



Michelle

Edith Zimmermann

Experiences and information on
Epidermolysis bullosa hereditaria dystrophica

All she needs is love

"Forget the many hours of distress – but remember what they taught you!"



About the Author

1954 I was born and grew up in Berne, Switzerland, a twin and one of six brothers and sisters. During my childhood, an urge to work with the sick crystallised. At the same time, movement and creative artistic activity were also central to me.

1973 I began training as a physiotherapist at the Insel hospital in Berne, Switzerland. After gaining my diploma I very joyfully began work at two regional hospitals.

1978 I broadened my activities to include specialised schooling and so completed the Bobath Course for the brain-damaged child, thus intensifying my occupation with handicapped children, their parents and training.

1980 I gave birth to Michelle, my daughter. Already at birth, Michelle's skin exhibited large, open wounds. She was comparable to a peach, easily damaged. Even the lightest pressure left very painful blisters and open wounds both on her skin and mucous membranes. The doctors diagnosed a disintegration of the skin in extreme degree (Epidermolysis bullosa hereditaria dystrophica) with the prognosis of very little chance of survival. Although not told to me directly, this prognosis spurred me on to battle for Michelle's life with all its demands and consequences. I was convinced that Michelle wanted to live; that she had an important task to fulfil on earth.

As a single, working mother a difficult and challenging path opened for me. Thanks to the wonderful assistance of my sister Therese, after only four months of hospitalisation, Michelle was able to come home and has been cared for at home ever since. This care has necessitated great demands right around the clock. I was forced to give up my job as a physiotherapist as I took on the intensive care of a sick child and all that this care entailed. Thus, day and night for the first two years, I cared for Michelle and I gradually learned to understand what true patience and gratitude mean.

Despite the advice and the helplessness of the doctors and despite great disappointments, I began to pursue my search for a treatment for Michelle which took into consideration the whole person. I felt I had to make my way alone.

1982 saw the opening of my own physiotherapy practice.

1984 I attended several courses in Germany pertaining to meridian therapy with colours. Subsequently, there followed a period of two years of intensive work in this field during which time I gained much valuable knowledge, especially with regard to colour properties and to the nature of the wholeness of the human being.

Thanks to my encounters with mediumistic sensitives and spiritual teachers, new and decisive perspectives slowly began to open up within me. Through meditation, more and more deep truths of universal life were revealed to me in answer to my searching.

In hours of great need and great pain, inspiration trickled through to me. I began, for example, by lying in a darkened room next to Michelle who lay in bed with eyes extremely sensitive to light, and I made up stories for her; stories which led Michelle to find inner peace, joy and harmony. Hence the stories and meditations for children began to develop.

1986 I brought my activities as a physiotherapist to an end to enable me to follow the inner calling, to become a teacher of meditation and counsellor. I strive always to help people to awaken the wonderful inherent powers within themselves to help them to an awareness of spiritual laws.

1992 found me resuming a job as a physiotherapist. Working with severely physically and mentally handicapped people is such a rewarding occupation for me. It is work which covers so many different aspects and levels and thanks to an expansion of awareness, the spectrum of my tasks is evergrowing. Painting on silk allows me on a soul level, to express myself through form and colour and to convey to others harmony, joy, peace, strength and trust.

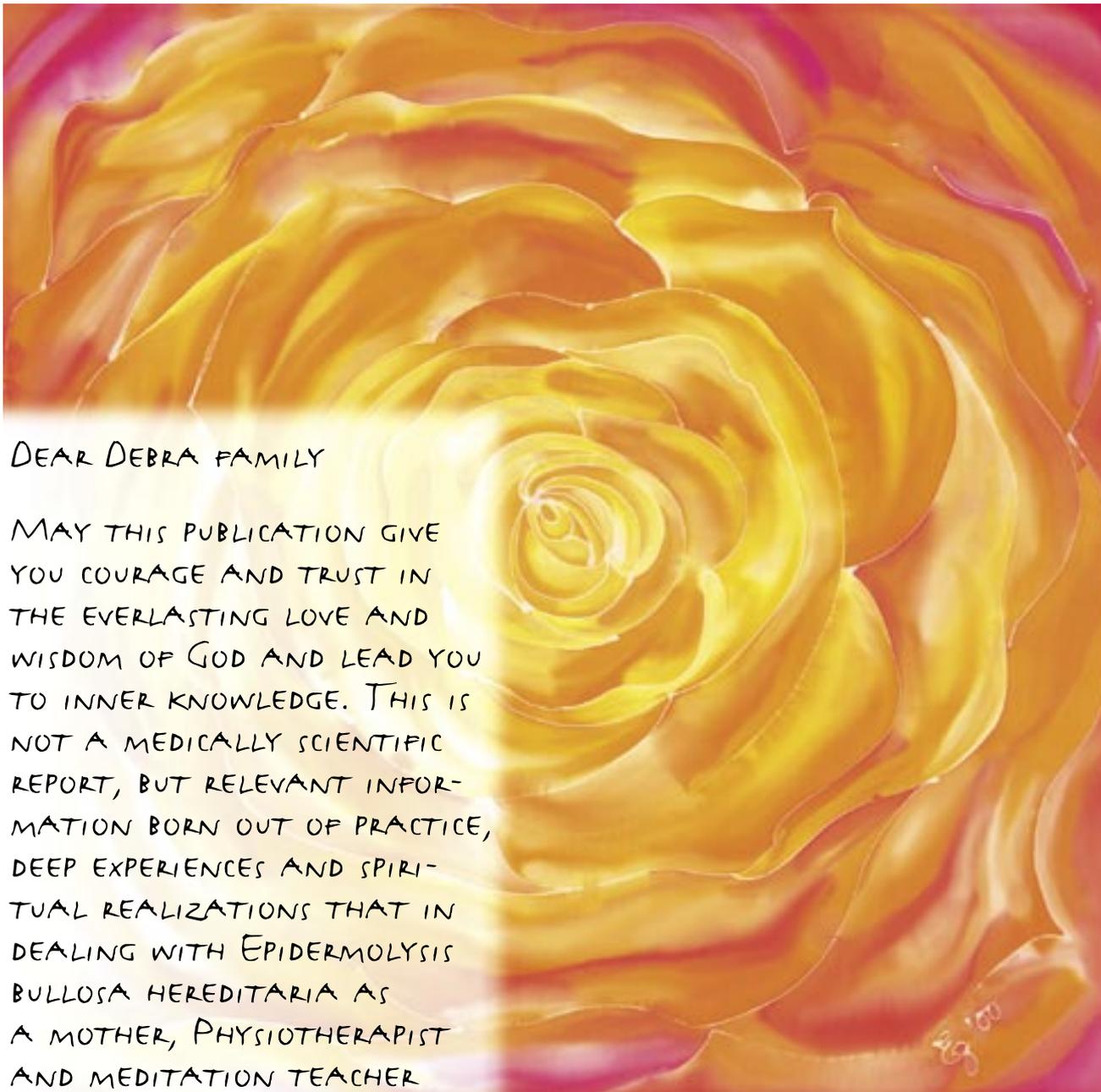
1996 Book publications "The Treasure Chamber" Aurel Aurelia the Star Child (fairy tale meditation).

