27 clinics, 10 university institutes, 62 outpatient departments, 330 specialist outpatient clinics, around 1400 physicians, over 2000 beds, around 100,000 inpatient treatments per year and over half a million outpatient treatments annually.

It would have been so easy to send me to the Vienna General Hospital (AKH). But no one–not one doctor–considered this. It would have been a decision that might have provided my parents with an early answer for what was really wrong with me–the reason for my agonies and ailments. Instead, it was recommended I go from one doctor to the next, to faith healers and dubious "energy healers". The diagnoses were manifold, but sadly never right.

Then came the friendly suggestion of a physician to my parents that they take me to the pediatric cardiologist, Professor Albrecht Beitzke in Graz (the capital of Styria), a very well-respected, extremely experienced and competent doctor who also worked at the Royal Brompton Hospital in London. It was a further attempt–one of many–to unravel the mystery of my distressing condition and its cause. “We thought, well maybe he can find out what is wrong with you” is how my father later described the hopes he had before that first meeting with the doctor, which as it turned out, forever changed our lives.

Professor Beitzke did an ultrasound check. My brother Patrick, who was just eleven years old at the time, sat next to me. After a few minutes the experienced physician announced in a clear and precise baritone, “Your daughter is suffering from pulmonary hypertension.”

Everyone in the room remained silent. It had taken three years before we finally found a doctor who was able to make a correct diagnosis and could tell us what really was wrong with me. We had always been told to “be patient”. Now, after only one ultrasound, this experienced, competent doctor was able to recognize what was really wrong with me.

In the first instant the diagnosis was a relief. Finally, the doctors knew what I had. Finally, we could begin with a correct and effective therapy. Finally, my suffering would have an end. However, only a few moments later, after I had left the room with my mother to have a catheter examination, my father was informed about the very disturbing truth regarding my illness. My father had been obviously relieved to hear the diagnosis and said to the doctor, “Super! And what are we going to go about treating it?”

Professor Beitzke took a deep breath, looked directly at my father, whose big, happy smile had disappeared in a fraction of a second and turned into a stony, fearful gaze, and told him, “Nothing. I am very sorry, but Maleen will not reach the second decade of her life.”

My brother Patrick, who was sitting next to my father, instinctively grabbed his hand and fearfully asked, “Papa, does that mean Maleen is going to die soon?”

“No,” my father answered in a strong, resolved voice, “that cannot and will not be.” He took Patrick by the hand, stood up and drove with him back to the Hotel Werzer in Graz (where we were staying) without uttering a further word. In the meantime, I was to receive a right-heart catheter and had to stay overnight in the hospital.

CHAPTER 7

The worst case

“ONE EXPECTED THE SITUATION TO UNFOLD JUST LIKE IN ‘GREY’S ANATOMY’, WHEN A SICK CHILD IS BROUGHT IN AND ALL THE DOCTORS RUN AROUND TO IMMEDIATELY ATTEND TO ITS NEEDS. BUT NOTHING AT ALL HAPPENED.”

Benita Fischer, my mother

It was the worst diagnosis that parents could imagine hearing. “It was like suddenly standing in quicksand and you start sinking, not being able to move and not sure if you should scream or cry” is how my father today describes the feeling he had when he first heard the conclusion. “I called all my friends, was completely hysterical. Even Rainhard Fendrich, the pop singer, tried to calm me down. This just cannot be true!”

My father left my brother Patrick by himself in front of the

TV in the Hotel Werzer, walked to his car parked in front of the entrance, unlocked the car, sat down in his dark blue Ford Scorpio and began to scream. He screamed and screamed and screamed–loudly, hysterically, like he was going crazy. "No, no, no." Tears flowed down his cheeks in a seemingly never-ending stream. "This just cannot be true."

He began to pray, "Dear God, please don't let this happen. The doctor must be wrong; it must certainly be something else, not pulmonary hypertension. Maleen will get better very soon."

The next day my father drove back to the clinic in Graz and arrived just as my heart catheter procedure was being done. He sat down next to my mother, who still did not know about my diagnosis. He then began to tell her the terrible truth, leaving (almost) nothing out. "Benita, Maleen's illness is something very bad."

My mother went pale with fright. "What do you mean?"

"Her illness is called pulmonary hypertension and there is very little that can be done." What the doctor had said about me not reaching the second decade of my life, for the moment, he kept to himself.

My mother was in a panic, clinging to the last thread of hope. "It just cannot, will not be."

At that moment Professor Beitzke came back from the heart catheter exam. “I am sorry to have to tell you that the situation is what we expected. The illness is at a very advanced stage.” Apparently the pulmonary vessels located at the ends of my lungs looked like little snakes, not exactly like those in healthy children. “It just isn’t possible that nothing can be done for her in this day and age,” my father desperately pleaded.

Prof. Beitzke just sadly shook his head. An eerie silence encased the room for an agonizing minute, then Prof. Beitzke turned to my parents and said, “I will make some inquiries.”

The nurses rolled me out of the catheter room. I was still woozy from the sedation. I had no idea what was happening around me, but I do remember the “pixi”, as I called the pricking needles–something I really despised. My parents only said that they were necessary in order to make me better. So I let them prick me, while my parents held my hands.

Finally, after quite some time, Prof. Beitzke returned and spoke to my parents. “There is a physician, Dr. Rabinovich in Canada, who is doing research in this field, then there is a Dr. Haworth in London who knows quite a bit about this illness, and I would suggest you visit the VGH (Vienna General Hospital), which is experimenting with calcium antagonists (calcium channel blockers).” Calcium antagonists actually are used to treat high blood pressure, but at the time they were also being tested for treating pulmonary hypertension–using a high dosage. Today, we know that this treatment is only successful in 20% of the patients. These patients are termed “Responders”. They can be grateful that they respond to nitrite oxide, which enables them to be treated with calcium antagonists. It was the next hope to which my family clung: maybe she is a "Responder".

We drove back to Vienna. Throughout the trip my parents did their best to give each other courage. "They have pills at the AKH (Vienna General Hospital) that will work; it's not as bad as we have been told. If you don't know how to treat it, then you also can't know how things will turn out."

I was not a "Responder", as it would turn out.

"Professor Beitzke was brutally honest" is how my father, Gerry, sees the situation today. "He only spoke the truth, factual and direct; it was the right approach." It did not change the situation. The prognosis was very bad–the worst imaginable.

How does one react when one's own child is confronted with such a prognosis? I have often asked myself this question. My parents drove me back to Vienna. Our first stop in the battle against pulmonary hypertension was Professor Wimmer, an expert on the subject. We first met her sitting behind an ornate baroque desk in her private office. She did an EKG and, after checking my results, she told my parents, "Yes, one can see the problem immediately on the EKG." I was sitting on my mother's lap and placed my pacifier on her desk. Dr. Wimmer immediately screamed loudly and threw the pacifier back at me. She then jumped up and quickly retrieved a cloth and wiped off the small damp mark. How could a three-year-old dare to "besmirch" this precious baroque desk with her pacifier? My mother shook her head but managed to remain silent–not an easy task.

Dr. Wimmer then sent me to the AKH to see two members of her staff, Prof. Ulrike Salzer-Muhar and University Prof. Manfred Marx, who at the time were experimenting with the calcium antagonists. At the end of the 1990s research in this field was still in its infancy and no one was aware that a right heart catheter exam had to be conducted using nitric oxide to ensure that such a therapy would even make sense. So we arrived at the AKH (Vienna General Hospital) and for an hour, absolutely nothing happened. My parents were at nerves' end. One expected the situation to unfold just like in "Grey's Anatomy", when a sick child is brought in and all the doctors run around, immediately attending to its needs after an expert diagnosis and a therapy is decided upon, but nothing at all happened. After waiting for hours my father finally asked, "Where is the doctor?"

A nurse replied, "He's on lunch break."

"I completely lost it" is how my father recalls the situation today. "I was convinced that it was their duty to run around just like in Emergency Room." Just at this moment nurse Monika came over to us. As things transpired, she would become a key figure in our lives. She is a resolute, strong, intelligent woman. She asked my father to accompany her to the nurses' room, which was only about three square meters in size and contained a small table and two chairs. She asked him to take a seat and then told him, "Please take a deep breath and try to calm down, Mr. Fischer." She then proceeded to tell him about the terrible illnesses and sad tales of other children. After hearing these sad stories, he slowly regained his composure.

I had an infection, pneumonia and my condition was very serious. I had to remain in the AKH for almost a month. During this time they were trying to get me adjusted to Adalat, a calcium antagonist. Dr. Schlemmer, the right-hand man of professor Wimmer, was initially my attending physician; later he was joined by Dr. Salzer-Muhar. Dr. Schlemmer was a gentle, kind-hearted soul who spoke in a soft, reassuring voice.

Yet despite the good care I was receiving, my family was still traumatized–my eleven-year-old brother Patrick because he saw how my condition deeply affected my parents. My mother couldn't stop crying and father was a broken man. They tried their best not to let me see any of this. Today, I can imagine what they must have been going through at the time.

My great-grandmother said something very smart to my father at the time: "If you are overcome by bad thoughts, send them away by thinking of something joyful. Believe me, that will help you." At the time my father was reading a book titled Mary, regarding the search for happiness. It actually did help to give him strength. Think about the good and happy things in life and when you do, a smile will appear on your face. "You only cry after you have been slapped" was another one of my great-grandmother's sayings. She must have been a very wise woman, because she had lost a child who was the same age I was at the time. It was after World War II and she was fleeing to Dellach by Lake Worth in Carinthia with her three sons. My great-grandfather was a prisoner of war there and among his duties was repairing heating systems. On her journey to him, she stopped in Zwettl, Lower Austria. Her youngest son was lying on a diaper-changing table on which a large powder box in a carton was standing that was used for babies at the time. In an unobserved moment he had managed to crush the box and breathed in the powder–he could not be saved. He was buried in Zwettl.

What was going to happen to me? The doctors treating me considered different therapy models, but all had their weaknesses. They had never really been tried before. There was a medication to be inhaled, but this had to be done every two hours–even at night. How could this function with a three-year-old? I was protesting every procedure with my hands and feet. My mother had to sit in my bed and take me between her legs and press against my chest until I was gasping for air and thereby inhaled the medicine. It must have been heart-wrenching to see me being tortured and hear my screams.

At a hospital the nurses are the most important reference points for the relatives of patients. They have more time than the doctors and, often react in a more humane fashion, as well as have more experience in the daily routine of treating specific illnesses than most of the physicians. My father often spoke with the senior physician, Dr. Marx, one of my doctors at the AKH that he trusted. “You are a university clinic, but my daughter has an illness that you are not familiar with. I have found the world’s leading expert on this illness and her name is Dr. Robyn Barst. She works at the New York Presbyterian Hospital. Fly with us to the Big Apple, it’s essential that university clinics continue to expand their medical knowledge and treatment capacities.”

“I agree with you,” he responded and submitted a corresponding request. However, his superior, Dr. Wimmer, refused to let him go.

Many doctors would accept the situation; however, this is not the way Dr. Marx thinks. Instead he took a leave of absence and, with his wife, flew with us to New York. He is a wonderful person. His wife is a veterinarian and his son is not only very well-mannered, but was very nice to me as well. Thereby the subsequent treatment in Vienna was secured. And all of a sudden, everything became very familiar.

Before we got onto the plane to New York, my father wanted to get his own life in order. My father decided to sell his travel agency, an undertaking that he had operated successfully for many years and enjoyed doing. Yet the situation I was in called for drastic measures and he did not hesitate for a moment. "I knew immediately that I had to rid myself of unnecessary burdens" is how today he sees the necessity of the decision at that time. "We organized exclusive tours to Morocco, Nepal and many other destinations for parties of two to six who did not want to go on a 'culture tour' by bus with forty others. I was able to get a good price for the agency. This allowed me to dedicate myself to my daughter as well as have more time for the family operation–our Schnapps Museum. I really wanted to continue to work at my former travel agency as an employee whenever my time allowed and 'TUI', the large travel company that bought my agency, were looking for a luxury segment agency and agreed to my conditions. It was also about time that I got the Schnapps Museum, that actually was a small liquor distillery, running again."

CHAPTER 8

A pump for life

“NO CHILD SHOULD DIE BEFORE ITS PARENTS.”

Gerry Fischer, my father

The New York Presbyterian Hospital is a place of hope for people who have reached a point in their lives where the next step could decide whether they live or die. It is the leading address for research and clinical studies, with 2200 beds spread out over numerous buildings, and is the largest hospital in the city. Over 120,000 in-patients are treated there annually. I was one of them.

It would not be unusual for a person to expect that a hospital located in the middle of Manhattan would have the features and facilities one is accustomed to in Austria or Germany. However, upon visiting the facility, this person might initially be rendered speechless. “It is a journey back in time, what one would imagine it looked like in Moscow in the 1970s" is how my father mercilessly described it, "like in the time of the Cold War." It is the university clinic for both Columbia and Cornell and repeatedly has been voted among the top ten hospitals in the United States, but the Washington Heights Family Health Center branch, located on 181st Street, is an antiquated, extremely austere and depressing building–frighteningly cold. Children's clinics in Austria have bright rooms, filled with fresh colors and toys. There is comfortable furniture, and smiling people abound. This is how we have come to know children's clinics, where hope and positive feelings are conveyed in such dire moments when people desperately need hope. But this here? Even the nurses are wearing gray instead of white–just as dreary as the surroundings.

The Presbyterian Hospital consists of numerous buildings. At the family center there is an examination section and a wing for beds. I was placed on the 11th floor of this wing.

"First we will visit your doctor," my father said to me. Five minutes later I was standing in the office of the woman who would save my life: Dr. Robyn J. Barst, the head of the Pulmonary Hypertension Center at the Presbyterian Hospital. Her research was focused in only one field: pulmonary hypertension in children.

