

# Julie and the sea shells

A book about the chronic skin condition lichen sclerosus





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Lichen Sclerosus Association Switzerland

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# Foreword

This little children's book is about lichen sclerosus, a skin condition even doctors are often not familiar with. In a playful way, it describes how a preschool-girl and her family deal with this chronic condition affecting the external genitals. By reading this delightful story to their child, parents can explain about the genital area and convey optimism regarding lichen sclerosus at the same time.

This book was initiated by the Lichen Sclerosus Association Switzerland. Every family of an affected girl should have this book and it should be made known to Gynaecology and Paediatric Congresses.

**Dr. Marlene Heinz**

Paediatric and Adolescent Gynaecologist

Note: For information about boys faced with lichen sclerosus please contact the Lichen Sclerosus Association Switzerland

*Dear parents, this book will inform you and your child about the skin condition lichen sclerosus. We want to support you by explaining what lichen sclerosus is and how it is treated.*

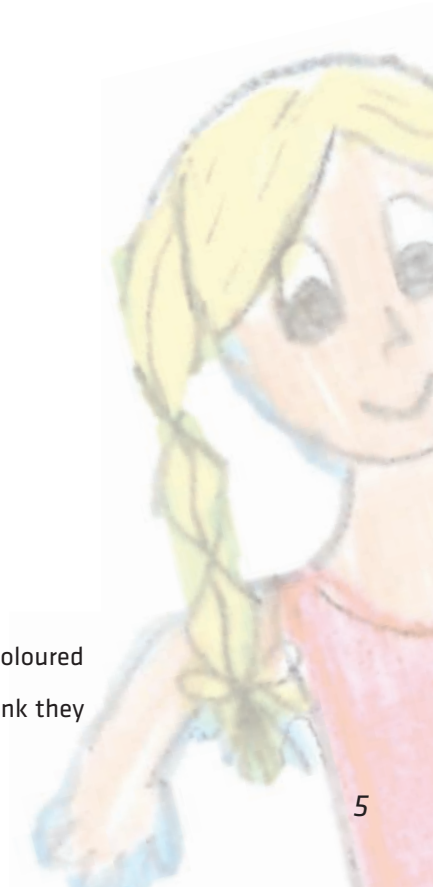
My name is Julie and I'm five years old. I go to kindergarten and have a lot of friends there. I live with my brother Leon and my parents in a little house with a beautiful garden. In summer I love to play outside.



This is what I look like:



In summer I love to wear swiny skirts and different coloured hairclips. I love my blonde plaits most of all because I think they look very cool.



My three-year-old brother likes my plaits as well because he can pull them, which I don't like at all.



What I don't like either is that Mummy or Daddy say „no” to me all the time. Or that we have to go to bed early. What things don't you like? I didn't use to like washing my hair or having a shower once. But I'm OK with that now.



Leon, Daddy, Mummy and I live on an island. An island is a piece of land surrounded by water, but you probably know that anyway. So if you want to visit me and my family, you have to take a boat. It would have to be a big boat because it takes quite some time to cross the sea to get to the island.

The name of the island is Borkum, which is located in the North Sea.

*What is your family life like?*

*What does your child like and what not?*

*What is your child really good at?*



Leon and I love to take our buckets to the mudflat. The mudflat is a sea that you can walk on. Not always, but twice a day, when the tide goes away. We call this “ebb”. And when the tide comes back in, we call it “flow”.

It is like my mood. Sometimes I’m in a good mood and other times I’m in a bad mood. Maybe you’re like that too. Sometimes you have to tidy up your room and other times your parents find time to play with you. Because of ebb and flow, I can’t always go out and swim. When the tide goes out, there is just sand and no water. Just imagine a huge sandpit and then you know what I mean.



The sand in the mudflat is very wet. You can find a lot of sea shells on the beach. They smell of salt and if you hold the big ones to your ear, you can hear the sound of the sea.

Sea shells are really hard on the outside and very soft on the inside. There are big and small ones, different coloured and plain ones. If you touch the sea shell, they feel hard, some rough and others smooth.

I collect shells because they are something really special.



