

DECIDING ON TREATMENT CONGENITAL MELANOCYTIC NEVUS

DECIDING ON TREATMENT CONGENITAL MELANOCYTIC NEVUS

Content

Introduction	5
---------------------	---

Part 1 Stories of parents	9
----------------------------------	---

Maarten and Linda Anouk	11
Rob Arthur	17
Marian Danique	21
Klaartje and Stef Diede	25
Jan en Roelinka Brecht	31
Marlous and Chris Cécile	35
Sandra Joep	39

Deel 2 Stories of people with CMN	43
--	----

Adri	45
Angela	51
Carine	55
Danique	59
Mirte	61
Roland	65
Thirsa	71

Introduction

Your baby is born, and everything is new. If your child is born with many or large birthmarks, congenital melanocytic nevus (CMN), you'll often have a lot to deal with. Many parents wonder if they should have the birthmark removed. And if so, at what age? What does the procedure actually involve? Can we wait until our child is old enough to decide for themselves? And what are the risks of doing nothing?

In the past, it was often thought that a congenital nevus carried a high risk of melanoma. Melanoma is an aggressive form of skin cancer that can develop from melanocytic nevi. Therefore, doctors at the time recommended removing CMN as quickly as possible. The idea was that once the nevus is gone, melanoma can no longer develop.

But we now know better. Several studies show that the risk of melanoma with most congenital birthmarks is lower than previously thought. Of course,

that doesn't mean it can't still be a worrying experience if your child has one or more visible birthmarks.

Deciding whether or not to have surgery isn't easy. A birthmark can be in a conspicuous area, like the face, neck, or arms.

Perhaps you're worried about how your child will feel later in life. Will they be bullied? Will they become insecure about their appearance? And how will you, as a parent, cope with that? Sometimes your own feelings play a major role in this.

On the other hand, surgery is a major intervention. It often means multiple hospital visits and sometimes multiple surgeries. Every procedure has risks. And even if the nevus is largely removed, a scar usually remains. It's also possible for the color to (partially) reappear later.

There are several ways to remove a congenital nevus. A doctor can cut away the nevus or use a piece of skin from another area. Sometimes, the healthy skin is first stretched with a small balloon,

called an expander, placed under the skin. This creates extra skin that can later be used to close the wound. Lasers can also be used to reduce the thickness or lighten the CMN. A laser can sometimes also reduce hair growth in the area. However, even with laser treatments, the nevus usually doesn't disappear completely, and the pigment can return.

Over the years, there's been increasing attention paid to what it's like to live with a visible birthmark. What does it feel like when people constantly ask questions? Or when, as a child, you feel like you look different from others? It's not just about the medical risks, but also about the impact on your child's daily life and self-confidence. And that's precisely what often makes the choice so difficult.

In this booklet, you'll read the stories of Dutch parents and young people who once faced this decision. They are all members of Nevus Netwerk Nederland, which translates as Nevus Network Netherlands, the Dutch communi-

ty for all those affected by congenital melanocytic nevi. On the following pages, parents share how they decided whether or not to have surgery. And young people share their experiences with having a birthmark or what it's like to live with a scar after surgery.

We hope these stories will help you think about what's best for your child. Because one thing is certain: there's no right or wrong. Every situation is different, and ultimately, only you, as parents, know what feels best.

Dr. Claire van Eijnden
Dermatologist Erasmus
Medical Center, Rotterdam,
the Netherlands

Marjolein van Kessel
Nevus Netwerk Nederland





PART 1

EXPERIENCES OF PARENTS



"She says she doesn't want any more surgeries – she's happy the way things are."

Maarten and Linda | Anouk

Anouk (8) was born with giant congenital nevi (CMN) all over her body. Her parents, Maarten and Linda, talk about the operations Anouk has had. These were successful, but not always without complications.

Anouk had her first surgery at just 6 months old, to remove the largest nevus on her head. “I think it was almost three inches wide,” says her dad, Maarten. “That was the biggest one. Besides that, she had lots of other nevi about the size of a 50-eurocent coin, and several smaller satellite nevi too.” Linda adds, “We’ve never counted them all, but I’d guess she has around fifty.”