1998 Establishment of the debra-ch Society.

Today I have my own physiotherapy practice in Schüpfen and also provide medial advisory services and meditation courses.

*Despite countless wounds and constant pain,
Michelle's eyes always radiate a light which
reflects her great enjoyment of life and her
courage to face life; a light which causes inner
strength and power in me to flow. Thereby our greatest
challenges in life provide our greatest
opportunities to grow spiritually when we humbly
accept them with love, and when we are able to give
ourselves entirely to the all-embracing love and wisdom
of God.*

E. Zimmermann



DEAR DEBRA FAMILY

MAY THIS PUBLICATION GIVE YOU COURAGE AND TRUST IN THE EVERLASTING LOVE AND WISDOM OF GOD AND LEAD YOU TO INNER KNOWLEDGE. THIS IS NOT A MEDICALLY SCIENTIFIC REPORT, BUT RELEVANT INFORMATION BORN OUT OF PRACTICE, DEEP EXPERIENCES AND SPIRITUAL REALIZATIONS THAT IN DEALING WITH EPIDERMOLYSIS BULLOSA HEREDITARIA AS A MOTHER, PHYSIOTHERAPIST AND MEDITATION TEACHER I NOW ENTRUST TO YOU. FULL OF LOVE, I DEDICATE THIS PAPER TO ALL THOSE ALL OVER THE WORLD AFFECTED BY EB.

Living without your skin

The skin, our largest organ, also breathing organ, serves as a protection and connects our organs in a reflective way. Our skin is also our organ of internal and external communication. The skin of a healthy person is smooth and velvet-like as well as elastic and resistant.

But the skin of EB-patients is extremely thin and vulnerable. Huge blisters are formed without any apparent cause. They arise at the slightest touch, looking like burns; the skin is torn, and at once open wounds appear on the external skin as well as on the mucous membranes (mouth, gullet, digestion organs, eyes, respiratory tract).

What does "EB" mean?

It means hereditary peeling-off in blisters. The genetic embodiment of the skin-layers is insufficient and leads to the formation of blisters. Different types and degrees can be distinguished.

This clinical picture is indeed extremely severe and greatly handicapping. Healthy people cannot really estimate the consequences: Blisters, wounds, continuous pain day by day, month by month, year by year – with the shocking prognosis of an increasing invalidity.

The daily life of EB-patients is characterized by pain, and the treatment of wounds takes hours. In addition to direct skin damage there are other problems (depending on the type and development of the disease) as follows:

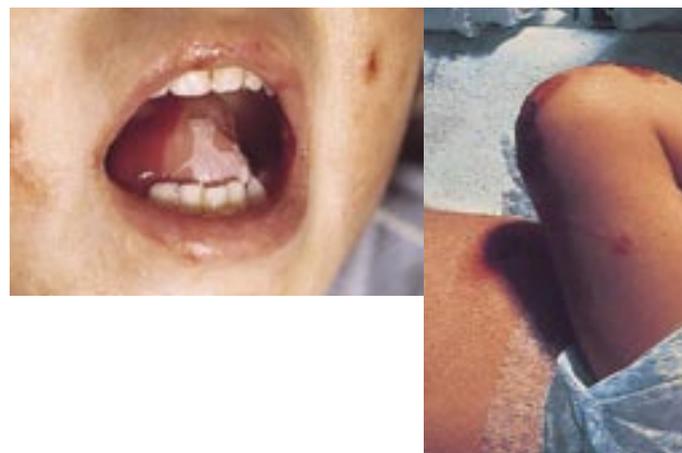
- Nails and hair falling out
- Teeth damaged or falling out
- Scars and deformities, especially on the fingers and toes
- Blisters in the mouth and in the gullet: problems of nutrition and digestion
- Blisters and inflammation of the eye mucous membrane: defective vision
- Blisters in the respiratory tracts: breathing difficulties
- Wounds which cannot heal: skin cancer
- Growth of the body decreased