*Do you have both sexes  
in your family?*

*Do your children have  
gender-specific prefer-  
ences?*

*What do you think exactly  
defines a girl or a boy?*

There are girls and there are boys. Boys and girls are sometimes alike and play together. Sometimes they have different interests. For example, I like to play with dolls, Leon prefers cars, I like to wear pink, Leon can't stand it!

My body is also different from Leon's.



Because Leon is a boy, he looks different from me.

When he's older, he might have a beard like Daddy or some stubble on his chin if he doesn't shave.



Boys like Daddy and Leon have a penis and testicles. Those are their genitals. Leon stands up to wee and it comes out of his penis. His penis is like a garden hose with a hole at the front. The tube on the inside is called the urethra.

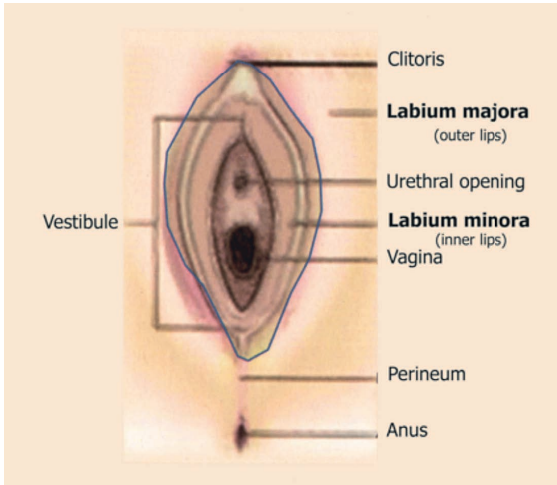
*We will explain later in greater detail about the skin condition lichen sclerosus. But we think it is very important that any child affected by this condition is not only an expert on the illness but also on the body, which explains this little excursion into anatomy.*

Mummy and I are girls. Mummy has breasts where milk used to come out to feed Leon and me when we were babies. I only have small nipples because I am not a woman yet.

Girls like Mummy and I have a vulva and a vagina. We have to sit down to wee. That's really annoying when we are outside. Leon can just stand behind a tree to wee, but I have to crouch and watch out that I don't accidentally wet my trousers. That's why I prefer wearing skirts.



When Leon and I play around on the beach naked, you can immediately see Leon's penis. My vulva and vagina are hidden like the inside of a sea shell. From the outside you can only see two folds of skin. They are called labia. If you pull them back, girls look like this:



At the top is the clitoris and at the bottom is the anus. If you pull back the labia, you can see two openings. It's best if you take the mirror, like the one you got with this book, and take a look for yourself. The hole at the top is the urethra. Like with Leon, it's where the wee comes out. The dark ring marks the vulva.

The lower hole is the entry to the vagina. This is where babies come out during birth.

*It is important to handle one's own body consciously. The sexual organs should be discussed in an uncomplicated and open way, naming them like eye, mouth and foot. Neither overstated, nor tabooed.*

*The condition lichen sclerosus occasionally occurs during childhood. Overall, about 4% of all women and 1 out of 900 children are affected. In the case of boys, the condition is often diagnosed as a phimosis.*

One day I was lying in my bed feeling sad. You might wonder why. Well, it was like this...



When I was as young as Leon, just three years old, I had this terrible urge to scratch my labia and bottom the whole time. Mummy took me to the paediatrician, but he didn't know what to do either. We tried a lot of ointments, but they didn't really help. Then, from time to time, my tummy hurt. And when I went to the toilet, it hurt because my vulva and bottom were very red and sore.