Deciding on Surgery

The decision about whether Anouk would have surgery was made just five days after she was born. “It all happened very fast,” says Linda. “They wanted to discuss it right away because the nevus was on top of her head. Once her hair grew in, doctors wouldn’t be able to monitor it as easily. The alternative would’ve



Above: left leg July 2017
Below: left leg March 2025

been to insert a balloon under the scalp to stretch the skin, but we really didn’t want to put her through that.”

Maarten adds: “We made the decision together with the dermatologist and the plastic surgeon. In the end, the doctors advised us to go ahead with surgery on her head.” Linda pauses, then says: “Talking about it now makes me think of everything we’ve been through. She ended up having five surgeries in total, because her scalp couldn’t be operated on all at once—it had to be done in stages.” Maarten continues: “And each time, while she was under anesthesia, they also removed a few other nevi.”

Since Anouk was already under

anesthesia, her parents agreed to have part of a nevus under her eye removed, along with others on her arm and leg. “Every year when we see the dermatologist, she has to undress completely so each nevus can be checked for melanoma. It’s not guaranteed that she’ll develop melanoma, but her risk is higher because she has so many. By removing a few extra nevi during each surgery, the check-ups now are a little less overwhelming,” explains Maarten.

“After five surgeries, we stopped,” Linda continues. “She started having wound complications, where stitches would burst open. We both work in healthcare, so we know how to take care of wounds—but when it’s your own child screaming in pain, there’s only so much you can do. If she wants more surgery when she’s eighteen, of course we’ll support her. But for now, it’s enough.” Anouk had her last surgery right before her fourth birthday, timed with her starting school. “We wanted her to begin school without constant interruptions for surgery, so she could just enjoy

being a kid.”

Preparing for Surgery

For the parents, the preparation process wasn’t too difficult logistically. “We got one phone call with a questionnaire, and it only took about fifteen minutes,” says Maarten. “The harder part was emotional—getting yourself mentally ready to go through it all. As the surgery day gets closer, you really do feel nervous and uneasy.”

Linda remembers: “When she got a little older, we started reading books with her. The one that helped the most was *A Bear with Spots*. Beyond that, we didn’t prepare much for her. For us, though, we had to arrange things at work—both of us wanted leave and to stay home with her for at least two weeks. We also needed childcare arrangements, because she couldn’t go to daycare for several weeks due to infection risks.”

Surgery Day

On the day of each surgery, Maarten and Linda would wake up early. Linda recalls: “Anouk

was still a baby. She couldn't have milk for six hours beforehand, so we'd wake up in the middle of the night to give her one last bottle, then go back to sleep. A few hours later, we'd head to the hospital. There she was weighed and given a wristband. Since she was so little, she was often the first to be taken in. While we waited, we were given a buzzer – one of those round ones you get at a restaurant. It would go off when our child was waking up from anesthesia, letting us know we could go see her. We were completely focused on that buzzer. When it finally went off, we could finally breathe again."

Linda adds: "Honestly, the anesthesia was the hardest part, scarier than the recovery. We always thought: We'll manage the aftercare, we can take leave, we'll get through it – as long as she wakes up. Most of the time, we could take her home later that same day. She'd be really nauseous and tired. I remember driving home and having to stop again and again because she was

throwing up. Once we got home, we put her to bed and she slept a lot, worn out from the anesthesia and the surgery. It was amazing, though – she bounced back quickly and was soon her cheerful self again. She really is such a happy kid."

The family had all her surgeries done at the Wilhelmina Children's Hospital (WKZ) in Utrecht, the Netherlands. "The experience there was really good," says Maarten. "We had a wonderful dermatologist, and the pediatrician who had been there at her birth stayed involved in her care. They were both calm, kind, and always took time to listen. Before each surgery, they'd ask how things were going – for example, whether she'd been having nausea. And when she had wound complications, they always made time for us quickly. Despite everything, we've had a very positive experience with how they supported us."