She was very short, approximately 1 meter 60 centimeters, but her very high-heeled shoes made her seem much taller. She was a very attractive woman in her mid-40s, thin with short, dark hair, a dark complexion, and large dark eyes. She was wearing a white doctor's coat; a stethoscope was dangling around her neck, from which some very impressive jewelry was also glistening–surely very expensive. She was a successful doctor who undoubtedly was a member of New York's upper class. In her small office, piles of paper were stacked on her desk and in the filing trays. To the left of her chair there were numerous photos and drawings that her little patients had given her: laughing, playing children, a little girl ballet dancing, another one playing basketball and, in between, old metal cash registers, like the ones we used in Europe in the 60s of the last century. At the back of the room there was a bed used for check-ups. I looked into her eyes and felt something that I had been missing in this hospital: trust.

"How are you, Maleen?" she asked as she offered me her hand. She spoke with my parents and Dr. Marx for a few minutes, after which I was taken to the infirmary. My mother explained to me that I was to undergo a heart catheter check-up, an examination that was not very complicated and would allow them to look into my body. I did not really understand what they were going to do to me, but I was afraid–very afraid.

A nurse approached my bed and tried to get a blood sample. She stuck a needle into my arm once, then again, then a third and fourth time. She could not locate a vein. After the seventh unsuccessful attempt my mother asked that this arduous procedure be stopped. I looked around the room. The walls were covered with wood paneling; a TV stood by a wall. It was one of those bulky old tube models that today you only find at your grandparents' house. I dozed off a bit. At some point a nurse came and rolled me into the operating room. Then everything went dark.

My parents were waiting in front of the operating room. Time went by. Only after several hours, which must have seemed like an eternity to my worried parents, did Dr. Barst and Dr. Marx come out of the operating room. They were strangely quiet and looked very solemn. A nurse rolled the bed in which I lay still sedated by them. Covers lay over me up to my neck. My parents looked at each other; anxiety filled their faces. What had happened? Dr. Barst asked them to take a seat. "What I just saw in your daughter with the catheter, I have never seen before" were her first words. My parents' anxiety turned into fear.

The normal pressure ratio in the lungs is between 0 and 10 mmHg; a pneumonia infection raises the pressure up to 20 mmHg. Everything above 25 mmHg is called pulmonary hypertension. My pressure in the lungs fluctuated between 70 and 170mmHg–my average being 163, without any action on Dr. Barst's part. "I have never seen anything like it," she told my parents. "We had no choice but to insert a pump inside her."

"What do you mean by 'inserting a pump'?" my father asked, not having any idea what this meant.

Dr. Barst's look became very serious. "In order to stay alive, your daughter needs prostacyclin, which can only be injected intravenously and is only effective for 30 to 60 seconds. Normally it is used in emergency cardiac arrest cases and has the ability to immediately open all the vessels in the body. However, it loses its effectiveness after a minute at the most; therefore the prostacyclin has to be pumped into Maleen's body every thirty seconds. It is a major procedure, but it lets her live."

My parents first looked at each other and then me in total bewilderment. On the other end of the tube that was protruding from my arm hung a small CAT pump, similar to the ones used in chemotherapy or pain medicine. The surgeon implanted a tube in my arm–a method that is not without dangers, but was absolutely necessary to sustain my life. The tube must be kept completely sterile; otherwise the risk of a heart muscle infection (myositis) would be too great. Additionally, in the case of a young child, it has to be firmly attached to the body so that it cannot be ripped out or torn during play.

Furthermore, every patient with pulmonary hypertension receives a blood thinner (anti-coagulant)–in my case, Marcoumar–whereby every fall, every slip, every blow could be life-threatening, because the blood in the body hardly flows.

As if all this wasn't enough, Dr. Barst then explained to my parents what possible side effects this procedure and the corresponding therapy could have. All the vessels in the body are opened by the prostacyclin. This also applies to the eyes, which results in a sensitivity to light. The medication also often causes headaches and pain in the jaw while chewing, as well as severe pain in the heels; it can be the cause of diarrhea and numerous other health issues.

When my parents flew with me to New York, their hope was that I could be cured. But was this the way it was going to be from now on–a tube protruding from my body, attached to a pump that basically determines if I live or die? What would this mean for me, and how would/could I live the rest of my life?

Taking a bath or swimming? Impossible. Sports, bicycling? Not possible. Events involving crowds? Too much of a risk for infections. School? Probably not possible. Concerts, visiting a disco when I am older? You can forget that.

From this day on my life would be very different. However, my parents were, and still are, the eternal optimists: “She is alive; that is the most important thing. All the rest we will be able to manage.” The good news was that our Vienna Regional Health Insurance agreed to cover the costs of my therapy. In many countries, even in the European Union, this is not to be taken for granted.

The next few days at the Presbyterian Hospital were intended to distract me, as it was necessary to do a second procedure. In this procedure the tube that now was going through my arm would be removed and replaced by a new one that would go directly from my chest to my heart. When I woke up again from this latest surgery, I instinctively touched the wound on my chest. The nurse stood next to my bed and asked, "Maleen, can I get you anything"

Still half asleep I managed to joke, "Caviar, please."

It was on this day that my parents tried to explain to me–a four-year-old–what had just happened to me. Why I, from now on, would have to live with a tube in my chest attached to a strange machine hidden in a backpack–a machine that pumps fluid into my body every sixty seconds. "I was terribly afraid that day, about you and your future," my father told me much later, "and it pained my greatly to have to see you lying with there with that tube. I, however knew that I could not remove it."

After a short while I was able to get out of bed. As soon as I was able to walk well enough, Dr. Barst asked us to visit her in her office. For the first time I looked at the photos on her wall a bit more closely. There were many pictures of children who all were wearing a pump. One of the girls in the photos was Hannah. She was twelve years old at the time, and one could see her playing basketball with a belly bag. Dr. Barst had done something very smart: she had invited a family, whose son was just a year older than I and also had a pump in a backpack, to join us. My parents spoke with the boy's parents while I played with him.

His name was Michael Pereggo and he was a pretty wild five-year-old–the backpack did not seem to bother him a bit. "You will see Maleen, soon you will have gotten used to it," Michael said to me. I smiled back at him. In the meantime his parents explained to my parents what they have to look out for, as well as what they have to when I have the first signs of a cold: "Don't hesitate, immediately take her to the hospital, because there could be life threatening complications." Michael was a real whirlwind and seeing him race around gave my parents and me a great deal of strength and hope. He possessed a great zest for life and seemed happy and satisfied. Meeting him really helped me feel better about my situation.

Michael showed me the tube that went through his abdominal wall. "See," he said, "it's only a tube, nothing else. You can still have a lot of fun even though you have to wear it..."

Back then a pump weighed more than 2 ½ kilograms–quite a bit of weight for a little girl like me. Today they are much smaller and lighter and therefore can be placed into a small belly bag; back then I had to carry it in a backpack. So we decided to find something out of the ordinary, or funny. I found a Teletubby bag that I liked. Tinky-Winky, Dipsy, Laa-Laa and Po became the heroes of my childhood. I saw them day in, day out and carried them with me all the time. I knew all the stories about their vacuum cleaner, Noo-Noo. I loved their language and all their cute, funny phrases in German, such as Tubbie schmusen (hugging), Nomal, nomal (again), or Winke, winke (wave). I still have the backpack today, and I find it terribly embarrassing!

Carrying the backpack really bothered me at the beginning. I wanted to be free, move around, run, jump, do somersaults—to do anything I felt like at the spur of a moment. Only it was just not possible. Besides, it really looked very silly. A girl always with her backpack, be it at dinner or even in the toilet. I hated this thing, even it if was keeping me alive.

My mother gave me a princess dress because I was so "brave", but in combination with a Teletubbies backpack even the cutest dress suddenly looked very funny. I stood in front of the mirror in the hotel room and cried.

I asked my parents many questions, but I did not get a lot of answers. How can anyone explain such a serious medical condition to such a small child? How is it possible to convey to child that has just come into to this world that it might only have a short time to live? There was no explanation that would make my situation seem better. In regard to the backpack I was always simply told, "You have to wear it all the time!" My parents were honest–well, at least as much as they could be. And this was a good thing.

The doctors also told me that there would not be a day without the backpack anymore. It quickly became clear to me that I needed the Teletubbies on my back to stay alive. Therefore I always took care of it. When I was a little girl I used to sleepwalk a lot, but even then I always managed to take my backpack along. My parents almost fainted when they saw me for the first time walking through the halls at night. But the backpack, which I must have put on in my sleep, was dangling, like always, on my back.

CHAPTER 9

Between fate and destiny

“MY SURVIVING THE FIRST FEW DAYS OF MY LIFE ON THIS PLANET MUST HAVE BEEN FATE—OR DESTINY.”

Maleen Fischer

Today they are going to take off my breathing mask. Finally, I will be able to breath freely again. After the emergency operation and the ensuing days, which were a period of life or death, it was a clear signal that things were getting better. The antibiotics have worked, the doctors seem to have gotten the infection in my abdominal cavity under control and even the condition of my lungs continues to improve. I probably will be able to be released from the intensive care unit very shortly and after some time be allowed to go back home to Cape Coral. Lying in a hospital bed gives one a lot of time to think about things.

Isn't life a collection of strange coincidences? If the doctor in the Lainz Hospital had not visited a little patient there and thereby happened to pass by my bed, had he looked at the floral painting on the wall–just because he happened to like tulips, which were depicted on it– instead of looking at my blue face, it inevitably would have meant my early end. I never would have been able to experience these past seventeen years that, despite all the deprivations, were wonderful. Yet this still is not the end–I will go on, hopefully for a very long time.

How often do we pass death by and do not see it? A step too early from the curb onto the street and the trailer of the passing truck knocks us down with its five tons of weight. Just a short, careless moment in the bathtub and we slip, falling backwards and the back of our head cracks against the edge of the bath. A CD that a bus driver wants to slip inside the player, a split second of inattention results in the death of twenty-two children as the bus smashes into a tunnel wall. All this sounds so unbelievable, yet it happens every day.

How many guardian angels does a person actually have? I have asked this question over and over again. How often is it possible to thwart destiny? Or is it really our destiny to survive situations and to cope with problems which normally would mean certain death?

What happened? What really went wrong on the fateful May 24, 1995 in the Lainz Hospital? Was not recognizing the pneumothorax the cause of my pulmonary hypertension? Was this the beginning of all my travails that, even at 17 almost brought me to the brink of death again? Could I lead a normal life today if something had not gone wrong back then?

For years my father tried to obtain permission to review my medical records, the documents that not only could provide clarity regarding the circumstances surrounding my birth, but also the cause of my illness. He wanted to know how my life-threatening situation came about–if mistakes were made, or if there was a virus making the rounds of the neonatal care unit. Were there more children suffering from pneumonia at the time I was born? My medical records, the documents that could provide answers to all these questions have, to this day, not been found. No one can explain their mysterious disappearance.

During the first years of my life my parents tried to maintain a certain normalcy in my life. I was a sickly, weak child. As soon as I was able stand and eventually walk I was always quickly tired and after even the slightest sports activity I was almost always completely exhausted.

We lived in a very pretty town house in the Vienna suburb of Altmansdorf. In our garden we had a small biotope. I developed great affection for animals at an early age, in particular for our Labrador, Dorée. Sadly, I never could really play with my little friends. Most of the time I was literally left breathless. I learned to speak English at a very young age. My older half-brother Patrick practically spoke only English with me, because his mother is American. We liked to watch American and English TV shows on Nickelodeon. I really adored Tabaluga, the brave little dragon created by the popular German pop singer, Peter Maffay.

Despite the pump there were phases in my life where I was barely able to breathe. It must have been around my sixth birthday when I again had a very serious crisis. Even if I just wanted to go into the kitchen, I was suddenly out of breath.

It was at this time that it became clear that I would never be able to attend school. The risks were just too great. I was sad when my parents informed me that I would have to be tutored at home. They added that they would try to make it as pleasant as possible for me. Being a prisoner in one's own home? Not able to make friends? No fun moments during breaks? This was going to be really boring.

I am a very social person. I love to talk to people, to listen to stories as well as tell them, to laugh and to cry whenever I feel like it. I already was like this as a child. Therefore to hear that I would never be able to do all these things was devastating. Only having the view from my room, always stuck within my own four walls, never being able to go out the front door every day, except when it was absolutely necessary—over the course of time this would be one of the most difficult challenges for me.

Even though my parents repeatedly told that this would mean less stress for me, and that I could sleep longer than the other children who had to get out of bed early in order to get to school on time, I still was very sad, because it also meant that from day one I had to take care of everything myself. I had to have my homework and all the subject matter finished at a specific time, had no quick way to check my work, could not ask a classmate if had a question, or even receive helpful hints. I was completely on my own.

At the age of five I had a kind of "pre-schooling" during which, from time to time, I was given subject matter to learn at home. Then came my first official school day. It was in September 2001 and it was pouring rain; the wind lashed furiously around our townhouse. It was a cold, gray and depressing morning as the doorbell rang. There stood my teacher. Sabine Walter was barely twenty-three years old and gave me a wide smile, her big blue eyes sparkling. She immediately won me over–and I think she was taken by me as well. "It's pretty cool to have your own private teacher," my father said to me and I thought for a moment, Actually, he's right; things could be worse… I also received a large school cone, which children traditionally receive in Austria on their first day of school. God didn't really send Sabine to me; it was the Vienna School Council. Sabine remained my teacher until my high school graduation. However, Sabine will always be much more: a friend for life.

I was officially released from the compulsory schooling, but this really angered my mother who said, "She has trouble with her lungs, not her brain!" She then proceeded fight this decision and demanded that I receive a normal education. This was when Sabine appeared and agreed to become my tutor in order to provide me with the formal education I needed. This certainly was not an easy decision at the time for the young woman, as it meant a radical change in her life as well. You go into the teaching profession to eventually get a job at a school and then, all of a sudden, for twelve years you are the private tutor for a seriously ill young girl that you have to teach the entire curriculum, from grammar to high school.