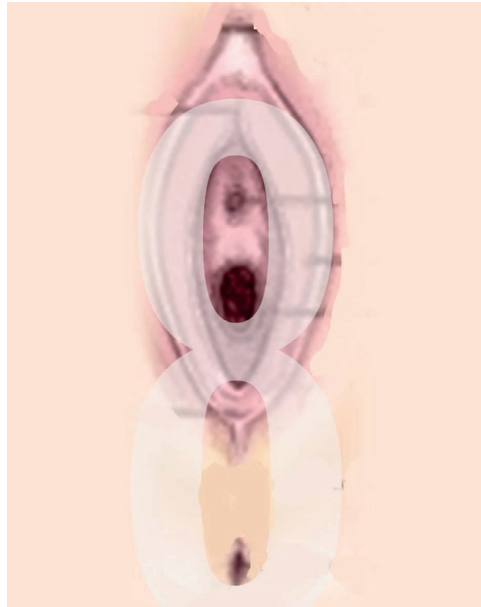
That hurt so much that I tried not to go to the toilet until I couldn't hold myself anymore. Afterwards I didn't even make it to the toilet at all. I wet my pants like a baby. Imagine that! I cried with anger and pain. Then Mummy and Daddy held me very tight. Sadly, it wasn't even summer so I couldn't wear any skirts. Ugh, that was awful! When it hurts, I don't like to wear trousers. I was so sad. Do you know what it feels like?



*It is not necessary to have a biopsy performed to diagnose lichen sclerosis. It can be diagnosed by experienced gynaecologists and dermatologists by asking about symptoms and examining the skin. It is not clear what causes lichen sclerosis, but it's thought to be related to an overactivity of the immune system.*

*The experienced gynaecologist and dermatologist will recommend and prescribe corticosteroid medication which should be applied directly to the affected skin over several weeks.*

Eventually, we found a really nice doctor, called Dr. Merry, and she told me that I had “lichen sclerosus”. That is Greek and means something like white hard band. The skin affected by this condition often looks like a white figure 8 around the vulva and bottom.



For the time being, I was happy that my pain had a name and I could do something about it. Dr. Merry gave me corticosteroid ointment. Cortisone is a hormone that is produced by our own body. If cortisone is put into an ointment, it helps the skin become healthier again. My doctor said that I have to use the ointment sparingly though.

The ointment works almost like chocolate. When I eat chocolate, it makes me really happy, but if I eat too much of it, I feel sick and eventually I will get tooth decay and become fat.



It is the same with cortisone. At first, I had to put the ointment on my skin around the vulva once a day before I went to sleep, and then, hey presto, the pain and itch simply disappeared. Now I have to use the ointment only on Sundays and Wednesdays. That is called „maintenance therapy” and this makes sure that it won't get so bad again.

*After a cortisone therapy for an acute outbreak of the condition, maintenance therapy will be necessary to help keep symptoms under control. In this case, cortisone ointment should be applied twice a week. There are other therapies as well but cortisone is always first choice.*



*Lichen sclerosus is incurable. Therefore, your child should learn how to deal effectively with his or her condition and ensure proper and consistent care of the affected genital area. Besides corticosteroid therapy, there are additional therapeutic approaches.*

I must make sure that I only put the ointment on the outside of the vulva and not inside the vagina because otherwise it burns. For two years now I have used the special ointment. My condition is chronic, that means it keeps coming and going. It is like the ebb and flow of the sea.

So that my vulva and bottom stay ok, I have a special beauty treatment:

- Twice a week I have to use my ointment as a maintenance therapy. If I have a lot of discomfort, I use the ointment daily for a longer time



- No soap on my genitals



- Only dry and warm pure cotton or silk underwear



- No bubble baths

- When I have been to the toilet, I always wipe from the front to the back (from the urethra to the bottom) with colourless toilet paper



- Ensure soft stools

- I clean with unscented cotton pads, wetting them with water before I use them

- I cream my genital area regularly using oils and care products



- I check with a mirror regularly



- I wash my hands after going to the toilet

- Before going into a swimming pool, I cream with a thick layer of vaseline (chlorid water is not good for my skin)



- If I feel like it, I bathe in oils or special care products to tend to the skin

- I change wet bathing clothes immediately

*Having a check-up with a gynaecologist or a dermatologist every 6 months or year is important, so that changes for the worse can be treated immediately.*

My kindergarten teacher, Mrs. Jolly, knows about my condition and supports me. But the other kids don't need to know what I have. Lichen sclerosus is nothing to be ashamed about because everyone has little problems which nobody else knows about. If I'm in a lot of discomfort, I tell my kindergarten teacher. She then calls my parents who come to help me. Mummy, Daddy and I decide together who can apply the ointment in emergency. I can always say "stop" if I don't want it.