The aim of Debra Switzerland is to offer help to affected patients, to their parents, and nursing staff:

- Providing professional medical care: dermatology, dental treatment, surgery, genealogical advice, physiotherapy, ergo therapy, diet counselling
- Psychological advice and care
- Advice in legal questions, health and general insurances
- Financial support, complimentary medical help
- Holiday
- Internal development and workshops for affected children and adults, parents, nurses

Debra – Dystrophic epidermolysis bullosa research association

DEBRA is the name of the worldwide organisation of self-help associations and communities of interests for EB-patients. The main office of DEBRA INTERNATIONAL is situated in England (UK). The estimated number of EB-patients worldwide amounts to about 30.000. In Switzerland the exact number is still unknown.



Debra Switzerland is here to support you!

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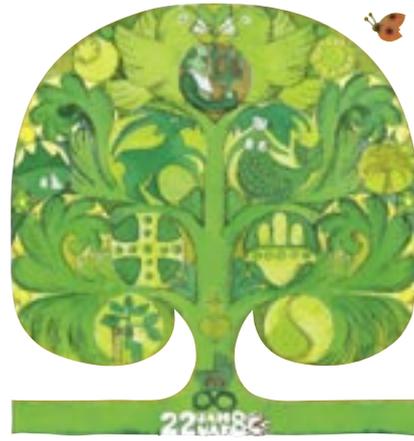
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Pregnancy



Birth

"Share my joy: it is so sad to be happy alone!"

My inner process of development began with my pregnancy in 1979, but is linked to a vision I had just before I became pregnant. I saw that my life would change dramatically, but I didn't know how. When I became pregnant, it became clear to me that as a single mother the way ahead would not be easy. Despite this, I continued to hear an inner voice: "Share my joy; it is so sad to be happy alone!"

This joyful message lifted my soul. I was reinforced by words of encouragement from my sisters. So, full of courage, I took off alone on my challenging journey, fully aware that in life there are no coincidences. For the time being, it was about saying yes to the pregnancy, to motherhood. All at once it hit me, that I already was a mother! I realized how crucial it is to utterly and completely say yes to oneself, and to accept a situation as it presents itself. I remember at the beginning of my pregnancy seeing an inner picture which was tailor-made for my present situation. I saw myself sitting alone in a sandy crater. I knew that it was my task to crawl out of this hole? So I took courage by the hand and began the tiring, sandy climb upwards.

I was absolutely convinced that behind everything a wise plan is at work, which at the time we are not always capable of understanding and explaining rationally. This inner knowing, that can only be heard when all else within is still, began slowly to penetrate my whole being. I became much quieter, more peaceful. Today I understand why in the first months of pregnancy, I felt victim to paralyzing exhaustion and had to rest and sleep an unbelievable amount. I felt as if I were in trance, in other words, that I was connected to a higher level of consciousness. While I was being trained in spiritual law, and anchored in spiritual truth, a deep inner preparation had once more begun.

So, by the end of the pregnancy I was able to crawl out of the "hole" in order to continue my path on other levels.

"You know, a difficult time is coming – but we'll make it"

On 22. January 1980 Michelle was born. Following a long, very tiring birth, I thought that I had achieved something, but on seeing her great wounds, my head filled with a thousand questions. Straight after the delivery I asked for my child to be laid on my stomach. Michelle did not cry. Silently, she looked deeply into my eyes with her dark doe-like eyes. In my heart I heard quite clearly her message: "You know, a difficult time is coming, but we'll make it".

This energy touched me deeply, flooded through me as it still does to this day! It is like a stream of light which has always carried, comforted and strengthened us, also in times of greatest need and pain. Without this fundamental energy, I could never have developed staying power, stability, steadfastness along with hope and healing.

The first night after the birth was unforgettable, heavenly sleep. It was by far, the most beneficial night I was ever allowed to experience. Already during sleep, I felt indescribable joy and inner peace. I awoke the next morning full of strength, courage, joy and deep gratitude. I felt I could not thank enough. Now I know that in this night I was immersed in pure God-consciousness.

What a blessing! The questions I had in my mind didn't just all dissolve, but the inner knowing, that everything is right as it is, was strengthened. I clearly felt that I was the mother of this God-given child and that light and love flooded and carried us both. Courage, faith and hope were felt and remarked upon by those who were with me. However, after only a few hours, came the first letting-go, releasing. For me, this was the actual birth in the true sense of the word. Because of a threatening Exikosis (drying-up) the hospital consultant decided to transfer Michelle to a childrens' hospital in Berne. The thought of having to give my child into the care of others, and myself to remain behind alone in hospital almost broke my heart. Thank God I had my sister Therese at my side, as she was during the birth.