My school day at home began promptly at 9 a.m. and finished–depending on the grade I was in–at noon, 1 or 2 p.m., just like at normal Austrian schools, five days a week. At the time I had a bedroom and a "workroom" that my parents had created especially for my studies. The wallpaper was a mint green with yellow stripes decorated with a small floral pattern. The curtains were yellow and made of sturdy linen. On the left side there was a small aquarium containing a Lionhead goldfish, a pretty large one, which I had for six years. It lived longer than I had been told it would survive. Next to the aquarium stood a somewhat antiquated computer and a printer. To the left of these items was a walk-in closet, which is still there today, covered by the same yellow fabric as the curtains. The rug on the floor was blue, something my father brought back from a trip to Morocco. Whenever I was studying my dog, Dorée would lie on it. Therefore, we later had to get rid of it because of the countless white dog hairs could not be removed even by the best cleaners. Right in front of it stood a green chalkboard and a wooden table with two swivel chairs–one gray with a colorful pattern, the other black. I always sat on the colorful one. This is where Sabine taught.

My bedroom had the same wallpaper as my "workroom" and a small chandelier in antique pink with metal leaves and three bulbs. I had a very small Samsung TV, its speakers decorated by hand drawn purple circles. On the wall, under the window, stood a children's chair in the form of a wooden duck on which I always sat when I watched television. Later, a Sponge Bob chair replaced the duck chair. On the right side of the wall my bed stood, which had a mast just like a sailboat that rose all the way up to the ceiling. At the head of the bed was a shelf with books and a built-in small reading lamp. On the wall next to the bed hung a large painting by the Viennese artist Kathleen Denis depicting small seagulls walking in the sand. The painting was a present, with a personal dedication by the artist and a quote from the Bible.

At the entrance to my room there was a wall shelf filled with Barbie dolls. At the time I was crazy about Barbie dolls and toward the end of my collecting days I had over one hundred. Some of them are still in my room today; others I gave away; others are stored in the attic. Barbie dolls were the only things I collected. I never managed to endear myself to anything else to such an extent. I also could never write a diary, because I never could get used to the continuity of it. I was never able to meticulously dedicate myself to one thing every day. Maybe, it was because since the age of four my illness has forced me to lead such a disciplined life in regard to my pump that it was impossible for me to deal intensely with anything else in other areas of my life. Perhaps this is why I so resisted accepting rules and norms in other areas, or enduring the monotony of the same processes every day. This indirect pressure to have to do something repetitively–be it only a diary–subconsciously caused me to resist it. With the Barbie dolls it was different, because they were usually given to me. Otherwise I never would even have dreamed of collecting them. If I was in a hospital, or if I was feeling bad after a difficult or unpleasant check-up, I immediately received a Barbie doll as a reward. Even my doctor in the AKH gave me a Barbie doll, because he thought I was so very brave. Therefore I saw my Barbie dolls as my babies, cared for them, combed their hair, dressed them appropriately and always put them back on their rightful place on the shelf.

After I got up my mother helped me to wash up and get dressed in order to make sure that my tubes and the catheter did not get entangled. The daily routine was never easy for me. Every edge, every corner implied danger. Every slip, every stumble could become a life-threatening situation for me.

As a child it is particularly difficult to control every movement. Even today I still cannot always do it. At the time we still had to change the bandage that covered the entrance wound caused by the tube in my chest every day. I really found this very bothersome and unpleasant. It really got on my nerves. Only later did I come to realize that this attention and fastidious hygiene was crucially important and the reason that I virtually never suffered any infections that could have endangered my life.

Particularly unpleasant was bathing. Only so much water was allowed in the bathtub so that it was certain that it never was able to touch my tube. For a small child this means only a few centimeters, the cannula inserts and the tubes are laid over the shoulders and the pump is placed next to the bathtub on the floor and covered up to ensure that no water is splashed onto it. I still do this today. At the time I was only able to sit in the bathtub. Today it is even possible for me to shower, but I have to place the pump outside of the shower. I have to be very careful that the bandage does not get wet. As a precaution, after every shower I change it, as every bandage on an open wound that leads to the heart is the ideal breeding ground for bacteria and infections. Changing the bandage lasts between five and eight minutes. One has to be very careful and remove it very slowly, disinfect the skin around the tube attachment and then place a new one over the tube, ensuring that it covers the entire area again.

My instruction began at 9 a.m. and before it started we had breakfast. If Sabine came earlier she had breakfast with us. There was a set time for breaks, just like a school, and sometimes during these breaks we took my dog for a walk. I also could tell Sabine whenever I was not feeling well and needed a break from tutoring. When my teacher left the house and my instruction was over, I usually immediately started to do my homework–something I had to do just like every normal pupil at school.

Afterwards I engrossed myself in my books. I have always loved to read and started reading very early on. As a small child I wanted to learn how to read really quickly and was very ambitious about it. My first book was "The Little Prince" by Antoine de Saint–Exupéry, who once saw the sun set forty-three times in one day. What does the fox say to the little prince after he discovered a rose garden? "One only sees clearly with the heart. Everything essential is invisible to the eyes."

The little prince always encounters people that are preoccupied with themselves. They do not see the really important things in life. How often have I had this very same feeling, when I encountered people who felt sorry for me, but did not understand that they did not recognize the essential things in their own lives? The proclivity toward money, success, working long hours, the ambition and the jealousy over the luck of others–what does all that mean when your life is finally over? At the very end, no one really regrets not having worked enough. My illness, despite all the dark hours I had to go through, has given me the ability to recognize the truly important things in life.

Have you told someone that you are very close to today that you love him or her? That they are very important to you? That you miss them when they are not around? It's better to do it today rather than tomorrow. No one really knows when the final hour will come.

CHAPTER 10

The angel next door

Steffi was my first angel. She is two years older than me and lives in the house next door. She already knew before my life depended on a pump, since the year B.P. (before the pump). Our friendship has outlasted the pump.

Between the ages of six and ten Steffi came to visit me every day. We lived only twenty meters apart and our parents were friends as well, which obviously made the situation much easier. The first years we were busy with my Barbie doll collection, despite the fact that she liked the dolls even less than me. The dolls, however, were omnipresent and so numerous that we eventually decided to play with them in various different ways. We had a small pond in our garden in which goldfish swam that Steffi and I always caught with our bare hands, only to put them right back into the water accompanied by our shrieks of laughter. Luckily the goldfish managed to survive all our childish antics unhurt, even though out of grand ennui, we also occasionally threw Barbie dolls out of the second floor window into the pond, which by the way, was no easy task. On my seventh birthday I was given a little garden house that immediately became our new playground and we finally let the goldfish alone.

My illness was never an issue for Steffi. She knew about it and accepted it as it was. We hardly even spoke about until I was a teenager. For that, I am grateful to her to this day.

In the evening I always had to go to bed at 8 p.m.; however, every evening before going to bed we did energetic exercises. My father tried to transfer all his positive energy onto me. He asked me to look inside myself and to send away all the darkness I encountered, put it all in an imaginary little boat that would take it away. After this, everything inside me should be bright. I really liked this little ritual.

Sometimes before this evening ritual I was allowed to watch a series on TV. Going to an event, to the Vienna Prater (amusement park), or just simply to a playground was at that time just impossible. Most of the time I never got beyond the garden fence.

Going to a restaurant was only possible on rare occasions. My first visit to a restaurant was the garden hotel Altmannsdorf in Vienna. It has such a beautiful, spacious garden–when one sits in the garden the other people are meters away. Thereby the infection risk was very minimal. The proprietor of the garden hotel was Bernd Schmid, a very charming, gray-haired gentleman. My father explained my situation to him before my first visit and from then on he took very good care of me. There was a table that was somewhat isolated and the waiters treated me like a little princess. Bernd sat down with us and I told him that I very much liked to dance to music at home. He loved the Greek Sirtaki and so we quickly found something to talk about. Bernd Schmid became a very good friend who sadly passed away much too early in 2011 at the age of sixty-six. In the garden of the hotel, where we often went for breakfast on the weekends, I spent many happy hours as long as was possible for me, because the backpack with the pump was heavy and my heels very quickly began to hurt.

I went to an ice cream parlor in Altmannsdorf for the first time when I was eight years old. This too was a completely new experience for me–all these different tastes to choose from, one more mouth-watering than the other. My grandmother, who had taken me, and I sat outside at a table somewhat away from the other guests. I particularly liked hazelnut. My maternal grandmother's name was Hildrun; however, as a child I could never pronounce her name correctly, so I called her Tati instead. I still call her this today.

I remember my tenth birthday particularly well, because on it was the day that I was allowed to go to a movie for the first time. The Grinch was playing, a Christmas comedy with Jim Carrey. The Grinch is fantasy figure that lives in a cave and hates

Christmas. Therefore he dresses up as Santa Claus and steals all the children's Christmas presents in Whoville. But one little girl befriends him and through her kind ways changes him completely–for the better of all. He returns all the presents and all the residents, including the Grinch, celebrate Christmas cheerfully together–a Hollywood happy ending. It was an unbelievable experience for me. My parents had chosen a screening during the week, which began in the early afternoon. There were hardly any people in attendance at this time. To be able to watch a film in a movie theater on a really large screen was like Christmas for me. My whole family went along, including my mother Benita, my father Gerry and my brother Patrick.

After this event went so well, a year later I was allowed to go the Vienna amusement park (Prater). Riding on a rollercoaster is still not possible for me today, but riding on the "ghost train" with my brother Patrick was really a lot of fun.

Going to pop concerts, something all young people do, was impossible for me: just too many people, too much risk of an infection, because I cannot afford to get sick. As my father has been a friend of the popular Austrian singer/songwriters Wolfgang Ambros and Rainhard Fendrich for years, I received backstage passes for their concerts. Thereby I was able to see their shows from the edge of the stage.

Once, Franziska Trost, a journalist from the Austrian daily newspaper Kronen Zeitung, invited me backstage for a performance of "The Dome" music show and I was able to get autographs from all the stars that performed in it.

Basically, my daily routine up to this day is defined by one constant: doctor's visits. In Vienna, I used to go four to five times a week to see a doctor. It was part of my normal daily routine–like going to the mall for others. I had check-ups, examinations and treatments virtually on a daily basis. I had different physicians looking after me. One was a doctor from Taiwan, Dr. Tsang, who has been looking after me since I was five. He is an acupuncture and acupressure specialist with an office in Vienna. Children with my illness generally develop a pointed sternum. Through his daily treatments I was able to avoid this unpleasant side effect. He also helped me build up my immune system. What really is unbelievable about all this is the fact that he treated me over ten years free of charge. He never once charged us his usual fee for such treatments. I will be forever grateful to him for all he has done for me.

There also was another physician, a doctor of alternative medicine. She gave me tiny pills called Globuli (homoeopathic globules), which I took for a very long time and which actually had some positive effects. I certainly felt much better after taking them. Through various methods she also tried to strengthen the energy flow in my body. By employing traditional Chinese medical practices she also managed to relieve the pain in my knees. Various "wonder healers" also besieged us, because they had seen and heard about me on television. Once they even danced around me in the moonlight bashing on drums. Finally, only a handful of alternative physicians remained that could be taken seriously.

I often celebrated Christmas in the United States, the simple reason being that I did not take to the cold air very well and staying in Austria throughout the winter could expose me to various infections and therefore was just too risky. For this reason my doctors insisted I spend my winters in a warm climate. We generally spent three to four months in Florida.

This is how the USA became my second home.

CHAPTER 11

My awakening

“I HAD A TUBE IN MY CHEST, AND SUDDENLY MY BREASTS STARTED GROWING.”

Maleen Fischer

I started going into puberty at 14. It was my first year in high school in Florida. My body had begun to develop a bit earlier, but now things really started to change. It is difficult enough going through puberty as a normal, healthy teenager, but having a plastic tube that leads directly to your heart located right next to a very intimate part of your body certainly is something that can be very inhibiting. Especially when a boy takes you in his arms and wants to kiss you–certainly not your everyday experience. Boys my age did not interest me at the time. Compared with girls, they were somewhat behind in their development. My girlfriends and I instead liked to flirt with the eighteen-year-old seniors.

With puberty came the inevitable conflict with my mother. Rebelling against one's parents during puberty might seem to be the norm, but with my mother it went far beyond the norm. We were used to being together all the time. My illness virtually required her constant presence.

Now the time had come for me to cut this parental cord. I was searching for my own life. I finally wanted to be free, meet my friends and have fun, without having to think too much about anything.

During my freshman year in high school boys our age didn't interest us at all. We were attracted to the senior boys.

I soon was part of Kayle's circle of friends, and she was the "It Girl" of the school. Kayle was extremely pretty, with striking green eyes, very tall with an athletic build. Her hair color varied according to her mood, from blond to brown to black. She had a very loud laugh and was a very extroverted person. When she laughed it could be heard throughout the school building. She quickly became the darling of all the boys. Jake was her ex-boyfriend and once he began to get interested in Maleen Fischer, Kayle had a problem with me. She tried to exclude me. I no longer was invited to parties. She openly admitted that she had a problem with me. Only in my last year at school did our relationship return to normal.

At school, we started VNN, Verot News Network, producing our own daily TV program. Our team consisted of nine people. Every class at our high school had its own TV set. Every morning when class began this “homemade” program was a must. It was a very well-produced school television program. I hosted the daily news show, alternating with a colleague, and thereby was on screen three times during the week. We produced almost ten minutes of programming per day. We reported on current events at our school, about sports events as well as about meetings of various school clubs. Furthermore, we also had international news segments. We had excellent equipment and I was able to read the news from a teleprompter. VNN immediately made me very well-known at school. It also raised the interest of the boys in me.

When I turned sixteen things really began to get very bad. My mother and I got into fights almost all the time. I had developed particularly well and was a “real woman”, not only physically, but in other areas as well. This was a very difficult time for my mother. She just could not let go. “You are sick, Maleen, and I just cannot allow you to do all the things you want to do” is what she always said when it came to restricting my interests. She did not want me to go high school parties. I had to be home by 10 p.m. at the latest. She always picked me up, something that is really not very cool at this age. Today, I understand her worries, but in puberty you really want to explore things by yourself and make mistakes, because only thereby do you really grow up.

