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Ungalahli Ithemba

Don't Give up Hope

(Expression in The Language of the Zulu)

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About the 2nd edition:

Certainly one or the other will wonder how the selection of the soap bubbles as a motif for the cover came about.

I looked for a motif for a long time and then found the most meaningful motif for me in the soap bubble.

You pay attention to all the different details. The way in which the colors meander into and around each other, twist, are born and then pass away. There are always new colors and patterns. Just like in our life, everything is in flux and a lot is changing, whether positive or negative. The variety in the colors, the mixtures and patterns are, in my opinion, an excellent synonym for the "diversity" of the symptoms of my rare disease. It is not for nothing that syringomyelia is "a disease with a thousand facets" and the path to diagnosis often means many years of frustration and confusion for many of those affected. Looking back on the odyssey, which led

me to my diagnosis through many wrong paths, the colors also represent the almost comparable complexity with which I was confronted in our health system.

Cover design: Frank Wolfgang Krüger
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Prologue

Rare diseases are rare.

While this may sound trite, it is descriptive of what's at the very core of the struggles of many patients. Patients who have had to embark on an odyssey of doctors and therapists for many years. Patients who, even from the people who are closest to them, are met with a lack of understanding; patients who doubt themselves.

The phenomena that accompany one of these rare diseases are presented in this book in a candid and moving fashion. The reader gets to experience the highs and lows, the reactions of those affected, their families, their close personal circles and the reactions of the "official" players up close and personal. Many patients will recognize themselves and their

own becoming in the context of their disease — this book will help you understand it.

In the hope of improving the situation of patients with rare conditions,

Prof. Dr. med. Uwe Max Mauer

Head of the Department of Neurosurgery

Armed Forces Hospital Ulm

Introduction

Sometimes life can radically change. Here, it is important to not lose faith in yourself; trust in the good, the people, and their willingness to help.

Through my book I want to encourage you to not give up in the face of heavy personal defeats. Because every morning, and here I am speaking from my own painful experience, still comes with its very own sunrise.

Chapter One: 2010

*Three things help with carrying
the toilsome burdens of life:
hope, sleep, and laughter.
- Immanuel Kant*

What's happened? I am standing next to a guardrail on a highway. It's snowing and storming. I am freezing. Next to me is a man who has introduced himself as a police officer on his way to work. I am looking for my car and find it pressed backwards up against the guardrail of the emergency lane — wrecked! Another vehicle slips and slides right into my tiny Opel Corsa. A young woman, like myself, on her way to work gets out of the car and starts walking toward us...

Alright, I am rewinding the movie: it's Saturday morning. I am on my way to work. It's snowing non-stop. My employer, a company that services sidewalks, offers among other things snow-management services. I am on duty today at the office. So into the car and off to Frankfurt via highway I go. The freshly fallen snow causes chaos on every single road. Snow removal and anti-icing com-

panies everywhere are overwhelmed and brine for the roads is beginning to run scarce. 18-wheelers are passing me left and right. I'm feeling uneasy and anxiously keep a close eye on the big trucks — some of which are getting dangerously close to me. When I try to change lanes, poor visibility due to the snowfall prevents me from doing so. I try again and start to skid — and from this moment on I am only left with a gap in my memory.

I come to and notice a man next to my car. What does he want? Does he want to rob me? He is trying to explain to me that I must immediately get out of my vehicle. Why? What happened?

My saviour, likewise on his way to work, had been driving behind me and noticed my unsteady driving, so he had kept a safe distance between our cars. He then explained to me that my car had slid toward the median, spun 180 degrees across all four lanes and eventually came to a halt after hitting the

guardrail of the emergency lane. I owe a great deal to this “Autobahn Angel’s” calm and collectedness in the face of such a dramatic situation. I was unable to reach my husband and would have been completely helpless on my own.

The police and a tow truck showed up relatively quickly. I declined the offer of having an ambulance called. I even felt up to it to ride along in the tow truck and drop off my car. In retrospect, a grave mistake, but more on this later.