Looking Back

Maarten remembers how they documented the whole process:

“From our very first hospital visit, we started a little book about Anouk’s journey. We wrote down every appointment, every date with the dermatologist and surgeon. During the first year, we had to see the pediatrician every three months to check on her development. At the hospital, we also saw the dermatologist and the plastic surgeon. She still goes back once a year for checkups.

The book has helped Anouk a lot. It has photos from before and after her surgeries. Sometimes she takes it out and looks through it. Every now and then she’ll even start a conversation about it. She says she doesn’t want any more surgeries – she’s happy the way things are.

“She often says, ‘I’m unique,’” Linda adds with a smile. “And she’s right. That’s also how we try to raise her – to know that everyone should feel free to be themselves. If someone has questions, they’re welcome to ask. But if you don’t feel like answering, you can simply say so – and that’s completely fine too.”

Linda also has advice for other parents going through something similar: “Make your own kind of memory, like we did with the book and photos. It really helps – both for your child and for yourselves. It gives you something to look back on and a way to process it all.”

Maarten agrees: “We’re dealing with this now as adults, but Anouk will process it differently as she grows up. If she ever struggles with it later on or wonders why we made certain choices, she can look back and read what we were thinking at the time. She’ll also be able to see how she felt back then and how she coped with it. We’ve tried to lay that foundation for her in this way.”

"At just two weeks old,
he underwent surgery
using a water jet technique."



Rob | Arthur

When Arthur (5) was born, he had a giant birthmark that covered more than half of his body. At just two weeks old, he underwent surgery using a water jet technique and then spent about a hundred days in the hospital. His father, Rob, shares what that was like and how they ended up choosing this treatment.

“The large birthmarks stretched from the back of his head down to his buttocks, across his ribcage, and halfway down his arm,” Rob explains. “Besides that, he had some bigger and smaller birthmarks all over his body. Over the years, many satellites appeared on his body and face as well.” For Rob and his then-girlfriend Anne, it was a big shock. “We felt very mixed emotions; joy for our first child, but also sadness, because you immediately see that something is not right.” At the hospital in Turnhout, Belgium, where Arthur was born, the doctors said nothing could be done. However, they did refer them to doctors in Leuven. “In the meantime, Anne had already gotten in touch with

Nevus Netwerk Nederland to look for treatment options,” Rob explains.

Making a choice for your child

Through Nevus Netwerk Nederland, they got in touch with a specialized dermatologist in Rotterdam where they could be seen within just a few days. “We went there with the idea of having Arthur treated, probably with a laser,” Rob says. “Not long after, we were able to go to Leuven for a scan to check whether there were spots on his brain. In the Netherlands they don’t do that, because even if they found something, there wouldn’t be treatment and they say it only makes parents worry. But we wanted it done anyway.”

After the scan, the doctors spoke with the plastic surgeon in Leuven. While Arthur was waking up from the scan, Rob and Anne were presented with a treatment option. They could start the next day with a new water jet technique, which was a kind of curettage [a method where a layer of the birthmark is removed with a sharp spoon, ed.]. With the water jet, they could take off the top layer without the risk of heavy scarring.

In just a few hours, Rob and Anne had to choose between the water jet treatment in Leuven or the laser treatment in Rotterdam. “That was a very difficult decision,” Rob says. “In both cases we weren’t sure of the outcome. In other countries, treatments are often high quality, but they’re not always covered by health insurance, and travel is a challenge. Money and time ultimately weren’t the reason we chose Leuven, but mainly because we had only two hours to make a decision. At the time, that was really stressful.” Looking back, Rob doesn’t see that time pressure as entirely negative. “It gave us less time to doubt or overthink. Although afterwards you do think, maybe we could have done a bit more research ourselves into other options.”

The treatment

Arthur underwent two surgeries in total. The back of his body was treated at 2 weeks old and the front a week later. “The treatment itself went very well, and the results were excellent,” Rob recalls. “But he stayed in the hospital for a long time - about a hundred days, I be-

lieve. Since the treated area was so large and spread across his entire body, it was essentially like he had an enormous burn all over. That took a lot of time to heal. On top of that, he developed several infections and inflammations one after the other, and he also lost some weight, which left him with very little reserves. That was tough.”