Stay in Hospital

*"I AM here. I love you as you are.
We are not alone!"*

There now followed four test-filled months. During this time in Efenau's Childrens' Hospital, I visited Michelle and cared for her daily. On the way to hospital I never knew what to expect and what was waiting for me as her state of health could change hourly or even from minute to minute. Grave swallowing difficulties, highly inflamed eyes and huge wounds and blisters all over the body, alternated with massive attacks of diarrhoea. The diagnosis EB was made by an assistant doctor given the job by a dermatologist at the University Clinic in Berne, with the comment that neither the form nor the severity of the illness could at that time be diagnosed. I could see by his serious attitude and read between the lines that they were giving Michelle little to no chance of survival.

Michelle lay naked in an incubator for two months. I was not allowed to hold her, which in itself is extremely difficult for a mother. One did not dare dress her for fear of not being able to keep track of new wounds and blisters. At the beginning, the blisters were not lanced for fear of infection. But the doctors soon discovered that the blisters, growing larger and larger were the cause of even greater skin infections.

I remember the assistant doctor saying to me as I was gently stroking Michelle: "It's your fault if you rub away her skin" I was never afraid that my conscious touch would harm my child. Just the opposite in fact – I felt how important it was (is) to lovingly touch the baby as much as possible. Touch is so very important for an infant. One can describe it as a wordless language in which varying energies are transformed and exchanged. It seemed to me, that the most important thing was to reassure my child: " I AM here; we are not alone; I am doing everything for you – I love you as you are!"

At the age of four weeks Michelle found herself in a life-threatening situation. I understood the insecurity and helplessness of the doctors and nursing staff. There was no known therapy and added to that, there was a lack of experience in the treatment of this gene defect. To the best of their knowledge, they suggested treating with Cortisone, Valium, antibiotics and vitamin E. Because my attitude towards orthodox medication was very reserved I thought about this for a long time before I agreed. I felt that I was not able to take the full responsibility for Michelle at that time, and so I trusted the suggestions of the doctors and agreed to a minimal dose with the option to stop if she grew worse. Because I was with Michelle for many hours every day I could watch her very carefully. I appreciated the openness of the nursing staff. I am sure that my profession stood me in good stead.

After only a short while, Michelle experienced additional difficulties such as constipation, flatulence, swollen eyes and apathy. Michelle seemed completely changed. The medicine clearly made her feel generally worse instead of better. I was convinced that it was better to stop ALL medication. Now I was ready to take full responsibility for the development of my child. It seemed very important for me to resolve to go my way, but nevertheless to remain open to the help of orthodox medicine. On one hand I felt very lost and alone and on the other hand I was filled with inner strength, conviction, courage and endless trust. Michelle's sparkling eyes and her cheering smile made me even stronger. I realised that "only" a symptomatic treatment, comparable to a case of severe burns, was possible. So I dared to strike forward alone, trusting the voice of my heart. Since that time, Michelle has not had any orthodox medication whatsoever.





“Don’t be sad – even though I can’t drink from the breast, I shall grow”

As a result of huge wounds and blisters in her mouth and throat, drinking for Michelle was made very difficult. After a period of 2 months I suggested to the nurses that we should try with me breastfeeding her, with the thought that the nipple is essentially kinder to the skin than the bottle teat. Michelle took the nipple into her mouth and immediately let it go again – she shut her eyes, shook her little head and looked deeply into my eyes. As the tears were streaming down my face, I heard inwardly: “Don’t be sad, even though I can’t drink from the breast, I shall grow” On looking back, I realized that for my child to be able to drink from the breast she would have had to create a vacuum with her lips, which for Michelle proved too great a mechanical stress. However for a very brief moment indeed, I experienced how wonderful it must be to succour a child on the breast, and I also learnt that it is not the most important thing. I realized that I could convey a mother’s love in other ways. Even if the pumping of milk can never be compared to the warm mouth of an infant, I was so unspeakably grateful for the mother’s milk which I was able to give Michelle over a 5 month period, and for every drop which she was able to swallow.

You make your own bed and lie in it

I also gave much thought to Michelle’s clothing, for is it not also protection, cover, and security? So my mother began lovingly to knit little silk socks and dresses with my ideas as her patterns; clothes which I never could have bought. In addition, I took Michelle a medical lambskin so that she could lie more comfortably, more softly. I found it was about time, after lying naked in an incubator for 2 months, for her to lie in a normal bed with a lambskin, at least for a few hours. I could see straightaway how much safer, more secure Michelle felt and because of this she slept more. How very important this sleep was, her only rest.

To be able to understand, the child must be able to grasp

I also took with me into hospital some simple toys for infants (no rough edges or corners). My opinion being that Michelle should be given the chance to develop as other children of her age could. If she was to be able to understand, to learn, then she should first be able to touch and grasp, despite wounds and bandaged hands. From the beginning, I attached importance to functional bandaging, i.e. dressings which in no way compromised or limited movements of joints or organ function. Unfortunately, at this time Mephitel was not available. Wounds were dressed with Mercusasept and Betadine, bandages which always stuck to the wounds. A change of dressings was extremely painful and took hours to perform.

There is a way – Upwards

When Michelle was 3 months old, the senior consultant thought that she would probably have to spend the first year of her life in hospital. I couldn’t believe it. I was well aware of how important and intensive development is during this first year. In my heart, I clearly felt that there would be a way but that I couldn’t force the issue. I knew that everything happens at the right time.