I choose two adults who I trust and who will help me if I have any worries.



My vulva and my bottom are a part of me just like my arms or eyes but you can't see them from the outside. They are very special just like my prettiest sea shell. My vulva feels a bit like a sea shell now, because my skin has become a bit hard and rough because of my lichen sclerosus.

My doctor, Mrs. Merry, looks after me very well, so I see her a few times a year. Because she has to look after other girls as well, she gave me a little hand mirror, like the one you get with this book.



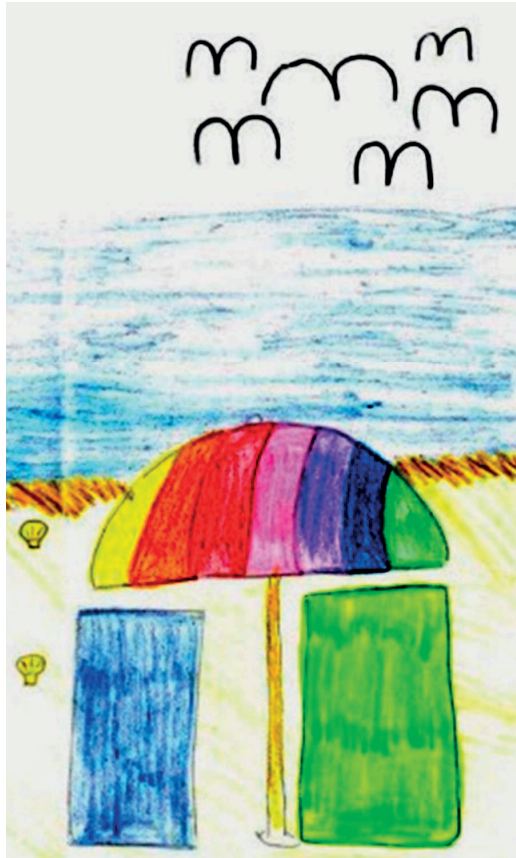
*Atrophy and scars should absolutely be prevented by consistent and adequate therapy.*

Mummy and I regularly check with the mirror if I have acute symptoms of my condition. I notice by the itching that I am having another flare-up. That is when I want to spend the whole day on a seesaw in a skirt and rub myself on it. But that is of course not good because it irritates the skin even more.

*Help your child to cope with this condition.*

A condition like this is a real challenge. It brings about changes, which my family and I have to live with and adapt to. Just like the ebb and flow of the sea. When the water has gone, you can't come to visit us on the island.

Although I have lichen sclerosus, I'm still a happy girl who loves to play in the mudflat and swim in the sea.





When I have a bad day again, Mummy and Daddy hold me tight and Daddy reads nice stories to me after he comes home from work. After a check-up by Dr. Merry, Mummy and I always go and get some ice cream or eat some cake. Sometimes we go shopping and I might get a beautiful new dress.



Sometimes my brother Leon is the sweetest little brother in the world. When I'm ill he even gives me his toy cars. Other times I could send him to the moon because he annoys me so much. But I think that is the same with all siblings.



*The following factors are important for managing this condition:*

- *Positive self-perception*
- *Self-discipline*
- *Self-efficacy*
- *Social skills*
- *Coping with stress*
- *Problem-solving skills*

*How much attention will  
you pay to this condition?*

Oh, Mummy is just coming into my room with a brightly coloured bag in her hands. Wait a moment, I want to tell you what is inside. It's a new skirt and a new box for my sea shell collection. Sometimes lichen sclerosis isn't so bad after all.



**This book was initiated by the Lichen Sclerosis Association Switzerland. It was developed, written and translated by**

- Dr. med. Regina Ebert (idea and text)
- Dr. med. Karin Wiedmer-Zöbeli, Paediatric and Adolescent Psychiatry (medical support)
- Dr. med. Marlene Heinz, Paediatric and Adolescent Gynaecologist (medical support)
- Gail, Nada, Lysann, Anita and Bettina (translation)

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Julie is five years old and has to live with lichen sclerosis, a chronic skin condition.

This little book written for affected children and their families explains and informs about the condition in a playful way.

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