I went on the first date of my life in January 2010 with Jake, Kayle's former boyfriend. I had known him for a while through a girl who was a year older than me and in love with one of Jake's friends. We ran into each other at various times when our clique met up. Jake was also a year older than me and went to Cypress High School in Fort Myers. My father drove me to the movie theater where we were to meet. It certainly was a strange feeling having your dad bring you to your first date. The theater was in Cape Coral and it was during the week. We watched Twilight, the first part of the saga. We were practically alone in the theater and had our Coke and popcorn in hand. We cuddled a bit, but nothing more. What I didn't know was that my father sat in a restaurant on the other side of the street, waiting. The moment I walked out of the movie theater I knew he was there waiting for me. Big Brother is watching you was the first thought that entered my mind.

I was together with Jake for only a short time. Then there was Alex, who was my boyfriend for a long time, which means in "teen-speak" that we were together for one year. He was born in Russia, but lives in the United States. I got to know him through school and then via Facebook. We spent a lot of time together.

Alex was often the reason for arguments between my parents and me. I was absolutely convinced that my mother could just not let go. I had real teenager affectations at the time.

I wanted to sleep over at my boyfriend's; I wanted to spend as much time as possible with him, but my mother was very much against this.

We got into terrible arguments. My mother and I both have very loud voices. When we argued the walls literally shook. My mother even confiscated my cell phone when she was mad at me. “You are not allowed to see your boyfriend,” she repeatedly told me.

Claudia and Carina, my two teachers, were in Florida at the time. They could not stand Alex and were of the opinion he was “not the right company” for me and completely sided with my mother. All of a sudden I had three women against me. I couldn’t stop yelling and was really bitchy, like a drama queen. I began to put on heavy makeup, using a lot of black kohl around the eyes, and wore mainly black clothes.

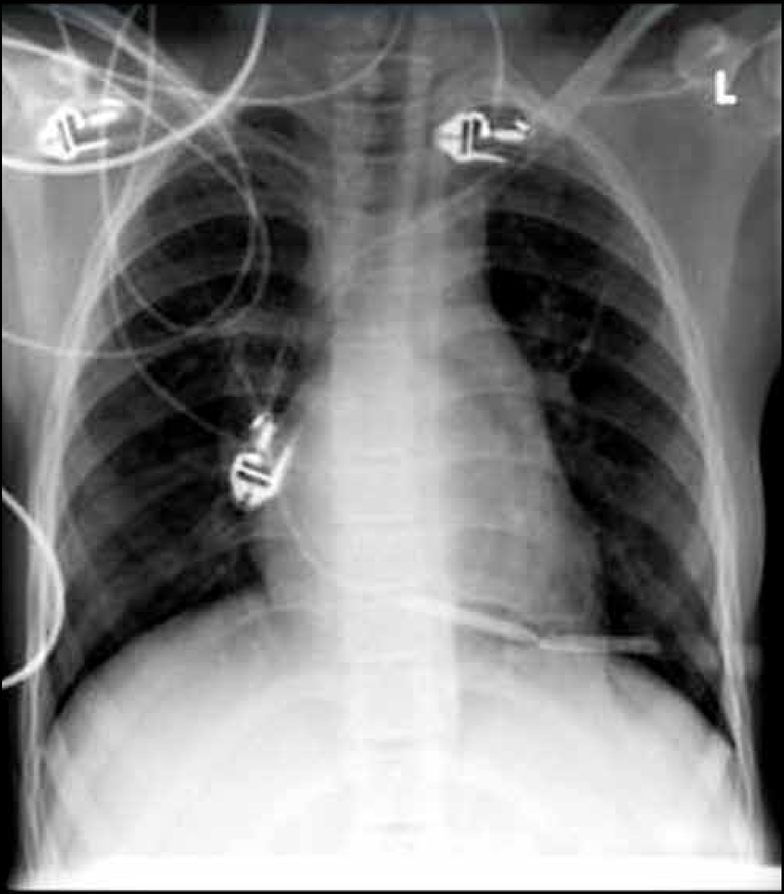
During these “eruptions” of puberty my father remained diplomatic. “I don’t want to get involved; these are your issues” is what he mostly said, and withdrew from the confrontations. I understand his position: lots of women screaming at the tops of their lungs and arguing is something a man has difficulty dealing with and knows he has nothing to gain by sticking around.

At seventeen our relationship began to normalize again. My mother and I were and still are best friends, even though my puberty sometimes stood between us. Between best friends such phases are normal, during which you keep out of each other’s way, or just need some space for yourself. You can be there for each other, but you don't always have to be together.

I am a girl just like millions of others–with wishes, desires and dreams. Now, I am almost grown up and still have plastic tube near a very private part of my body–one that leads directly to my heart.

The end of school also brought about the end of my puberty. Now I am a young woman. I am sure that I will miss school very much, as well as my girl friends, as well as those that I got to know better over time. On our last day of school Kayle came up to me, the former "It Girl" of our high school, who in the meantime had been replaced by younger and even more attractive girls. She hugged me with tears in her eyes and said, "Please forgive me, Maleen, for how I treated you for a long time. I really like you and I will miss you very much."

I looked at her and smiled. "We both have gotten older, Kayle, and smarter. That's the way life is."



X-ray photograph of my chest, AKH Hospital Vienna

Fischer Maleen

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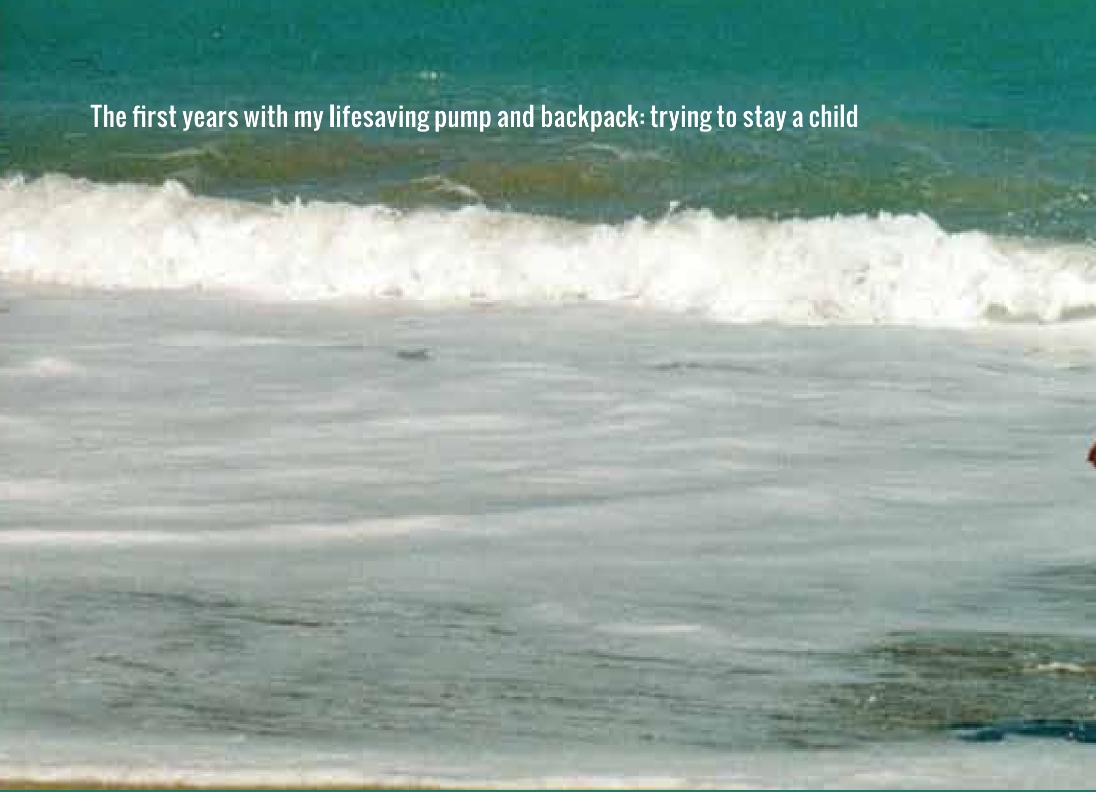
With Dr. Robyn Barst, my hero and the physician who saved my life

Changing the catheter at the AKH Hospital, Vienna, 2004

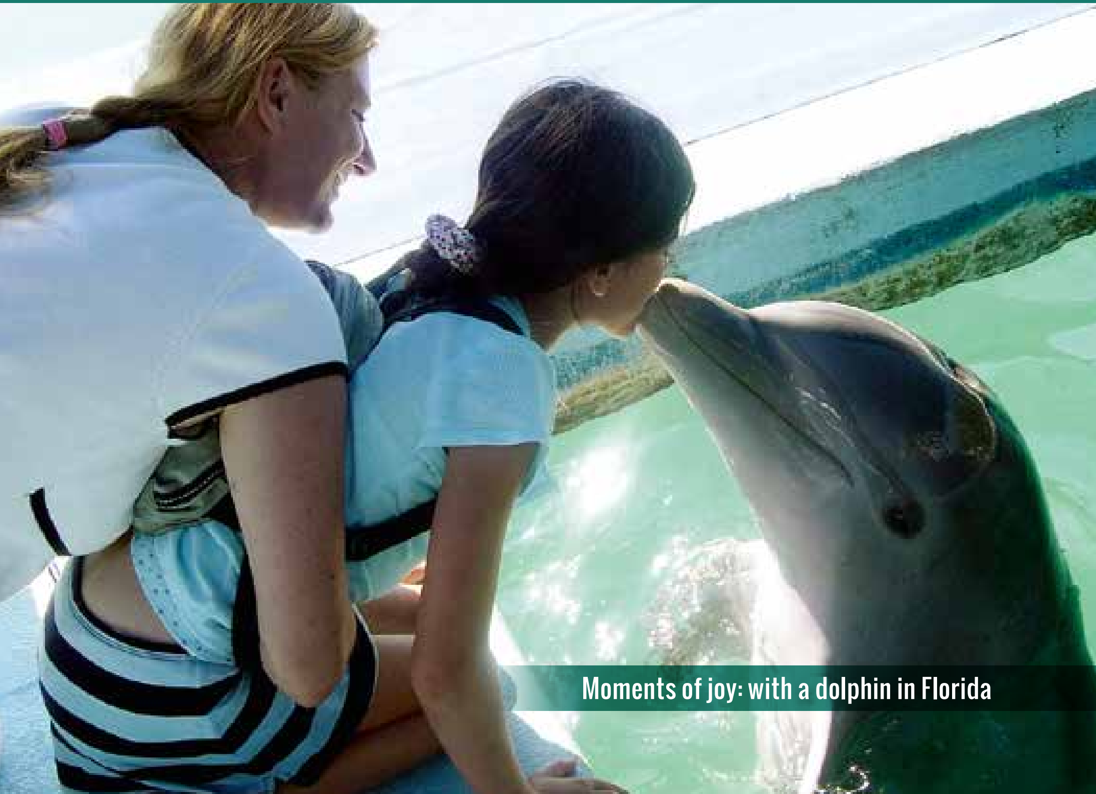


The first years with my lifesaving pump and backpack: trying to stay a child

▼ With Dr. Manfred Marx (below left), my physician, at the AKH Hospital in Vienna

▼ Ultrasonic control at the Presbyterian Hospital in New York City

▲ Angel from just outside the door: my best friend, Steffi



Moments of joy: with a dolphin in Florida

▲ With my friends, the famous Austrian pop singers G. Danzer, R. Fendrich and W. Ambros

Breathtaking charity concert for our PH initiative

My family, my little world: with my father (Gerry), mother (Benita), and dogs (Dorée and Ebony)

My 11th birthday: happy to be alive

▲ At home in my room ▼ My first television appearance at ORF TV in Austria

▲ VNN at Verot High School: we produced a television show!

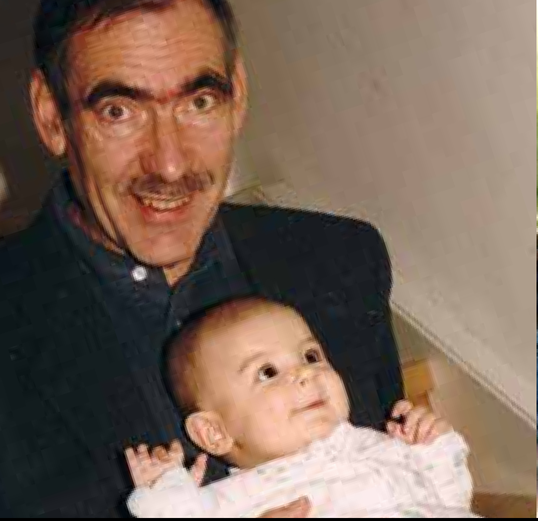
In 2010, I received the Leading Ladies Award

With Dominik, my love, at the high school ball

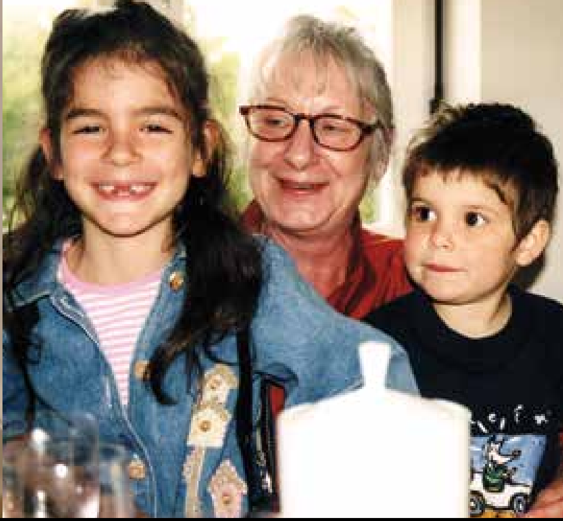
▼ With Karl Lagerfeld in Paris and Passsau (below) ▲

▼ With Marilyn Manson

My secret passion: painting



▲ As a baby with my grandpa, Helwig



With my grandmum Hildrun and cousin ▲

▲ My first day at school: learning at home

With my grandparents, Gerhard and Erika

My big brother, Patrick

CHAPTER 12

Learning for life

From early on I was a good student. From grammar school to my second year in high school I received only A's on my report card. In my third year of high school I got my first B–in math.