Rob and Anne had to lean heavily on each other. “That kind of grief is normal for all parents in situations like this. Everyone handles it differently, and as a couple it’s not always easy. But we talked a lot and supported each other. That’s important, because you can’t really prepare for something like this. The support we found at Nevus Netwerk Nederland also helped a lot.”

Since the treatment, Arthur has had to go for regular checkups – every six months in Leuven, and every six months with a dermatologist – basically an appointment every three months. “Even though we don’t worry about it too much, Arthur’s risk of skin cancer is still higher. By checking regularly, we can catch changes early. We trust that process completely.”

Rob is very satisfied with the final result of the water-jet treatment. "I'm glad we chose Leuven," he says, "and not Rotterdam. With the laser treatment, they apparently can't adjust the depth as precisely, but with the water jet they could. That's why Arthur now has hardly any scars. It turned out really well."

Mental impact

Because Arthur was so young, he doesn't remember the surgeries. But Rob notices that lately he has become more aware of his birthmarks. "Every now and then people comment on them, especially on the birthmarks that are very visible, like on his face. 'Do you have chickenpox?' they ask. And we say, 'No, he was born with a giant birthmark.' So yes, little by little he's starting to realize that he's a bit different from other children."

That's why Rob and Anne decided to bring in a psychologist. "She can help him with his self-image, to accept himself as he is, and also prepare him for comments and teach him how to respond to things

he doesn't like." Rob himself also notices that Arthur gets looked at more often, for example, when swimming. "As a parent, you can't help but feel a bit afraid of how that will go later in his life. Kids can be so harsh with each other when it comes to bullying. And a boy like him is becoming more and more aware of that. So yes, I do fear bullying." Rob hopes that there will be more awareness of situations like Arthur's. "That's also why I think this interview and this booklet are a good initiative. As a parent, especially in the first week, so much comes at you. Then it's really helpful to be able to read about the different options."

"As parents, we saw obstacles
in her future. We kept wondering
what life would bring for this
tiny baby."



Marian | Danique

Our daughter Danique was born in 2005, so now we have a lively teenager running around the house. I am the mother of a beautiful 16-year-old daughter. She has a birthmark that runs diagonally across her chest, left upper arm, and back. As she got older, other birthmarks appeared on her body.

Early surgeries

When she was four weeks old, she underwent surgery to remove the top layer of skin covering the entire large birthmark. Danique then spent almost two weeks in intensive care. This was a pretty tough emotional period for us. Once she was home after her hospital stay, we were finally able to recover a little from the rollercoaster ride we had been on since her birth.

As parents, we saw obstacles in her future. We kept wondering what life would bring for this tiny baby. What struggles would she face? Of course, there have been problems, but overall, almost none of our fears have come true, and she has enjoyed a carefree childhood with lots of friends. She has grown into

a sociable and intelligent girl.

At age 2, she had another operation to remove a few smaller nevi that were thick or in uncomfortable places. One was too large to remove in a single surgery.

During a conversation between me and Danique when she was about 4 or 5 years old, she asked about spots on her body and the conversation turned to the nevus with a scar. What had happened to it? She got angry when she heard what had happened and said that the spots were part of her and that they should not be removed. We then decided not to do any further treatments unless medically necessary. It is up to Danique to decide what she wants to do with her body. She is beautiful just the way she is.

Growing up

The elementary school period actually went quite smoothly. There was one incident that stuck with us as parents. The class always had to wait outside in rows of two until the teacher came to get them to go to class. There was one boy who didn't want to hold Danique's hand

because she looked different. That evening we told her it was sad for him, because he couldn't handle holding hands with someone who looked different. She wasn't the problem.

At the end of every school year, we would meet the new teacher for the following school year to tell them who Danique is and how we were going to start the new school year.

But by fifth grade (for ages 8 and 9), Danique was done with that. She said: "Everyone already knows me, and if anyone has questions, they can just ask." We as parents respected her choice completely. Summers and vacations are always a bit more difficult. That's when we go to new places where people don't know Danique yet.