Quite unexpectedly two weeks later, nurse Barbara excitedly told me that I could take Michelle home. Nurse Barbara was for both Michelle and me, the most important person in the hospital to whom we could relate. It was Barbara who had looked after Michelle the most and she had taken both of us into her loving care and helped and supported us both. For us, her presence was like a ray of warm sunlight. Ascension Day 1980 was to be the great day. Since then, my sister Therese and I have always taken care of Michelle at home.





Nursing Care, Aid

- In my opinion loving, regular, precise care in a friendly, welcoming room is of the utmost importance. Still today, I dress Michelle's wounds at least twice daily. I have developed pure silk ointment dressings (Bourette silk, undyed, 60°C washable, cut into strips and spread well with ointment) which I have used for many years.
- Well-ried and tested and absolutely recommendable and advisable is the Junge oil-dispersal apparatus. It allows a gentle, nutrient bath, the basis of which is olive oil.
- Urine therapy, an ancient folks-remedy from Asia is, in my experience a most effective "homeopathy" which can be used either internally or externally at all times, as long as the individuals concerned agree to it. At the infant stage, the mother's morning urine can be used. I have concerned myself thoroughly with this therapy. The book by Dr. U.E.Hasler, a Swiss medical doctor, titled: "Your Own Pharmacy is Within You" awoke old knowledge in me.

Oil therapy

Mouth rinsing with cold-pressed sunflower oil or olive oil works to prevent inflammation, detoxifies, activates the immune system and strengthens the gums. Rinse one tablespoon of oil around in the mouth for at least ten minutes, before taking any food or drink and until it turns milky-white and watery. The oil must never be swallowed – just spit out, rinse the mouth and clean teeth.

I have noticed that everything that helps detoxicate and purify the blood (be it teas such as nettle, Laba-cho or Neem* works very well for healing wounds and cases of itching. Also, sufficient liquid intake is extremely important.

*a holy tree from India

Massage with Oil and Ointment

I believe that each person should find out for themselves what is good for them and what is to their taste:

- Face massage (including the ears.)
- Head massage (eg. by washing or drying hair.)
- Foot and Hand massage (in cases of scarring and tightening of the skin pure lavender oil can be very beneficial, on its own or mixed with ointment.)
- Back massage (promotes overall health and well-being)
- To stimulate the healing of wounds, I always massage very gently around the wounds before I dress them
- In cases of accidents, skin defects and infection, we've seen good results with Bach's Rescue Remedy cream. It workes very quickly as a soothing ointment-dressing.

Additional Aids

- real lambskin used as padding support
- Corpomed cushions, (used when breastfeeding) for pain-free positioning.
- Tempur mattress support overlays for gymnastics or for use while sleeping
- Exercise equipment/apparatus, home trainer (bike machine)
- three-wheeler, Trimilin, large gymnastic ball
- soft, orthopaedic shoe insoles have proved successful
- for small children, sandpits filled with dried lentils





Nutrition, Dental Hygiene

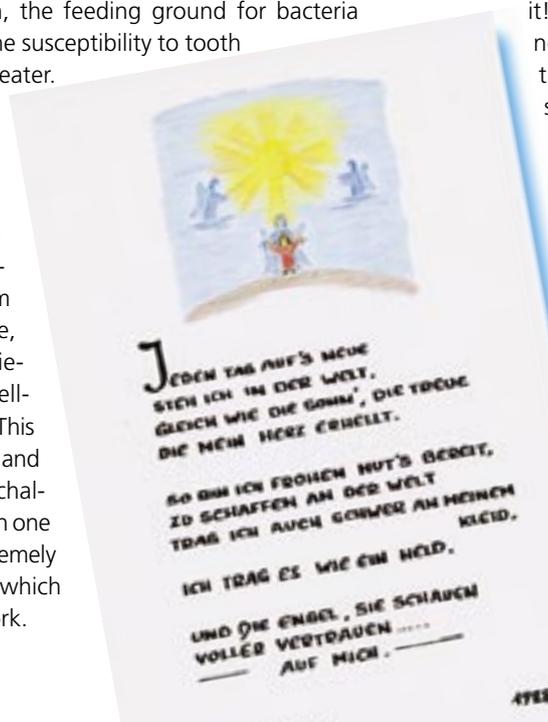
"A decisive factor in eating or preparing food is our frame of mind."

Thoughts are energies which effect our bodies and consequently, our health. Positive thoughts influence our food considerably. If the situation around the dining table was quiet and harmonious, then Michelle was much more able to eat and swallow. Water is of extreme importance for our health. Helpful tips and studies concerning water are to be found in the following two books: "Tracing the Mystery of Water" by Johann Grandner and "Messages from the Water" by Masuru Emoto.

Daskalos, a great healer from Cyprus, advised us to feed Michelle with whatever she wanted. At all times of the day and night we would prepare food for Michelle, that is, when she could swallow food or drink. Even today, it is most helpful for Michelle if meals can be refined by adding butter and cream. We laid great value on eating quietly together at a nicely laid table. A favourite and very beneficial occupation for Michelle was baking and cooking with Therese. It was one of the most important therapies for her hands and through it she became very interested in eating.

Her dental care began with the appearance of her first teeth. Because of the continual open wounds and blisters in her mouth, the feeding ground for bacteria was intensified and the susceptibility to tooth decay was all the greater.