The first four years of schooling, equivalent to grammar school, I was taught all the subjects at home by Sabine. Because the subject matter was much more extensive in high school my parents looked for an additional teacher who could help me with the expanded subject matter. Early on my father tried to find a high school that would supervise my studies. The idea was that I would receive the subject matter by mail or email and only have to go to the school for the exams. My father never has told me how many schools in Vienna refused his requests, but it seems that it was quite a few. Finally the Dominican Sisters School (Domikanerinnen) agreed to supervise me. My parents had the idea to find a high school graduate who had particularly good grades in important subjects and wanted to earn a bit of extra money to assist me. A young lady named Claudia got in touch with us. She became my teacher in math, physics and chemistry until my graduation from high school. The Dominican Sisters recommended her to us, because of her outstanding scholastic achievements at the school. She had an immeasurable amount of patience with me and was able over and over again to gently and calmly explain various processes and correlations, which I somehow had difficulty grasping.

Over the course of time I would have more and more teachers. Claudia's sister would tutor me in geography and history. Today, Claudia is 24 years old and Carina 22; both are studying medicine. Claudia at the time had just graduated from high school and Carina came a year after her high school graduation to tutor me at home. I also had a Spanish teacher for two years, as well as an English teacher called Gretl for three years, who not only taught me proper grammar, but the typical American pronunciation. Over the course of my stays in the United States I was able to improve my English to such a degree that now many Americans assume I am a US native.

We had to arrange the teaching schedule according to the itinerary of my teachers. This meant that there were no set times and we had to make up a new one every week. This was very strenuous and certainly more work-intense than at a normal school. The usual breaks after fifty minutes of class were not part of our learning schedule. We mostly did blocks of two-hour long stretches. At the beginning it was two of these stretches, then three, and later we did up to four a day when there were exams or tests. This individual tutoring certainly has its advantages, but also many disadvantages. You have to be much more concentrated than in school, because the focus of the teacher is entirely on you. Questions that a teacher generally asks the whole class can be answered by anyone according to whim and mood. If you don't respond at all during class, the teacher might ask you a question directly. However in my case every question was directed at me and I had to answer every question by myself. At school you have the luxury of thinking of other things for five or more minutes–this is not possible when you are being tutored privately. Letting my mind wander was just not an option–it would have been noticed immediately.

On the other hand by being tutored privately you learn a lot more. If there was something I just did not understand, it was explained to me for as long as it took for me to finally grasp it. This certainly is a major advantage over classroom learning.

The subject matter to be covered was specified by the school and adapted for the respective semester. A fellow pupil, Julia, always came by my house to bring me the schoolbooks and notes I needed. My teachers always tried to go through the same subject areas that were being taught in the respective school level and according to my age. If we were faster in a subject and further along with the required material, we moved on to another subject until we again reached the same level.

In the USA I was finally able to attend a school in 2010–the

Bishop Verot High School. This was a completely new experience for me. Initially I had to get up at 4 a.m. because I did not know how much traffic there would be in the early morning and I also had find out just how my new daily routine–everything from washing, getting dressed and getting all my books and notebooks ready–would take, so I first had to practice. I had no idea what to expect from an American high school class. I didn't like the school's dress code at all, but it was mandatory. It consisted of a polo shirt in various colors with an embroidered school emblem–the letters BV in black and gold–and khaki pants or relaxed fit shorts. Pants in my favorite color were not allowed, nor were jeans or stretch pants. Girls were only allowed to wear shoes with low block heels or ballerinas. Boys could wear sneakers, but open shoes were forbidden.

On the first day of class I came into the room and there were already twenty students waiting, and I did not know a single one. The advantage was that I did not really know what school was like. Especially in the United States I had no idea what to expect. I only hoped that there would be no obnoxious "bitch" in my class, like the ones you always see in American high school movies or in sitcoms, that I would have to argue with all the time and be subjected to personal animosities. I was really afraid of a situation occurring were someone shoved me in such a way that my lifeline, my tube, became disconnected, was ripped out, or broken.

The first hour of a school class that I experienced in my life was biology. At the beginning I didn't understand a word. For every subject there was a separate class. The learning structure is completely different than the Austrian school system.

There is a science class that also covers biology and other sciences. The subject matter is dealt with more slowly and is presented in a more understandable way. A very nice lady from the school administration led me to my desk. I sat next to two very friendly girls and, from the first moment on, I felt very comfortable here. Along with science class I also had a math class, an English class, a health class—which covered health issues and household economics—as well as a Spanish class.

The school administration informed all the teachers about my health condition, but not the students. If and when I told someone was left up to me. So at the beginning I did not say a word to anyone. I wanted to wait and see how things developed.

My high school had a reputation for being very strict. Every student had his/her own locker. Additionally, at night bars were rolled out and locked to protect the lockers. In the morning they were unlocked and rolled back to the walls, where they remained throughout the day. One morning at the beginning of my high school days I went to my locker and found this gigantic girl standing in front of it with a very mean look on her face. She was almost two heads taller than me, with a very muscular build. I said "Hi" and waited to see how she would react. She hissed at me and accused me of saying bad things about her–something that was not true. I did not react directly and decided to ignore her, mainly because I had no idea what she was talking about. This really made her angry. She swore at me and pushed me against the locker bars. I fell down and she ran away. I checked to see if everything was okay with my tube and pump. Everything seemed to be in place, but I decided to call my mother anyway. She immediately informed the school administration about the incident. The attack really made waves at the school and the girl's parents had to come to see the principal, who explained just how life-threatening such an attack could have been for me. The girl apologized to me and, as a result, word of my illness quickly spread throughout the school.

I never again would have any similar problems at my high school.

CHAPTER 13

Let’s savor the moment

„DEAREST, DON’T LOOK AT ME WITH YOUR EYES SO DEMANDING. BECAUSE WE ARE FATHER AND SON DOES NOT MEAN I CAN DO EVERYTHING. I CANNOT MAKE YOUR DEAD CAT ALIVE AGAIN. HERE AND NOW, I CANNOT SAVE YOU FROM THE PAIN. IF A GOODBYE HURTS YOU THEN YOU ARE THE WISE SOUL THAT IS STILL HALF LIVING ON THE OTHER SIDE. TEACH ME WHAT WISHES ARE REALLY WORTH WISHING FOR. AND BE PARENTS FOR EACH OTHER, DEAREST, WHAT DEEP JOY! ONE HELPS THE OTHER, STEP BY STEP BACK INTO THE LIGHT.”

André Heller, Liebster Du (Dearest you), written for his five-year-old son, Ferdinand

Being sick makes one lonely, for we have never learned to deal with illnesses. What does one say to a seriously ill person? How does one deal with their desperation, their helplessness and their fear? The helplessness of those that encounter a sick person is comparable to the helplessness of a sick person understanding and dealing with his/her disease. One just does not know what to do. In the course of my life I have often experienced people, who once they heard the story of my life and its travails, just did not know how to react toward me–once again completely helpless.

Dumbfounded. This is how many people react to my illness, how they approach me. And this is wrong. People who are ill long for closeness to relieve them of their loneliness. Illnesses should not create barriers, but usually this is what usually happens. What does one say when encountering a seriously ill cancer patient, who has lost countless pounds, has shrunken jowls, gray and wrinkly skin? "It will get better" and "Don't give up the fight!" are the platitudes that one always hears, before the unbearable silence sets in. Confrontation with sickness is something that our society tends to avoid–people who are ill are avoided as well; they are ostracized. It's better not to see them, better not to be confronted by suffering; it's better to stay in one's still–ideal world.

In dealing with sick people one can only do one thing wrong: doing nothing and avoiding them. When I was small I had the feeling that I was imprisoned at home. I was not really allowed to go out of the house except to quickly rush to get into the car, only to get out again when no one was around. We hardly went to restaurants, because people were there and smoking was still allowed virtually everywhere. I spent the first part of my childhood at home and wished to have other children, other people around me. I would have been happy to have others close by me and for them to be able to deal with my illness in a neutral manner.

I don't want or need any pity. I want people to see me as I am: as a young girl that wants to savor every moment of her life. I want them to laugh with me, to be happy, to have fun and not just feel pity for me. I would wish that all people could be this way with people who are seriously ill. We sick people do not want to become depressed, because our surroundings, the people around us, are drowning in pity. Let's savor the moment!

A doctor at the AKH once told my parents about her experiences with terminally ill children. She explained that they had an almost wise approach to death, completely different from dying adults. They had an unbelievable dignity and, calmly asked questions about what the end or heaven would be like, if they would be in pain, or if dying "would hurt". Mostly they remained serene, in harmony with themselves and went without sadness into the light. With their parents it was completely different: they felt powerless, distraught, full of fear and often in complete despair and let their children feel their pain. Therefore the terminally ill children were more worried about how their parents would be able to cope with the death of their child.

Isn't that really crazy? The dying child cares for his/her parents, because they–the adults–cannot cope with the situation?

My parents are a bit different. I did see them every now and then being distraught. However, from the very beginning they conveyed something positive, that things would be all right, that I still had a lot ahead of me. If they had not battled for my survival from the very first moment they heard my diagnosis, my story could have had taken a completely different course.

The lack of other people in my earliest childhood determined my relationship and closeness to my parents. My mother Benita is like my Siamese twin. From the very beginning she spent virtually every day and night with me.

My father Gerry was also always there for me. He has spent my entire life battling for me, searching for doctors who could heal me, or at least treat my illness and make life better for me. He contacted pharmaceutical companies and pleaded with them to do research on pulmonary hypertension, as well as trying to find investors to fund the research.

My grandmother Tati has always been very present in my life as well. When my mother had to work, she always stayed with me, or when my parents went out for the evening–something that hardly ever was the case, and then only when I already was eight or nine years old. I never had a babysitter, because my parents thought that this was too risky for me. Someone had to watch over me who knew what to do in an emergency–if, for instance, my pump stopped working–because it all had to be dealt with in a matter of minutes in order to keep me alive. At the beginning we still had the "big change", which required the tube that was close to the heart to be regularly replaced. During this exchange it was necessary to always hold the connection up in order for it to remain sterile. Tati was able to do this, if was necessary.

When I was small she would come three or four times a week to visit. She is quite a remarkable person. Today, she is in her late sixties and one of the best grandmothers one could ever imagine. Tati got divorced when my mother was twelve years old. I know my grandfather, Helwig, but we hardly ever see each other, as he lives in Strasbourg, France. I don't even call him Grandpa. Our relationship is very loose, even though he is a very nice, intelligent man. He is a professor in Strasbourg, also works for NASA and specializes in radioactivity and nuclear power plant studies. I saw him for the first time at the birthday celebration of Tati's sister for which he flew down to Vienna. He then came every two years.

My father's parents are also still alive. My grandmother Erika and my grandfather Gerhard I see once a month, at Christmas and on my birthday. If I am not in the USA, we always spend the 26th of December with them in the country in Lower Austria. Grandpa I see more often, because he still works with my father in the Schnapps Museum. At Christmas, Papa's cousin with her three children, Jessica, Jennifer and Jamie, also visited.

Also part of our extended family is Mama's sister Arianne with her two children, my cousins Nils and Kira.

It really is quite wonderful to have a family–to be with people for whom you don't have to act differently than you are, who know you and love you with all your weaknesses, problems, fears, or idiosyncrasies. It helps to have a family when you have to spend most of your time at home and it seems like the walls are ready to cave in and bury you in despair.

CHAPTER 14

Maleen, home alone

As a child I never liked the story about Rapunzel. The fairy tale about an unhappy girl that is locked away in a remote tower somehow always reminded me of my own situation.

Maleen, home alone–is how I often felt. How does one manage to get through the seemingly endlessly long day, after my teaching sessions have finished? Being at home can be very enjoyable, but it also can be very boring.

Reading was my first great passion. I literally devoured books and could hardly stop reading when a story really fascinated me. TV also was an option. But that too can get on one's nerves. My grandmother Tati and my friend Steffi were my connection to the outside world. Then there was my computer, but it never really became my friend. I am not a nerd who stares at a screen the whole day or plays computer games. That actually drives me crazy. My Labrador Dorée used to be my most faithful companion. I played ball with him in the courtyard or ran with him in the woods. I always tried to distract myself with something new. Sometimes I would draw. I would print out a picture from my computer, put a piece of paper over it and copy the lines. Then I discovered writing. I really liked writing short stories and poems. I spent a lot of time writing these. I found crime stories very exciting. I would often pretend that I was a detective or an agent who had to solve a very difficult case. Poems I mostly liked to write in English. I really adore Greek mythology, and the stories of the ancient world have always fascinated me.

I wrote most of my poems about Joan of Arc, The Maid of Orléans, the French heroine and Roman Catholic saint who fought so bravely for France during the Hundred Years' War against the English and their Burgundian allies. She must have been a very strong, fascinating woman. She was betrayed and captured, then sold to the English, sentenced to death by the Inquisition and, on the orders of the Archduke of Bedford, burned at the stake in the marketplace of Rouen. I have no idea why Joan of Arc's life has fascinated me to such an extent. Maybe because she gave her life for her beliefs and fought bravely to defend these, yet in the end was betrayed and put to death. Writing about her almost became an obsession. To this day I still have a great respect for fire, not to say a good portion of fear as well.

Despite these sometimes very intense "distractions", again and again it felt like I was just killing time. How do I manage to get through the next hour? I have posed this question often in my life.

Being sick can become very boring.

CHAPTER 15

Don’t let fear into your heart

> “OUR LIVES LAY IN GOD’S HANDS. HE LEADS US BY AN INVISIBLE CORD ON THE PATHS WE HAVE CHOSEN, TOWARD THE INTENDED GOAL.”
>
> Maleen’s great grandfather Ernst

I am not afraid of death.