Often, people stare and whisper. It never stopped Danique from being herself. If she wanted to swim, she swam. She never let others spoil her fun. This wasn't always easy for us as parents. Sometimes we felt really sad when our child was stared at and talked about.

We tried to ignore it, though some days were easier than others. But by the end of every camping trip, she'd always made new friends to play with.

She is now in her fifth year (for ages 16 and 17) of secondary school and is becoming a strong young woman who knows exactly what she wants, and especially what she doesn't want. You can't fool her, and she follows her own path. She stands her ground at school and knows when to ask for help if she needs it.

Although that's not necessary when it comes to her birthmark. She is confident and has a solid, loving, and stable foundation that ensures she can take a punch. She has a nice group of friends around her with whom she does fun things. Danique is truly part of a group and does not stand on the sidelines. Quite the contrary.

If only we knew sixteen years ago what we know today. She hasn't always had it easy, but she is growing up to be a beautiful and strong person. We have no doubt

that she will find her way in the adult world.

See also part 2: Danique.

This story was previously published in the NNN anniversary magazine, May 14th, 2022.

"In the end, we decided with the dermatologist and plastic surgeon to have surgery after the first six months."



Diede and Klaartje

Diede (10) was born with five large congenital birthmarks, and now she has more than a hundred in total. She has had two surgeries, the first on her face, knee, lower back, and hip, and the second on her face again. The first surgery was when she was 6 months old, the second about a year later. Diede shares her story together with her mother, Klaartje.

“She was born in a regional hospital in the Netherlands, where they initially had no idea what exactly was wrong with her,” says Klaartje. “My father is a general physician, and immediately after Diede’s birth, he spent the night searching the internet for information about giant birthmarks. He contacted an expert in this field, Dr. Pasmans, professor of pediatric dermatology at Erasmus MC, Sophia Children’s Hospital in Rotterdam, the Netherlands. When Diede was 6 days old, we went to Rotterdam for a consultation with this dermatologist.

The pediatric dermatologist discussed possible treatment options:

doing nothing, surgery to remove parts of the birthmarks, a tissue expander procedure, or scraping away the giant birthmarks. The doctor said that it is not advisable to put a baby under anesthesia during the first six months. She said, ‘Just enjoy your beautiful baby for the first six months.’ In the end, we decided with the dermatologist and plastic surgeon to have surgery after the first six months.”

Cosmetic and medical decision

Klaartje and her husband Stef agreed with the doctors to go ahead with two surgeries. “The birthmarks on her knee, back, and hip were quite large,” Klaartje explains. “We decided to remove them not for cosmetic reasons, but mainly because of the risk of melanoma. That was the doctors’ advice. Removing the entire CMN (which covers half of Diede’s head) would be an extremely intensive and lengthy tissue expander procedure, requiring Diede to spend years in and out of hospital. From a cosmetic perspective, we decided only to remove a smaller part of the birthmark on her head and

face, near her hairline.”

Diede’s parents didn’t have to prepare much on the day of the procedure. “We got up early in the morning and drove to the hospital. The operation took about an hour and a half, but it felt like a very long time to me. She had to be put under general anesthesia, so I held her and she became like a limp doll that I had to lay on the operating table, which is not a pleasant sight or feeling. The operation was successful, although she did develop an infection at the hairline.”

During her first two years, Diede had six checkups a year, since that’s when children grow most rapidly. Now it’s down to once a year. “She doesn’t like the multidisciplinary checkups, but she knows it must be done. She has to show all her birthmarks from head to toe, which means undressing, and that’s not comfortable for a 10-year-old. But the doctors are all very kind to her, right?” Klaartje asks. “Yes,” Diede answers quietly. Diede and her parents always end the day with a pleasant shopping trip and dinner. “Ultimately, we had to make the

decision for Diede,” says Klaartje. “That’s difficult, of course, because you don’t know if you’re doing the right thing. But with the help of my father and the various doctors in Rotterdam, who provided excellent guidance and advice, we were able to make a well-considered decision.”