So we deliberately invested a great deal of time in dental care and hygiene. Thanks to the loving cooperation and tireless instruction from my eldest sister Helene, herself a dental hygienist, Michelle has well-cared for white teeth. This is a great achievement and was in fact a great challenge for Helene, when one considers the tiny, extremely vulnerable mouth in which she blindly had to work.



Schooling, Education

The Playground – comparable to a Battlefield

The danger of being injured while playing with other children was magnified a thousand times for Michelle, but despite this, I didn't want her kept away from other children and additional dangers. In my opinion, it was better for her to learn to cope and find her own way in a group of children; so important for schooling and life in society.

When Michelle was 4 years old she visited playschool once a week. In order to promote her movement abilities and to strengthen her behaviour in a group situation, I opened a children's group whereby she could also participate. When she was 6 years old, Michelle went to public kindergarten on two afternoons a week. As the class had twice as many children attending as is normal, the local council employed an additional kindergarten teacher for these two afternoons. Following on from these afternoons, Michelle later attended a Rudolf Steinerschule for a period of nine years. We are extremely grateful that she was allowed to be a pupil at such a wonderful artistic school and that she was looked after by so many understanding and loving teachers. Michelle's school years proved to be a very difficult period of her life. It was as if she always had to run for the moving train and jump on it! Despite many forced absences, Michelle never had to repeat a year, even though there was always so little time left, after spending hours on her daily care routine, for her homework.

At the age of 16, Michelle had the opportunity of completing an interim year, with additional private instruction, at an animal clinic. It was difficult for her to find a suitable apprenticeship, and so my elder brother Leo, a manager and interior designer in a designer furniture business, created an apprentice position for Michelle so that she could learn the business of working in an office. At the present time she is at a private school, training to become a commercial employee.



Leisure Time, Animals, Dance and Theatre

Alongside such very time-consuming, intensive care (on average 6–8 hours a day) there remained practically no free time for Therese and myself. Mountains of dirty washing pile up even today within a very small space of time, along with huge amounts of cleaning work, far more than normal. In the early years, we used the daily care time as play time. Nursery rhymes, songs and music were very helpful aids for forgetting pain. In recent years we have had most intensive conversations, particularly concerning relationships, partnerships and sexuality.

Animals have always meant a great deal to Michelle. The way she held herself, for example, always visibly improved when she walked the dog or marched alongside the horse. Michelle has ridden horses since she was 11 years old. Thanks to this, she has been able to experience nature, and has become more independent, more self-confident, with a greater sense of responsibility because of it. The joy and love of animals has always been much stronger for Michelle than fear of renewed injuries and infections. Happily she has earned great respect by this, I mean to say that Michelle truly understands the language of animals.

Dance and theatre belong to Michelle's life. She has the ability to slip literally from her own thin skin into playing the role of others, which is what the theatre is all about. Above all she loves to observe and study people. Oriental dance is a part of her (her father is Moroccan), indeed, it's in her blood, as is Flamenco dancing. For Michelle, dancing provides wonderful training in posture and deportment. Despite countless pain, joy has released a great deal of healing energy in Michelle. For me, it's as if her soul dances freely, out of her physical body.



Family

My sister Therese

The family environment is of paramount importance in our lives. Over the past years my parents, all my brothers and sisters, my brother-in-law Daniel and my sisters-in-law have all been extremely important in helping us maintain our physical, emotional and spiritual well-being in addition to helping with our financial needs. I would never have been able to master the situation alone with Michelle without the ongoing assistance received from them.

My, or should I say, our strongest and most devoted support has been and still is my own sister, Therese. One month before Michelle was born we moved into the same house together. In her function as godmother, or second mother to Michelle, she has shared our burden over all these years, accompanying us through the various phases of heaven and hell, never once leaving us isolated with our problems. In fact, it was twenty years ago that she decided to give up her career as a structural engineering draftsman in order to provide us with her "selfless service of love".

We have virtually worked together hand in hand from the very beginning, and being able to maintain such a spiritual partnership with one's very own sister is an extraordinary blessing indeed.

I cannot find the words to express the gratitude I feel in my heart for this expression of love. And I wish there were more families in the world such as the one I was blessed with, a family where brotherly and sisterly love are actually lived on a daily basis.

"All she needs is love!"

Many years ago "Daskalos", an esoteric Christian mystic and healer from Cyprus, said to me: "All she needs is love!". It's as simple as that! But what is love? Deep down inside I knew exactly what he meant, and at the same time I was also aware that this could be a long process, involving constant work on and within oneself and one which would not be realized overnight. This message spurred me on to continue meditating, in a constant search for inner truth.

Years of trial

"You cannot give up now!"

During the first two years I nursed and looked after Michelle twenty-four hours a day (comparable to an intensive care unit except that the nursing staff consisted of only two people). Because she suffered from intense itching (neurodermatitis) during the night and thus hardly got any sleep, we obviously got little rest ourselves. During this time I learned how to "let go" within the space of a few minutes and to use and appreciate these brief moments of relaxation. Still there were times when I lacked so much energy that it was difficult for me to believe that I would find the strength to even open my eyes and get up. At such moments, however, I heard a voice inside me say: "Edith, you cannot give up now!" And when I stood up, it felt as though huge hands were resting on my back, spreading a pleasant feeling of warmth and strong energy all over my body. I became very calm, completely awake and capable of doing my chores in a concentrated manner.

Despite this, my chronic lack of sleep continued over four long years simply because each night I had to get up at least ten to twenty times to either calm, nurse or feed Michelle.