Many people have asked me about the inevitable and are very surprised by my response. From the very second of our births only one thing is certain: at the end of our journey through life, death awaits us. No one knows what might come after. No one can actually tell us about his or her experiences in the “beyond”, because no one has ever really returned. We do not know if death is actually the end or just a transition to something unbelievably beautiful. Why should I be afraid of something that I know nothing about, have never seen and never experienced?

As a small child I was afraid of needles. Too often they were stuck into my little veins. I knew what they looked like. I knew the feeling when the metal hollow needle with a gauge value of 24 and an outer circumference of 0.7 millimeters was stuck into my body. I was well-acquainted with my enemy. I knew what to expect. I was afraid, because I was conscious of the fact that every injection, every peripheral vein catheter inserted is associated with pain. It hurt.

I am afraid of needles, but I am not afraid of death.

This approach works quite well for me. Naturally, there are phases in my life when I am not so sure about things. I have had to be anesthetized many more times than most young people of my age. The seconds before a procedure, before a difficult operation, the moments before you doze off are not coupled with a concrete fear, but with thoughts like, "Will I wake up again?" It's not a feeling like, "Oh God, I am dying now!" but more a kind of uncertainty that overcomes you.

I don't know how often I have been told that I am brave. Am I really, just because I refuse to die, because I continue to battle the inevitable? What does brave mean? Is it saving a child that has fallen into raging river and is in grave danger? Is it standing in front of heavily armed terrorists like at the Westgate Mall in Nairobi in order to let other innocent bystanders escape? Is it a fireman who battles his way through burnt steel and smoke in the World Trade Center twin towers, which could collapse at any moment, to save those trapped inside? There are so many people in our world that are true heroes and have done much more than I. They are brave; I am only a tireless fighter trying to survive.

There have always been situations in my life when my pump threatened to fail me, when infections threatened my health and once again my life hung in the balance. In such moments I tried to be brave. But mostly it was the knowledge that anything else in this situation would not make much sense.

It was April 2009, a cloudy day in Florida. My father was in Jupiter, about a four-hour drive from our home, where he wanted to play golf with a friend. My mother was spending a few weeks with me in Cape Coral and after she picked me up from school we went to eat lunch. I had just ordered a Philly cheese steak when I suddenly noticed that some kind of liquid was dripping down my back. I went to the restroom and looked at my back in the mirror. One look sufficed; I immediately knew that a part of my tube must have broken. I was not too worried, because the tube consisted of two parts, one located between the pump and a transparent centerpiece. It has to be replaced once a week–something that is easily done. The other tube is white and connects the centerpiece directly with my heart. It is implanted and can only surgically replaced.

We drove home and my mother prepared everything for the “Big Switch”. This calls for the transparent tube to be replaced and cleaned. As soon as the pump is started after this “Big Switch” the tube is routinely disconnected using a plastic clip in order to ensure that it does not have a leak. We did this, but the pump did not start operating as it should have. It gave cause for alarm because if the connection between the tube and the pump had been intact, even the smallest leak or break would inevitably cause a shrill, loud signal to sound. This, however, could not be heard. It was not a good sign.

There were only two possibilities. The first possibility was that the new, unopened tube had a defect, which somehow did not seem very likely. The second possibility could only mean that the white tube leading directly to the heart had a leak. This meant we had to get to the nearest hospital as quickly as possible. My mother instantly picked up the phone and called my father, who immediately turned around and was on his way back to Cape Coral. My mother taped the apparently damaged connection piece and continued to check it over the course of the next few hours. It was late at night when my father finally made it back home and immediately started calling various hospitals in order to find out which hospital in the vicinity was familiar with invasive tubing. We had never had an emergency in Florida before, so this was a completely new situation for us.

When I woke up the bandage was wet again–an alarm signal. “We immediately have to go to the hospital,” my mother said nervously and quickly packed up everything we needed. She helped me get dressed and put me in the car. My father took the “repair kit” out of my closet, which was always there for just such incidents, as well as a second practice kit (an expired kit). It was everything an experienced surgeon needed in order to repair a torn cannula to the heart and reconnect the link between the pump and the heart. As I said, everything an experienced surgeon needed, mind you.

The problem with this procedure is that it is not normally taught as a part of surgical training. Only specialized hospitals with their own wards for pulmonary hypertension have experience with my disease, but even there not necessarily with this procedure. Therefore, each “repair kit” also contains a medical specialist’s instructions on how to carry out the procedure.

The nearest hospital was directly in Cape Coral. My parents rushed me into the emergency admission and explained the situation. The doctors on duty deliberated for a short period of time, only to decide not to attempt the operation–after $1000 had already been debited from my father’s credit card for taking my blood pressure and other basically unnecessary procedures. In order to understand these decisions it is important to know that for American hospitals and their physicians’ liabilities are very different than those generally valid in Europe.

If a procedure goes wrong, the hospital and the surgeons responsible can be sued for millions in compensatory damages. This is a risk that many doctors just will not take, particularly when they have absolutely no experience with a surgical procedure. We left the emergency admission and got into our car.

Our second attempt was the children's hospital in Fort Myers. A young doctor immediately said she could do the procedure. However, after her tenth unsuccessful attempt to insert a vein catheter—she was not able to find a vein—I asked her to stop everything immediately. She looked at my mother in exasperation and said, "Tell your daughter to calm down and let me do my job."

My mother, however, responded: "She is your patient, not me. If she does not feel comfortable with you, then I understand and respect her decision."

When I threatened to pull the needle of the crook of my arm, the doctor finally relented.

Once again we sat in the car and my father began to make calls. Finally a nurse we knew recommended the Lee Memorial Hospital and a specific surgeon, Dr. José Francisco Manibo. She told us that he has many cancer patients who have similar catheter connections with pumps and therefore has experience with these. She called him up–in the meantime, it was 2 a.m.–and he immediately got into his car drove to the hospital.

We also drove directly toward Lee Memorial Hospital. “How are you doing; everything okay?” my mother asked me. I said yes, even though I felt slightly dizzy. I was completely calm and that surprised me. I was not nervous at all. I was not crying; somehow I had confidence–in my mother and that everything would turn out all right and in life. The calmness that I radiated transferred to my mother.

Dr. Manibo, a physician in his late thirties of Spanish descent, was waiting for us at the hospital. He greeted me and looked into my calm eyes, smiled and said, “Okay, where are the instructions? Let me look at them.” My mother gave him the two “repair kits”, the expired one on which to practice and the intact one for the procedure. He took some time to study the instructions; he then went over to my mother and began to go through the procedure with her, as she was going to be his assistant. Dr. Manibo spoke honestly to us. “I have never done a surgery like this before. I normally do not repair these things, but exchange them.” Not exactly the reassuring words we were hoping to hear…

“But,” and this was the decisive statement that rekindled our hopes, “I will try to do it anyway if you want me to do it.” My mother hugged him. I was prepared for the procedure. We were brought into a separate room of the emergency unit. A nurse went through a questionnaire with my mother. Only later did we find out that it was their way of making sure that my mother was calm enough to work through the procedure with Dr. Manibo. She was, because years before in New York she had been schooled for just such a procedure. After sterilizing everything, Dr. Manibo said, “Whenever you’re ready, we can begin.”

First a vein catheter was inserted, through which the prostacyclin would be injected into my body for the next twelve hours. As the tube was now in my elbow and not leading directly from my chest to my heart, the dosage had to be slightly increased. Dr. Manibo cut through the tube, inserted a small metal piece into it and slid a plastic pipe over the cut. Into this a special glue was injected that could, if one was not careful, clog up the entire tube, which would have necessitated an immediate emergency operation. This was the worst-case scenario, which we certainly wanted to avoid. Everything had to completely sterile. Dr. Manibo had extremely steady hands. I was not allowed to move. The tube was placed on my body and I had to remain absolutely still for four hours–not one movement, not even a millimeter. Even the smallest jiggle could invariably have had serious consequences and the whole procedure would have been for naught. After a further eight hours I finally was allowed to go the restroom, but otherwise had to remain in bed.

Finally, after twelve hours my mother reactivated the repaired tube–not Dr. Manibo, who did not want to take the risk yet. If the pump detected resistance, perhaps caused by a clogging of the tube going to the heart, an alarm signal would immediately have sounded. My mother and I looked at each other–not a sound. We smiled broadly in relief. The pump to my heart was functioning perfectly again. After twenty-four hours of chaos and stress, we all felt an immense weight lifted from our shoulders. The repaired tube would go on to last another three years after this emergency procedure.

CHAPTER 16

A lonely battle

“DR. BARST, WHO EXAMINED MALEEN, SAID TO ME, ‘GET ME 10 MILLION DOLLARS AND I WILL FIND YOU A CURE.’”

My father, Gerry Fischer

When my parents were confronted with the fatal diagnosis about my illness, the situation regarding pulmonary hypertension was dire, if not hopeless. There was no known cure. There also was very little interest in actually finding one. Too few people around the world suffered from this rare disease. If it’s not a potentially lucrative business, then there is not enough incentive to invest in research. That’s the bitter truth.

Imagine your child is dying and no one is doing anything about it.

This was the situation my parents found themselves in fifteen years ago. However, anyone who knows my father Gerry knows that he is just not willing to accept this supposed fact as a foregone conclusion. At that time the Internet was still in its infancy and searching for information or contact addresses hardly brought about any viable results. Searching for information regarding unusual or rare issues pretty much showed the limits of the search engines at the time. So instead one had to meet people, use the telephone, go to libraries, refer to specialist literature and have a great deal of patience.

My father started on his quest to learn more about my illness, trying to find doctors and scientists around the world who were doing research on my disease. He called physicians, who in turn called colleagues abroad who knew someone who in turn had heard about someone who just might know something. “The first weeks were pure hell, as we only found doctors who had zero expertise regarding PH” is how my father remembers the beginning of our battle for my survival. “It was a strange time. I lived off Coke and sweets and hardly slept, because I was just too hyper to sleep. Every night I spent long, agonizing hours searching the web, which at the time was nothing like it is today. I was certain about only one thing: I had to find a doctor who could save my child.” His main contact was Prof. Sheila Haworth at Great Ormond Street Hospital for Children in London. She was the first person to tell him about a pump that was being used to combat pulmonary hypertension. “I couldn’t imagine what this could be.”

Dr. Robyn Barst, the head of the Pulmonary Hypertension Center at the Presbyterian Hospital, who my father found in

New York after an exhausting search, saved my life with this pump. Flolan, the medication made by the pharmaceutical giant GSK, was the only drug at the time that was able to help me–and I still use it today. It is a prostacyclin and was developed for intensive care patients to help resuscitation measures in trauma units. By chance it was discovered that it also could be used to treat pulmonary hypertension. However, Dr. Barst also made it very clear to my father that a cure was only possible in the distant future and if millions of dollars were invested into researching the disease.

Pulmonary hypertension is a rapidly progressive disease, which damages the lungs and the heart, usually resulting in death. It leads to an increase of blood pressure in the pulmonary artery pulmonary vein, or the pulmonary capillaries, which together are known as the lung vasculature. The most common symptoms are shortness of breath, blue lips, fatigue and leg swelling. Many people wonder why they have shortness of breath of after taking only a few steps on a staircase. This could be an early sign of pulmonary hypertension. The symptoms of pulmonary hypertension are often not very specific, which is why patients with PH often are wrongly diagnosed with asthma or other illnesses.

The bitter truth is that this disease can affect anyone of any age at any point in his or her life. Even an adult can, from one day to the next, become a victim of PH. Those between fifty and sixty are most susceptible. An early diagnosis is essential for survival.

If the disease is not treated, fifty percent of those affected die within a span of two years. The mortality rate for pulmonary arterial hypertension is even higher than that of breast or colon cancer.

Today it is assumed that approximately twenty-five million people around world are affected by pulmonary hypertension. The WHO still classifies it as a "rare disease".

There are a number of life-prolonging pharmaceutical therapies; however, most of them are only suited for one of the five types of pulmonary hypertension: PAH. The only potential curative treatment for some patients is a surgical procedure for chronic thromboembolic pulmonary hypertension (CTEPH). For this form of PH, we recently got the first non-invasive treatment this year. Even though some patients could qualify for a heart-lung transplant, it is not always the solution, particularly when the cause has not been established. If the cause remains undiscovered then the new lung could be damaged again. There are not enough donor organs and not every person affected meets the necessary requirements. Therefore a precise diagnosis often makes the difference of living with or dying from this disease.

It must have been a very lonely and difficult time for my father when he decided to give up his previous life and dedicate himself completely to helping me with my battle against this disease. "There was no way I was going to allow my daughter to die just because no one wanted to do research on pulmonary hypertension. Therefore, I decided to commit myself to drumming up funds for financing the necessary research as well creating a better awareness of and acceptance for those affected by this disease."

The many obstacles that had to be overcome already started with the choice of a supplementary health insurance. Initially all insurance companies refused to insure me.

"Finally it was the Allianz-Versicherung (insurance company) that, despite Maleen's condition, acted in a very humane manner and insured her" is how my father describes the actions of an insurance company for whom compassion is still a measurable quality.

It soon became clear to him that he could not fight the battle to keep me alive by himself. He needed allies–people who suffered the same fate, doctors who were engaged in the battle to find a cure, or least a legitimate treatment, as well as parents who faced the same fears. Therefore, in 1999 my father Gerry Fischer established the Kinder PPH Forschungsverein (Children's PPH Research Association) as a platform to help combat pulmonary hypertension, an organization he still manages to this day. The association was situated in two small rooms in the Vienna Schnapps Museum that he managed together with his father–my grandfather–after he sold his travel agency in order to be able to have more time for me and help me deal with my disease.

He called his friends, Austrian pop/rock stars Wolfgang Ambros, Rainhard Fendrich and Georg Danzer, and asked them if they would make an appearance at a PH fund-raising dinner. All three immediately agreed. This gala dinner, an evening in January 2001, with the motto Atemberaubend ("Breathtaking"), brought in 30,000 Euro. Numerous other activities were to follow and "Breathtaking" became a series of events.