Fear of white coats

After her second surgery, when Diede was about 18 months old, she developed a fear of doctors. “From then on, anything involving her body was scary. Think of the hairdresser, the health clinic, or the dentist. We hadn’t expected that beforehand. She was very afraid of white coats. When we had to go for a check-up, we asked the doctors if they could take off their coats, because that helped relieve half of the misery. She would always skip into the hospital, but as soon as they called her name, she would lie down on the floor, hit, scream, and stamp her feet. Things she never normally did, but which arose purely out of panic. Because she was so scared, we had to hold her in a headlock so that the doctors could

examine her.

At home, we played lots of ‘doctor’ games, even with a white coat. But when I put it on, she hid behind the curtains. She was so scared.” Klaartje even hung the coat in the living room so Diede could get used to it. “At first, she walked around it in a huge circle. After two weeks, she finally put it on and started playing doctor. As she got older, it became easier to explain and prepare her for checkups, but at age two, that was nearly impossible.”

Diede adds about her hospital visits today: “I don’t like going, but once I’m there, it’s okay.” Klaartje nods: “I think we’ve been really well supported. We had two doctors we could email any time, day or night. The plastic surgeon even replied on Sunday evenings when we were worried about her wound.”

Looking back - how things are now

“I think we made the right decision to have those operations done,” Klaartje reflects. “The only unfortunate thing was that the first operation was postponed for two weeks. During those two weeks,



“Ultimately, we had to make the decision for Diede. That’s difficult, of course, because you don’t know if you’re doing the right thing.”

Diede started crawling. So, when she had surgery on her knee, pressure was put on the wound. The plastic surgeon hadn’t expected her to crawl with that wound because it would be too painful. However, on the day of the operation, Diede was already crawling again. As a result, the wound on her knee opened up completely. This left a large scar on her knee, which she used to be proud of but now, as a teenager, she struggles with.”

Today, Diede still has a large birthmark on part of her head.

On the side without the birthmark, her hair is thinner and straighter. On the side with the birthmark, it’s very thick and curly. “She gets a lot of compliments on her beautiful hair,” Klaartje says.

Diede says that her head can get very hot because of the CMN, especially when she is exercising. “Because I can’t sweat there, because the heat doesn’t escape as easily,” she explains. Klaartje adds: “Her head warms up extra on the other side, so during breaks in a hockey game on a hot day, she always wants water to cool her head.”

Klaartje and Stef once worried that Diede would be bullied, but that hasn’t happened. “I thought people at the pool would constantly ask questions about what she had, but it never happened.” At the start of each school year, Diede shows her classmates a short video from Nevus Netwerk Nederland that explains giant birthmarks. “It was a cool video, right?” Klaartje asks. “Not really,” Diede laughs. “But it’s nice, because then I don’t have to explain ten times what I have. Some kids at after-school care ask if I drew on my face with marker, but then I just explain that it’s a birthmark.”

Diede and Klaartje hope that by sharing their story, they can help others.



"Nine times out of ten,
I forget it's there."



Jan and Roelinka | Brecht

Brecht was born with a large birthmark on her forehead. For her parents, Jan and Roelinka, deciding whether to remove it was a difficult choice. In the end, a doctor removed part of the birthmark, and the part that remained was shaped into an eyebrow.

The first worries

Jan and Roelinka join the conversation to explain the choices they faced, since Brecht herself remembers very little.

“When she was born, we saw the birthmark on her face for the first time,” says Roelinka. “It was about five to seven centimeters wide, stretching across her forehead and bending toward her nose bridge. We didn’t know what it was, and the midwife didn’t either. I’ll never forget that a doctor in training phoned a pediatrician on the spot, describing what she saw: ‘a dark, wart-like birthmark with hair on it.’ That’s when we were referred to a plastic surgeon.”

Finding the right care

Three weeks later, they met with the plastic surgeon. “The way he treated us was awful,” says Roelinka, her voice still heavy with emotion.