My longing for several hours of restful sleep thus continued to grow. Slowly but surely the thought that someday I would again sleep peacefully began to manifest itself in my consciousness and in time became a ray of light on the horizon for me. Finally, after 16 long years, my strongest wish finally came true.





Hands

Learning to walk a tightrope

"You know, now I've learned something new again"

Just take a minute to recall how often a child falls while learning to walk. During this part of her life, Michelle's attention, concentration and balance was much better than that of normal children. She could not crawl because it would have put too much strain on her hands and knees, immediately causing huge blisters. She was thus forced to skip an important stage in normal development on the way to learning how to walk. It was as though she had to learn to walk a tightrope and was subjected to the same acute risk of being hurt and the danger of falling. One could say it really was a "high" school.

At the age of 15 months she was able to walk by herself. At age three she fell down very hard on her hands and knees and as she lay in bed afterwards she said to me firmly: "You know, now I've learned something new again!"

This statement brought many questions to my mind and I asked myself: "What had she learned?" Okay, looking back at her younger years she had learned to be cautious, considerate, circumspect, patient and farsighted. She had learned to anticipate potentially dangerous situations and concentrate on moving safely through crowds. Had this not been the case, she could not visit a disco today and dance amongst hundreds of people.



"God has no other hands but yours."

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To see Michelle lose all her fingernails and toenails during the first six months of her life was very painful and difficult. However, I soon began to understand the wisdom behind this situation. The lack of fingernails prevented her from severely scratching herself quickly and thus hurting herself in the process. At that time the itching was a severe additional problem. Later I myself diagnosed neurodermatitis*. Anyone who is familiar with this skin disorder knows what it means to fight permanent itching, but can you imagine suffering from this in addition to EB? For several months my two hands no longer sufficed to bandage Michelle alone. Within seconds after removing the bandages, she would begin to scratch herself to the point of bleeding. I didn't know how to prevent her from injuring herself any more than she already was. Unimaginable! My sister and I spent many nights at her bedside making sure that she would not scratch herself, using our hands to soothe and comfort her.

From the very beginning, I very consciously cared for Michelle's hands, massaging them and helping them to be creative. But the numerous recurring wounds, on her hands and arms alone, severely interrupted and inhibited growth. As she turned seven, the scars and contractures began continually to increase. I felt completely helpless and sad. In earlier years I was convinced of my being able to counteract these contractures with selective physiotherapy. I was not willing, nor could I accept such a deterioration and restriction in her condition. Ever since then I have become very aware of hands. I have always considered my own hands as being very "holy". Are they not one of the most delicate and perfect tools? Even a slight restriction in the movement of one finger can mean a significant hindrance in life let alone the restriction of all fingers on both hands. What a terrible handicap, and one which makes us dependent on other people! Over the years I have cried many tears simply over Michelle's hands until one day the following quote fell into my hands: "God has no other hands but yours". I meditated quite ardently on this truth and finally realized that large hands full of light were working through Michelle's small, crippled hands. Furthermore, during all these years my hands have been allowed to develop into healing hands, not only for Michelle, but for many other people as well. In fact it was Michelle who told me over and over again that my hands were her real painkiller.

*an atopic eczema skin disease with severe itching



Eyes – Moments

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Michelle's eyes suffered from an incredible number of injuries and wounds. Because they were highly inflamed and also sensitive to light, we spent many months in the dark. While other children played in the sun, Michelle sat in a dark room, eagerly awaiting sunset and the cool night. Countless times she had hoped to be able to reopen her eyes at least briefly, eyes which during the day were hidden behind high protection glasses (snow goggles). And how happy she was when she could at last see what was on her plate or get a glimpse of her toys. During these eye attacks, we had to care for her as though she were blind, the only difference being that she was also acutely in danger of injuring herself and thus needed additional, more difficult nursing. During this period, Michelle's hearing, sense of touch and clairvoyancy developed considerably.

Because I too was forced to sit in the dark, I obviously could not read a book to her. Instead I began to use my imagination and tell my own stories, stories which gave her peace of mind, happiness and harmony. Then I began to develop these stories into fairy tale meditations for children. The moment I recognized that my calling was to write down the stories the "Land of Color" and pass them on to other children, Michelle's eye attacks were considerably reduced. It took nine years for me to realize my first book called "Treasure Chest".

Michelle's condition improved substantially when she reached the age of 17. As we looked into the possibility of her learning how to drive, the ophthalmologist diagnosed many scars on the corneas of her eyes. The eyes were no longer round and as a result her eyelashes grew inwardly, constantly injuring and changing the eye. The eye doctor removed the eyelashes on the lower lid under the microscope and since then Michelle's vision improved considerably. She is very thankful to him for freeing her of these lashes since they prick her eyes like daggers. She also values the fact that she can call upon his help whenever needed.

You might ask what I learned from these numerous painful hours in the dark. The following quote from Frauke Plaschnick fell into my hands several years ago and explains exactly how I feel:

"Enlightenment does not mean standing in the light, but learning how to see in the dark in order to find the light."



Puberty

Even for those who enjoy perfect health, puberty is a very challenging time in life, in addition to being very important for later development. Looking back on the years of puberty they were probably the most difficult for Michelle. Despite her tremendous will to live and her love of life, she would still fall into deep depressions. This is not surprising, for at that time her body was one big wound (and this for approximately five long years). It was hard, mutual work and time spent "polishing the facets of our inner diamonds".