In 2002 my father also took over the self-help group, Lungenhochdruck (Pulmonary Hypertension patient association), which had been established two years earlier by PH patient Klaus Körner, who sadly died from complications caused by the disease one week before his 30st birthday.

In 2006, famous Austrian musicians Rainhard Fendrich, Wolfgang Ambros and Georg Danzer appeared as Austria 3 at a charity concert for pulmonary hypertension in the Vienna Prater (amusement park). It was to be the last concert by Austria 3 in Vienna. Thirteen thousand people attended the show and cheered me as I went on stage with the popular radio presenter Matthias Euler-Rolle. Standing in the gleaming spotlights I proceeded to thank all for coming to the event. I just started talking and thousands of people cheered me on. I have seldom been so touched as I that I was at that moment. My father was so proud of his 11-year-old daughter.

In the same year Circus Roncalli also held a charity gala for us in a tent right in front of the Vienna City Hall and three years later they did it again. I was allowed to make an appearance with the world champion magician Tony Rei. To this day, I have never revealed to anyone the secrets behind his fascinating illusions.

In November 2008, Atemberaubend was staged at the Wiener Stadhalle (the main Vienna events center). Christian Kolonovits (one of Austria's most accomplished composers, the Mozart of our time) directed the Vienna Symphonic Orchestra, and many of Austria's most popular rock and pop stars made appearances, including Wolfgang Ambros, Christina Stürmer, Stefanie Werger, Opus, Marianne Mendt, Andy Baum, Schiffkovits, Valerie, She Says, Gary Lux, the A3 band and Mondscheiner. The net proceeds of the event again were used to support research to find a non-invasive way to measure the status of and raise awareness for pulmonary hypertension.

Generally, children with pulmonary hypertension must undergo a right-heart catheter procedure every six months, or at least once a year, when a new medication is employed. The procedure involves an examination during which a small tube with a camera is slid over an artery into the heart. This means a stay at the hospital, many needles, fear, anesthesia and the traumatic experience of being rolled into the surgery room on a hospital bed. A small hole is made in the groin that, due to the blood thinning drugs, takes a very long time to heal. The PH Association has set itself the task of facilitating and supporting research to find a better and less bloody examination procedure. The net proceeds of Atemberaubend were used to support these efforts.

On the Thomas-Oswald-Platz, located in front of the Vienna Planetarium in the Vienna Prater, the Platz der Meilensteine (Milestone Square) was created. For a minimum donation of twenty-five Euro, a milestone–a brick embedded into the ground with one's name and a saying or slogan of one's choice–can be purchased as a sign of solidarity with those suffering from pulmonary hypertension. Currently over 15,000 milestones have been embedded, with the proceeds going to the PH Association and for research projects.

My father has also spoken with various government officials and politicians, including the Austrian Chancellor, the Austrian Minister for Health, and EU commissioners in order to obtain their personal support for research projects regarding this disease. He received the 'Golden medal of honor for special achievements for the Republic of Austria' from our Federal President.

He also began to speak with several decision makers in order to convince them to invest money to find better methods of treatment for this debilitating disease. "At the beginning I hardly was able to get appointments. However, after we continued to get more and more publicity from various media sources, the doors suddenly began to open for us."

Soon the website www.lungenhochdruck.at was put online, which provided comprehensive and well-founded information regarding pulmonary hypertension. It also presented special centers and offered the possibility of making donations to facilitate national and international research efforts. A medical advisory board was also created that included numerous leading experts in the field.

And finally, my father initiated a billboard campaign throughout Austria to create better awareness of the problems of pulmonary hypertension. The slogans and subjects were very dramatic and disturbing. One billboard showed a little girl with her cuddly toy in child's room, only instead of a bed in the room there was a coffin. Another picture showed a young woman at a bus stop with one leg in a casket. There also was a man in a garden watering his plants from an open casket. The slogan was very disturbing and stayed in people's minds for a long time: "Thousands of people in Austria suffer from pulmonary hypertension–without knowing it."

In 2011, for a further billboard campaign, everything was immersed in blue. People in the posters had signal blue lips and hands. The clear message: "Problems climbing stairs? Tired? Breathless? These could be signs of a disease that can kill."

Such public campaigns move people, shake them up, make them more aware and force them to think about an illness that hardly anyone had heard about before–and, above all, hardly took notice of. When it is about our cause, my father can fight like a lion. The billboards were printed free of charge and all those involved in their creation also did not charge for their services. The billboard space was provided at a charity fee as well.

"The biggest problem concerning pulmonary hypertension," my father points out, "is that you do not look sick. You don't have sunken cheeks, don't have a pale pallor, are not emaciated and are not sitting in a wheelchair. You just do not look sick." There are patients in the country, just like a young peasant woman in Upper Austria, who are verifiably suffering from PH, but are seen as malingerers, hypochondriacs, or just plain lazy. No one, not even her parents, understood that she simply could not do the strenuous farm work. Finally, her father listened to her appeals and gave her the emotional support she so desperately needed.

Also, thanks to the awareness initiatives of patient associations around the world, supported by the pharmaceutical companies such as Actelion, Bayer, GSK, Eli Lilly, Pfizer, and UT, there is more commitment to research the deadly PH disease. My father is also president of the European Association for Pulmonary Hypertension, established in Vienna in 2003, which works hand in hand with the American patient association.

Media attention is the most important and effective method in the battle against my disease. Only if people learn to recognize symptoms and to understand that it can affect everyone–at any time, without any warning–and that only if a comprehensive cooperation between physicians, scientists, pharmaceutical companies, politicians and government agencies evolves is there hope for the millions of people around the world suffering from this deadly disease. I know that one day a cure for this insidious disease will be found. I firmly believe this, because hope dies last.

CHAPTER 17

Where there is a shadow, there is also light

“YOU ONLY HAVE TO FIND THE LIGHT.”

My father, Gerry Fischer

During an interview in 2009 with Uschi Fellner, the publisher of the Austrian women’s magazine Madonna asked me who my idol was and like a shot, I answered, “Karl Lagerfeld.” His fashion designs without a doubt are really wonderful, but what impresses me even more is his unbridled will. He is a workaholic and a man of unbelievable discipline. In only thirteen months he lost forty-two kilos because he wanted to fit into the very tightly cut suits from Dior-Homme (men’s) designer Hedi Slimane, whom he greatly admired–even though he stated in interviews that personal vanity was his driving force. Nevertheless, his workload is remarkable. At his age, somewhere between seventy and eighty years–no one really knows his exact age, except himself–he designs collections for Chanel as well as for his own label, constantly travels around the world and is his own best model.

Lagerfeld once said, "When someone puts on jogging pants they lose control of their life." I can really relate to this statement, because I hate jogging pants, mainly because I always had to wear them for my many examinations and during my frequent stays in hospitals. However, this is not the main reason for my admiration of and high regard for him.

I learned early on not to fall into the trap of letting my illness define me. "Make something out of your situation": that was my motto from very early on. There is nothing worse than succumbing to self-pity or worrying constantly about what else can happen or go wrong in your life.

Even when things were very bad, when I felt terrible or really sick, I always asked myself the same questions: "When will I get well again? What can I do to make myself feel better?" In the end, I alone am responsible for my life–not my parents, not my doctors–no one but me. Like every girl my age I am a bit vain–sometimes even a bit more so. Despite all the pain I felt during my time in the intensive care unit of the Lee Memorial Hospital I asked for a magnifying mirror to tweeze my eyebrows. By the end of the second week, when I was able to breathe on my own again, I asked that my hair be washed regularly. The nurses first thought I was kidding, but I meant what I said. Letting yourself go is the beginning of the end. The smallest inaccuracy in the mixing of my medicines and my life would be hanging on a silvery thread. I cannot take such a risk. Therefore very early on I had to learn discipline, even though deep inside I really was quite chaotic. But in this life I just cannot afford not to be disciplined. Therefore, Karl Lagerfeld is my role model; he would understand me–or so I thought.

Two weeks later I received a call from Alexandra Stroh, an editor at Madonna magazine. "We have organized everything; Karl will meet you in Passau (Germany)," she told me enthusiastically over the phone. I almost dropped my phone in excited disbelief. She then added, "There is an awards ceremony at which he will be honored for his photography and you will present him with the award." I was speechless–something that rarely happens to me.

A few weeks later I drove with my father and the editor up to Passau. The ceremony was a rather small-scale event. I presented Mr. Lagerfeld with the award and was able to exchange a few words with him. I looked into his face as he was smiling at me and tried to see his eyes behind the tinted glasses he was wearing. The eyes are the mirrors of your soul. That is why I always first look at people's eyes–well, at least when there isn't a dark glass in front of them. For an instant it seemed that I would be able to catch a glimpse of his as well. For a brief moment he looked up and the tint of his glasses that was a bit weaker toward the bottom gave me an almost intimate insight. What strong, expressive eyes. Karl Lagerfeld was incredibly friendly to me.

After a few minutes of chatting amicably about Vienna, he said goodbye, shook a few people's hands and left the hall.

Back home again this meeting still occupied my thoughts for days. What a confident man, who seems to stand above it all, albeit in good way. I thought about what I could give him as small token of my appreciation for being so kind to me. On my bookshelf there was an old illustrated book about fashion and art in the early twentieth century. The book must surely be at least fifty years old, as the photos are black & white and the subjects very unusual. I don't think it is even possible anymore to create such a depth in photos using today's digital cameras. My parents tried to find a second copy of the book and, by chance, found one in a second-hand bookstore. I wrote a personal, handwritten letter, thanking him for his time and kind words, as well as telling him how much our meeting had meant to me.

The world-famous fashion designer Karl Lagerfeld is said to have a library containing more than 300,000 books. I thought that one more book from me would surely land on one of the upper shelves of his collection, placed there by the assistant of his assistant, but what can a child give a man who is one of Germany's richest and probably has more than I could ever dream of?

Nothing happened for a few months. Then one day I unexpectedly received a letter from this famous designer's personal secretary with an invitation to be Karl Lagerfeld's personal guest at the Chanel Haute Couture Show being held in Paris in June 2010. I almost did a somersault on the red-brown leather sofa in our living room and yelled so loudly that my mother had to hold me back. "Please be careful, or you won't be able to breathe!" For weeks I fretted about what to wear. I simply had nothing suited for such a festive occasion. Finally my father found a vintage Chanel top in a second-hand shop. It was dark, adorned with tiny white dots, and when he gave it to me I was absolutely thrilled beyond words. I adore this piece as much today as when I first received it from my father and I can be seen wearing it on the cover of this book.

In Paris we stayed at a small hotel, the Bel Ami, located in Saint Germain des Prés, just around the corner from Karl Lagerfeld's favorite coffee house, Floré. Upon our arrival the invitation for "Mademoiselle Maleen Fischer" was already waiting for us at the reception. We took a taxi to the Grand Palais, where the fashion show was to take place. At the entrance dozens of photographers were lined up, and we walked over the red carpet and wondered which stars we would be able to recognize. We then were led to our seats. We sat in the third row, with a great view of the catwalk and all the VIPs. Anna Wintour, the legendary editor-in-chief of Vogue magazine, sat diagonally across from me in the first row.

My heart started racing when I saw Jessica Alba sitting opposite me. Jessica Alba! She looks even better in the flesh than on magazine covers. I understood right away why she was voted "the sexiest woman in the world." I thought for a second how embarrassing it would be, on a scale of one to ten, to go over to her and ask her if I could have a picture taken with her. Who cares? I thought. A chance like this you only get once in a lifetime. So I grabbed Alex, the journalist who accompanied us to Paris, by the hand and we marched over to her. Alex cheekily announced to the bodyguard, "This is Maleen, the most popular it-girl in Austria; she just wants to say hello to Jessica!" He let us pass.

Jessica jumped up and said, "Hi Sweetie" put her arm around me and a picture of us together was taken. She asked me, "How did you get here?"

"Karl Lagerfeld invited me," I responded.

"Karl invited you? He doesn't even invite me; I had to organize it myself," she said, apparently very surprised by my answer. "Congratulations!" Jessica smiled at me and wished me a great evening.

Once back at my seat, I quickly grabbed my cell phone and immediately called my brother Patrick. At the time his whole room was plastered with Jessica Alba posters. "Guess who I just ran into? Your Jessica!" He screamed into the telephone as if he had just won the lottery.

The show was exactly what I had expected: simply phenomenal. When it was over there were many minutes of applause; even Anna Wintour stood up and clapped, and Karl Lagerfeld made a short thank-you appearance on the catwalk. Afterwards most of the people stayed in the Palais–everyone wanted greet him, shake his hand, embrace him or have their picture taken with him. Camera teams from around the world wanted a sound bite from him for their reports. In this celebrity fray I saw Baptiste Biabiconi, Lagerfeld's muse at the time, whom apparently no one really recognized. We went over to where he was standing and Alexandra used the same line she had used earlier and introduced me as "Maleen, Austria's it-girl." He immediately went into a pose, put his arm around me, his cheek on mine, raised his hand into the air and put the other on his hip–a real posing pro, but that is to be expected from a top male model. And just like that, I had a second photo for my album.

After a while–people were practically still standing on one another–we considering leaving, but I still wanted to see Karl Lagerfeld one more time, just to greet him or wave to him. A simple smile in return would be more than enough for me, I thought. We managed to move within five or six meters of him. All the cameras were still focused on him as all of sudden he saw me. He immediately interrupted his interview, called out "Maleen", came over to me and gave me a warm embrace. He also placed two very slight kisses on both my cheeks, which all the photographers present immediately documented. I could hardly believe that he had remembered my name. But it got even better. "I really appreciated your present, the wonderful book about fashion in the early twentieth century." Now I was really flabbergasted. He began to rave about Coco Chanel and about the various other protagonists of the fashion scene at the time. It's hard to believe, but Karl Lagerfeld, situated in the fashion capital of the world, had actually taken the time to look at the illustrated book Maleen Fisher from the Meidling district of Vienna had given him. "How do you like it here?" he asked me.