“He said, ‘It’s not her problem, is it? She’s sleeping fine here, it doesn’t both-

er her, and just because it bothers you, we should remove it? That’s not how it works.’ That was awful. He also told us they would need to take photos of the birthmark every six weeks to monitor changes”.

Two weeks later, we returned and told the doctor how we felt. After all, we didn’t know what it was, and suddenly we were dismissed as if we wanted our child to have surgery when it wasn’t necessary. We felt that if it wasn’t necessary, we wouldn’t do it.” *In the meantime, the doctor had contacted another doctor in the Dutch capital of Amsterdam. This doctor said that Brecht should have been treated when she was two weeks old by shaving it off.* “Then he dropped that plan and wanted to start using a tissue expander,” says Jan. “At that point, we thought, wait a minute, we’re going to look for the right help ourselves first.”

That search brought them to a nevus gathering organized by Nevus Network Netherlands. “Suddenly, we didn’t see Brecht’s nevus as as such a big problem anymore,” says Jan. “There were so many different people there, and we had some really nice conversations.” Roelinka nods. “People understood us

very well and said that Brecht's nevus was just in an unfortunate place. They told us about a great dermatologist in Rotterdam who was very knowledgeable about this type of nevus. We made an appointment with him for a second opinion."

Two surgeries

"In Rotterdam, the doctor immediately told us that taking photos every six weeks was unnecessary," says Jan. "He said: 'If something changes, you'll be the first to notice.' He also explained that a tissue expander wouldn't work for Brecht, because it would stretch the skin so much that later she might not be able to close her eyes properly." Instead, he suggested removing part of the birthmark. By then, Brecht was 2 years old. "If it had been on her back, we wouldn't have done it," says Roelinka. "But in the supermarket, other kids would point, and people sometimes made silly comments. That's why we eventually agreed to partial removal.

"The operation was a day procedure," Roelinka continues. "Because we had to travel from the north of the country, we were able to stay at the Ronald McDonald House overnight so that we could be at the Sophia Children's Hospital in

Rotterdam early in the morning. That same evening, we drove home with Brecht in the rain and ended up in traffic. 'What a fun day we had, didn't we?' said Brecht, who loved days like this. All that attention, and she always got French fries afterwards." Jan and Roelinka did their best to make the operation as positive an experience as possible. "Luckily, she really went along with it," says Roelinka, "even though not everything went smoothly. The first time, the IV went wrong and her skin got pinched, so there was lots of crying. The next year, when it happened again, they immediately switched to a mask instead."

During the second surgery, the doctor used the remaining birthmark to create an eyebrow. "He saw it as the perfect in-between solution," says Jan. "If she ever wants the rest removed or lasered later, she can decide for herself." Making such permanent decisions for their daughter wasn't easy. "As a parent, you always wonder whether you've done the right thing," says Jan. "Back then there were no guidelines, so you didn't really know what to expect or which options were best." "In a way, it helped that some options were no longer available," adds Roelinka. "We were already too late for dermabrasion, and

honestly, I was relieved we didn't have to put a two-week-old baby through that." Looking back, they were very happy with the outcome. "I think he had already removed 80% during the first operation," says Roelinka, and Jan nods in agreement. "Yes, truly professional work."

Living with an eyebrow-shaped birthmark

What does Brecht herself think of her mole? "I don't know any better," she says. "Nine times out of ten, I forget it's there." The mole on her forehead is perfectly shaped like an eyebrow and is hardly noticeable at first glance. "Every now and then I get a comment about it, especially because I work face-to-face with customers. As my mother said, sometimes they make a silly comment, which is not meant to be hurtful at all; from burns to bruises, and once someone asked me if I deliberately draw my eyebrows in two different colors," she says laughing. Still, she wouldn't want it any other way. "Once, as a joke, I drew on a 'normal' eyebrow with makeup, and it looked really strange."

"I think my parents made a very good decision for me," Brecht adds. "If it still looked like it did back then, that would



"During the second surgery, the doctor used the remaining birthmark to create an eyebrow. He saw it as the perfect in-between solution,"

be the first thing people noticed about me. Now, it just looks like an eyebrow and works as one. I'm very happy with how it turned out. And no, I never got bullied for it, which is what many parents are afraid of. People know where the line is themselves, and you can't always predict how others will react. What you want yourself is much more important.