When her menstruation began at the late age of 16, her skin definitely became smoother, clearer and more balanced. Since then she has also had less attacks; in other words the formation of blisters is clearly stronger one week prior to menstruation (especially in her mouth and eyes). We observed an unmistakable connection between hormones and sexuality. It is already a well-known fact that the skin of EB patients heals almost completely during a pregnancy! Perhaps future medical research will also take a closer look at the hormonal aspects related to EB.

Minuten nach der Premiere stürzte sie so unglücklich, dass alle Vorstellungen abgesagt werden mussten. Jetzt steht die hautkranke Michelle Zimmermann mit ihrem «Sternentanz» wieder auf der Bühne. Musste es erst dunkel werden, damit man die Sterne sieht?

Sterne leuchten nur, wenns
Vom Fall und Aufstieg der Michelle

Profenarbeit für «Sternentanz». Am 10. Februar ist im Berne

tipp

E s klingt etwas trübsig, wenn sie es sagt: «Drei Tage lang war ich traurig. Flipp, hübsig

Fachdruck, ist heute noch



The world's wounds

"I hope and pray that people will finally wake up"

Shortly before her 20th birthday Michelle was privileged to act in "Dance of the Stars" ("Sternentanz"), a theatrical piece which had been written explicitly for her by Livia Anne Richard. Following the successful premiere performance, Michelle had a serious accident: She fell head over heels down a seemingly endless staircase. This resulted in extensive wounds on her skin. The left side of her body even looked as though it had been peeled. Michelle compared her pain literally to purgatory and expressed strong doubts that she could stand this agony to the end, saying: "Don't be sad if I die tonight, I will return very soon." On the way home following the accident she cried out loudly saying: "I hope that people will finally wake up and again recognize all-embracing love!!!"

For the first time in her life she considered taking pain-killers. She knew that we had no such analgesics at home but, if necessary, could get hold of something quickly. Then she meditated intensely for a short period of time and afterwards reversed her decision, saying in a convincing tone of voice: "No, I refuse to take anything!" And she stuck to her decision, despite having to suffer the most horrific pains when her dressings were changed. The wounds on her body resulting from this accident resembled the various world continents. Three months later she was again on stage.

Strength comes from resistance

Many years of tireless activities followed on different levels. Probably the greatest challenges for me in all those years was not to give up, despite Michelle's recurring wounds and severe setbacks, to continually try and give my (our) best, and despite extreme exhaustion to unconditionally accept sadness and maintain serenity, in other words to see beyond my daughter's external appearance. This, for example, did not mean overlooking the tiny hands with their scarred fingers but simply accepting them as they were. These were long and painful development processes which were not easy to cope with. It required a substantial amount of self-discipline, sacrifice, perseverance and endless trust in God's love.

Faith in God

*There is always a reason behind suffering –
Nothing is incurable*

I do not believe that sickness is equivalent to punishment. Instead I consider it an opportunity to find one's way back to the eternal spiritual laws. Each day I try to let go of my mistakes and fears, to forgive myself and others, to not prejudge people or hold onto the past but rather to recognize that each day and moment we are given the opportunity to begin anew.

I came to understand that man is responsible for his own well-being, that man's own wrong way of thinking and actions cause him to suffer, separating him from the divine life source. Negative thoughts such as anger, hate, envy, jealousy and fear block the flow of life energy and prevent us from accessing the healing sources of divine love.

The moment we turn around and recognize that we are not separated from this universal love energy we call God is the moment we will find ourselves relieved of all burdens. I have learned not to put energy into pain, infections, all the wounds and the sadness, but instead to surrender myself to and quietly recognize the one supreme power inside myself:

*God is omnipresent
God is omnipotent
God is wisdom
God is love*

Even though the way for me has been long and steep, today I am thankful for everything I have been able to learn on the way. Together we have worked to develop the finer qualities of life within ourselves, virtues such as understanding, patience, forgiveness, tolerance, generosity, courage, trust, gratitude, happiness and true love!

Since I have never doubted divine wisdom, I have always been connected to the eternal source of strength. I have often been asked "Where do you get your strength from?" and my reply has always been the same:

"It is not my strength and I do not take it. It flows within me and I pass it on. It belongs to all of us. It flows through us and the entire universe. It lives in everyone, waiting to be used and to flow onwards!"



**s dunkel ist
Zimmermann**

Gestern die zweite Premiere.

h in
zeit
ende: die 57 die Pressebe-
sprechung. Sie habe diesen Sturz
vorher nicht gewusst, erklärt Zimmermann.



Compassion is consciousness which expresses itself in words and deeds.
Compassion is the art of not inflicting pain on others.

Compassion sees neither faults nor weaknesses in others and does not differentiate between good and bad people.

Compassion knows no boundary between two countries, two religious lines of thought or two religions.

Compassion knows no ego and thus denies the existence of fear, desire or passion.

Compassion forgives and simply forgets.

Compassion is the expression of love in all its abundance.

Mata Amritanandamayi

Filled with love I would like to dedicate this booklet to all people around the world affected by EB.
My thanks flow to my twin brother, René, for all his graphic work, as well as all my spiritual and earthly friends, and of course Therese and Michelle, who have led me through the darkness into the light.