I enthused about the "City of Light" and told him how much I enjoyed this wonderful event. "Karl, I am very grateful to have been able to be part of this memorable evening," I told him very sincerely.

He looked at me, smiled again, embraced me one more time and said, "We will surely see each other again. Most certainly." Then he took his leave, walked by the all the journalists still waiting and, without uttering another syllable, left the Palais.

"When it gets dark, you must remember that you are the light," my father has repeatedly told me since my earliest childhood. "Because of your illness you will experience moments that no other girl your age will ever experience. Where there is a shadow, there also is a light. You only have to find it." Now I was suddenly standing in the middle of a very bright light.

This light gave me strength in my darkest hours. It's like those memorable encounters with people whose kindness, charisma and warmth tell me that it's not important to be a celebrity, or well-known. It's about not losing that so important human touch¬–the ability to feel and express empathy for others. Most of the really very prominent people in the world are actually quite normal. They know that it is important to appreciate life despite, or maybe because of, all its idiosyncrasies. For fifteen years I have been living a balancing act between life and death. I often suffer from great pain and there are many things I cannot do–and probably will never be able to do–things that are very normal for girls my age. Yet, despite all the serious complications my illness causes, it also allows me to experience things that I never would have been able to, if I did not have this disease. But I must truthfully admit that there is no real consolation knowing this, and I would at this very second do without all these supposed advantages and unique encounters if I only could be healthy. This, however, is sadly not the case.

This was made bitterly clear to me a very short time later. Alena was a very fun-loving young woman, barely twenty-four years old. We got to know each other a few years earlier at a patients' meeting in Vienna. Even before I had met her my father said to me, "You will like Alena; she is a really cool girl. Even though she is a few years older than you, I'm sure you two will get along very well." She came to the meeting with her pump dangling nonchalantly from a black bag around her hips and we immediately connected. She was an art designer for websites, had a great eye for visual structures and really knew a lot about computers and modern technology. We watched videos on YouTube and painted a picture together. At some point she wanted to create things herself and not just on commission. It was her dream to be a respected artist one day. I think she would have loved nothing more than to design really cool things that she visualized in her mind.

Alena lived in Prague and we spoke English with each other. The health care in her country compared to Austria was about the equivalent of Cold War times. The clinics in Prague are in no way comparable to our standards in Austria, or those in most of Western Europe and the United States. Therefore, she again and again came to Vienna, because she continually experienced problems with the adjustment of her medication. "Your doses are not adjusted correctly; you are not getting enough medication," my father repeatedly told her. "It is weakening your heart; you must do something about it. Please be careful!" When she came to Vienna, she would stay with us. However, once she returned home to Prague, she again only received doses normally given to an infant of the life-preserving medicine. We stayed in contact via MSN or telephone.

We saw each other again at a patients' meeting in Rome. In the meantime she had gotten engaged to a Frenchman and proudly told me about the new man in her life. Alena dreamed of Paris and a carefree life. We spent three really wonderful days in Rome. We went to restaurants, for walks, shopping, laughed a lot, enjoyed our time together and even went to church together. Faith always gave both of us strength in our lives. However, I noticed that Alena's condition was worsening. Twice she lost consciousness. “How often does this happen?” my father asked her.

“It’s been happening more and more often lately” was her response. It was evident that something was wrong with her. My father immediately said to her, “Alena, you must come to Vienna with us for a few weeks in order for us to help you and let the doctors there adjust your medicine properly so that the pressure on your heart is reduced. You will feel better, believe me.”

In the meantime she was not even allowed to drive a car, because she would have fainting spells more and more frequently.

Finally, after months of coaxing on our part, Alena came to Vienna. She was only a shadow of her former self and she had great trouble breathing. In the meantime her condition had become so life-threatening that she needed an immediate lung transplant. “Her chances of survival are not very good,” her attending surgeon at the AKH told my father. In the meantime, her heart had been irreparably damaged by the wrong doses of medication.

She was taken into surgery but died a few hours later on September 29, 2009 at the Vienna General Hospital (AKH).

Shadow and light can be very close together.

CHAPTER 18

Rainhard and the rosary

“JESUS, WHO RAISES BELIEF INSIDE US,
HE STRENGTHENS HOPE INSIDE US,
HE IGNITES THE LOVE INSIDE US.”

Rosary prayer

The wishes of stars can sometimes be very simple. Dumplings fried with eggs–this is what Rainhard Fendrich (in Austria as famous as Bruce Springsteen in the U.S.) wanted to eat when he came to visit us. Where can he get a traditional Austrian meal in Mallorca or in Berlin?

I have known Rainhard ever since I can remember. He is a close friend of my father Gerry, and in the meantime has become part of our family. As he primarily lives in Mallorca he always spent a few days with us when he came to Vienna. On the last floor of our townhouse we have a guestroom that used to be my brother Patrick's room, but he moved out a while ago. It even has a small bathroom and somehow, over the course of time, it became Rainhard's sanctuary. He is almost like an uncle to me, with whom I played and prayed with as a child.

My parents became very spiritual because of my illness. Since my earliest childhood I have been accustomed to our family praying together before going to sleep. At the beginning my mother and my father always came into my room, sat down on my white wooden bed, and together we would recite the Lord's Prayer. Rituals can provide one with a great deal of strength, just in times when things are not going so well. Initially, I would ask God every night, "Why me? Why me, of all people?" Then, after a period of time I answered the question myself: "Why not me of all people?"

Praying can help to build up trust and provide confidence in learning to understand that what has happened to one can have a greater purpose. Whenever Rainhard stayed with us he would come by my room to say goodnight. He then would sit down on my bed and tell me a story, or sing me a song while playing his guitar. Finally we would pray together. That also was our ritual. Once, when he saw the rosary over my bed, he explained to me how to pray with it. In his childhood, Rainhard was an altar boy and at the time, even considered becoming a priest. He was really very enthusiastic about this phase in his life: "The frankincense, the ringing of the bells, the magnificent monstrance–it all fascinated me at the time. I really liked life in the church community where I grew up, the Catholic boys' boarding school, in the Erdberg district of Vienna. It was like a second family for me."

Rainhard is very devout person. This is something that really bonds us together. He, sadly, is also well acquainted with the feeling of helplessness and has had to deal with many very difficult circumstances, such as the death of his young daughter Theresa, who died at the age of only seventeen months. "That is the worst thing that can happen to a person," my father has repeatedly said. He moved into Rainhard's house for while in order to give him all the support he needed at the time.

During the time of a very difficult personal crisis that became very public, Rainhard hid away from the hounding reporters in our house for a few days. My parents told me at the time, "If anyone asks you about him, just ignore them, or tell them he is not here." My father explained the many headlines in all the papers like this: "Every person makes mistakes. That, however, does not change who the person really is." I really like Rainhard, today just as much as before.

The Austrian pop icon Wolfgang Ambros is also a family friend. Since he moved to the Austrian province of Tyrol we don't see him very often anymore. When he still lived in the Vienna Woods we would visit him frequently, or he would visit us. It was through Wolfgang's and Rainhard's frequent charity concerts for the PH cause that this disease became much more public in Austria. This was very important, because only by raising awareness for this potentially deadly illness, as well as helping people understand the patterns of the disease, can pulmonary hypertension be treated properly and in time.

CHAPTER 19

Because I am a girl

"I AM WHAT I AM."
Gloria Gaynor

According to statistics, the average life expectancy of a person with pulmonary hypertension is 2.8 years. The main reason for this disturbing figure is that pulmonary hypertension is only diagnosed at a very late stage of the illness. The longest surviving patient with PH is a woman who has been living with a pump for twenty-four years and, just like me, has received Epoprostenol (Flolan).

I have been living for fifteen years with a pump and it is my goal to set a new longevity record.

When I was still a child and had just learned to read, I saw a newspaper lying in our townhouse kitchen. It had a photo of me on the front page. I couldn't believe it and immediately started to read what was printed in large, dark letters above the picture: "This little girl must die". My father, who had just walked into the room, quickly picked up on the fear in my face and then saw the headline. "Am I going to die?" I asked him.

He picked me up, carried me over to the round table in our living room, put me down again and gently stroked my head. "Look, my dear, only if you are not treated will this happen. But you are getting the best treatment possible and therefore nothing can ever happen to you."

Today, I am a young woman filled with all the dreams that one can imagine at this point in my life. Will it ever be possible for me to have my own family? According to the current state of medical knowledge, I will never be able to have children. My medication will not allow it. Currently no woman with PH has ever survived a birth–and no child in the womb.

I would very much like to have a family. There are, however, other options, such as adoption. I am still too young to rack my brain about that now. I just want to enjoy my love for Dominik and savor the time we spend together without having to think about the future–not even about tomorrow. I do not live in the past, like many people tend to do. I am living for here and now.

Ever since Dominik and I have been together, I have had all my medication stored at his apartment. Therefore, I can mix it by myself at his place. I even have a replacement pump there.

Dominik immediately gave me a drawer in the bathroom to store all the things I need and cleaned out an entire closet for me. No man has ever done anything like that for me before.

The graduation in Florida and the final exams in Vienna are finally over and now I am wondering what I should do. I really would like nothing more than to do my master's at Stanford University and to do my bachelor's at Webster University, which allows me to do my studies in Europe and in the U.S., as well as online, if I am hospitalized. Based on my grade-point average and my other credentials it would be possible for me to be accepted. However, the college tuition fee is something else again: tens of thousands of US dollars per year, then the books and all the other costs. That is just not possible for me at the moment.

I would really like to study communications and Spanish. My goal is to become a newscaster. It is an occupation that my disease would easily allow me to do.

Should nothing come of my desire to become a newscaster, then I would like to find an occupation in a social profession. I could also imagine becoming an event manager. I always have to take one thing into consideration though: how far can I extend myself ? How will my work affect my health ?

As a child I had a frequently recurring dream. I still have it every now and then today. I dreamed about a little boy named

Henry. They were very strange dreams. He lived in the 1930s, was about ten years old, wore short blue overalls and had on a checkered shirt. He had blond hair and his face was very pale. His face looked very old and he was very clever, perhaps you could even say very wise.

Henry liked to play with fire. In every dream he and his brother somehow ended up on a spiral staircase that was leading downward. This scene was repeated again and again in my dreams. I could never figure out what it meant, but just recently I have begun writing a story about Henry.

Henry is a child that overcomes his fears, because he has learned to have hope, to trust in the good and never lose faith, because he knows that hope always dies last.

Henry's story has a happy ending, and I hope that it will be that way in real life as well.

Epilogue

“WHOEVER SAVES ONE LIFE
SAVES THE WORLD ENTIRE.”

“Schindlers List”, Thomas Keneally

I owe my life to Dr. Robyn Barst.

Dr. Barst, as the head of the Pulmonary Hypertension Center in New York’s Presbyterian Hospital has since 1982 dedicated herself to researching and treating PH and is considered one of the leading experts in this difficult medical field. When I was just a little girl she implanted the pump that has kept me alive–and will hopefully continue to do so for many years to come. But she has become much more for me. We developed a bond of friendship, the kind of friendship that only can be between a child and a woman of around forty. I trusted her with my life and felt safe and secure in her hands. We saw each other at least once every year for check-ups and sometimes at congresses at which she shared her immense knowledge on the subject with her colleagues as well as patients.

She had a become beacon of hope for thousands of people everywhere suffering from pulmonary hypertension. From her small office in Manhattan she directed doctors around the globe and informed them about the latest therapies and technologies, doing as much as possible to help save patients in the farthest corners of the world. Even though she was considered "The Expert" in the pulmonary hypertension field, she always remained humble, managing to retain her down-to-earth manner. This little woman with the dark hair and rimless glasses fought tirelessly day and night against PH, because she loved people and failure was "not an option", as she once told me.

A few years ago Dr. Robyn Barst became seriously ill. The diagnosis and the prognosis were not very optimistic, but with the same strict discipline and the same strong ambition that she invested in fighting for the lives of her patients, she took up the battle for own life.

It was February 2013, while I was lying in the terminal ward of the Health Park Medical Center in Fort Myers, Florida, battling for my life that a nurse handed me my cell phone and I heard Dr. Barst's voice on the other end. She sounded very weak and asked, "How are you, Maleen?" I told her about all my recent travails. "Don't give up, you will make it," she said in a soft, frail voice. "Your illness will not get the better of you. I have just spoken with your attending physicians and told them what to watch out for. They have everything under control."

I swallowed hard and asked, "How are you doing, Dr. Barst?"

"Well, not too good, either," she responded. "I am also lying in a hospital."

It was an irony of fate that this pulmonary and respiratory expert had been stricken by lung cancer.

"You must not give up!" I pleaded with her.

She remained silent for a moment and then said, "Let us pray for each other."

"Yes, let's do that," I quickly responded.

"Take care, Maleen, and don't ever give up" were the last words I ever heard her say to me.

Even though she was seriously ill, lying in a hospital over 1700 kilometers away, Dr. Robyn Barst was still concerned about my treatment, instructing the attending physicians on my care and imparting me with the courage to battle on. One week after my discharge from the Health Park Medical Center, Dr. Robyn Barst reached the end of her journey on our planet.

She died like a true heroine.

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At the age of three, Maleen Fischer was diagnosed with pulmonary hypertension and, since there was no treatment for this fatal disease at the time in Austria, the doctors sent her home. Her life expectancy was only a few years. Since this initial diagnosis, Maleen has battled this disease every day of her life with amazing courage and resilience. Few people around the world suffer from pulmonary hypertension; thus, researching a cure for this disease would not be an important endeavor for science. A small bag that she always carries at her hips pumps medication directly into her heart via a catheter every 30 seconds—it is the reason she is still alive today. In As If There Were No Tomorrow, this fascinating 18-year-old young woman tells her story for the first time. Maleen's inspirational message is that: "Every person's life and fate has positive aspects. You only have to search for them."