My auto policy stated that it’s up to the insurer to pick the repair shop in case of a collision. Since I was unable to reach someone there I had to park my damaged car in the lot of the towing company over the weekend. With public transportation, it took me 4 hours to get home.

My husband and my boss were already looking for me. Both knew of the accident; I had left my husband a voicemail and informed a colleague at

the office. On top of everything came the concern about my husband who was in the middle of getting his degree and who had an exam in Munich the following Monday. For this reason, I also refused any and all discussions about getting examined at the hospital and took him — in his car — to Frankfurt Main Station on Sunday afternoon even though my knees were still a bit unsteady as the shock of the accident had really shaken me.

Sunday evening was when it all really started: nausea and vomiting were followed by chills and shaking. I suddenly fell over and blacked out. I was terrified: what had happened? I could not remember. I was disoriented with my pulse just throbbing in my head. Concerned by what was happening, I searched the phonebook for an orthopedician; I still refused to get an exam at the hospital. After all, orthopedicians have x-ray machines at their practices. I asked my father-in-law to accompany me to the

doctor and prepared myself for a long wait. By then I had already informed my employer.

As I got dressed I noticed that I suddenly could no longer walk in the shoes I had broken in a long time ago, although the heels were not even that high. I could not make sense of anything; why were my knees suddenly shaking as I was putting on my every-day shoes? At some point I realized that the heels of the shoes were to blame. My father-in-law was about to be at the door, and, although he is a very patient and loving individual, I felt increasingly uneasy because suddenly it took me so much longer to do anything and I was unhappy with myself. I am a punctual person and almost never leave someone waiting for me; especially not when I am asking them for help. My eyes raced across my shoe rack — which pair might fit me? After all, all of my shoes had at least some heel to them. I was overcome by panic; I definitely did not want to step

out in socks. How embarrassing! Since my husband and I had the same shoe size, I started digging through his shoe closet. Finally, a pair of trekking shoes with no heel! I was happy and put them to the test right away: hurray, that works! While my legs were still wobbling, now I could get them somewhat under control again. Outside, three inches of fresh snow had accumulated — no matter, with two additional pairs of socks I could now leave the house!

For the next two years, those sneakers were the only shoes that I was able to go out in. I was not spared the funny looks and stupid remarks. It did not bother me, because in them I was at least able to move around. This experience taught me to respect that people who might look a little different or wear shoes that do not really go with the season or whatever other styleconvention might actually have some kind of difficulty with walking. Up to this point, after all, I had been quick to pass judgements

out of ignorance myself.

With my husband's unfamiliar sandals on my feet, I was now awaiting his father's company for the doctor's visit. Luckily, that doctor happened to be a so-called "D-Doctor". At the time I had no idea what that abbreviation meant. The "D" was short for "Durchgangsarzt"—the official term for a specialist in either traumatology or orthopedics. A "Durchgangsarzt" is authorized by Employer's Liability Insurances to treat cases of injury resulting from accident or negligence, so I was in the right place — phew! I felt god awful from the drive to the doctor; I was no longer able to think clearly. The orthopedician diagnosed shock, released me from work for two weeks and told me that things should be better after a period of rest. In addition, he wrote me a prescription for a neck-brace.

Alright, I thought, two weeks will go by like nothing! I wanted to go back to work and not be

stuck at home because I like to be among people and work productively! Now, all that was left was to purchase the neck-brace. I was already dreading having to wear that thing.

A lady from an orthopedic specialty store visited my home and brought several different models to choose from. Death defyingly, I tried to wear it at all times, but that did not work. After two days, I finally gave up. I choked, and the vertigo got even worse, so off into a corner with that thing! Two weeks had gone by and my health was becoming poorer and poorer. I oversalted our food or the pepper shaker fell out of my hands without me noticing. I constantly dropped something or injured myself while doing housework — without feeling a thing. Only, I was often surprised to notice either the bread or the cutting board turning red. A fly on the wall might have thought I was practicing my throwing and sweeping skills for a polter-