Advice for other parents

"We would advise other parents to do the same," says Jan. "Take your time and follow your instincts. Make sure you are well informed about the available treatment methods and choose a doctor you feel comfortable with." "It also helped enormously to talk to other families at Nevus Netwerk Nederland," says Roelinka. "I would definitely recommend that."

"The impact of a birthmark on your face is enormous, so removal ultimately seemed like the best option to us."



Marlous and Chris | Cécile

When Cécile (6) was born, the large birthmark on her cheek came as a huge surprise to her parents. They suddenly faced a very uncertain period: should they remove it or not – and if so, how? In the end, they chose removal, first through excision and later with a tissue expander. “It was really intense, but luckily the medical team supported us so well.”

“The pregnancy was already difficult, and the delivery a C-section – was also high-risk. So, when she was born healthy, my main feeling was relief,” says Marlous (40), Cécile’s mother. “But when my partner Chris held her, he said, ‘Um, don’t be alarmed, but there’s something unusual.’ She had an enormous dark birthmark covering a quarter of her face. It stretched from her mouth to her ear and into her neck, like a flame. No one knew what it was, not even the doctors. That’s when the worry really set in.”

Remove it or not?

The doctors referred the family to Amsterdam University Medical Center (Amsterdam UMC). Within six weeks, they had their first appointment. “At the time, the top expert in birthmarks was there,” says Marlous. “In the meantime, we researched a lot online. I was able to

separate the reliable information from the nonsense, so I didn’t let it scare me.”

At the UMC, the plastic surgeon presented two options: do nothing, or remove it, which she estimated would take two surgeries. Marlous recalled, “That was tough to hear, and a very hard decision to make.”

Together with the surgeon, they discussed the reasons for choosing removal with the doctor. “The younger you start operating, the more flexible the skin still is and the fewer complications there are,” Marlous explains. “She also told us the chance was high that the birthmark would later grow hair and become rough. And she encouraged us to think about the long-term impact, like how difficult it might be for her as a teenager. At first, I thought that was nonsense. We thought she was gorgeous, with or without the birthmark. But then I remembered the second day after the birth in the hospital. A nurse had come to me in a panic. “You didn’t give your child chocolate milk, did you?!” she blurted out. She hadn’t read Cécile’s file. That was very intense for us. Situations like this forced us to face the facts. There is no right or wrong. The impact of a birthmark on your face is enormous, so removal ultimately seemed like the best option to us.”

Surgeries

In the end, Cécile had a total of seven operations. She was 4 months old when she had her first operation, and 7 months old when she had her second. Pathological examination revealed that her birthmark was not CMN, but another type of congenital giant birthmark, the nature of which is not entirely certain. “Then we had to wait a year for the scar to heal. But then her mouth grew crooked. Cécile is unlucky in that she develops unsightly scars, so instead of a nice thin line, the scar ended up being three centimeters wide. Unfortunately, two surgeries would not suffice; number three was scheduled when she was 2 years old. Then the coronavirus pandemic hit and all operating rooms closed two days before the procedure. For more than a year, there was no treatment available for Cécile.”

While waiting, Marlous and Chris began to have doubts: “Do we really want to do this this way, or are there perhaps new developments in the field of laser treatments? We asked for a second opinion at Erasmus Medical Center in Rotterdam, and ended up at the CMN clinic,” says Marlous. Cécile was 3 years old by the time they were able to visit this multidisciplinary clinic, where they felt very comfortable. “Her situation was examined from different disciplines.

They understood us, and they wanted to continue her treatment. Another surgery was scheduled without a long wait.”

The results were good, but not good enough. They then tried laser treatment under anesthesia, but that didn’t work either. Together with a child psychologist, Marlous and Chris ultimately opted for a tissue expander, which involves stretching the skin with a subcutaneous balloon. Cécile was just 6 years old when this process began.

The tissue expander

“Since the start of the expansion process, Cécile has been receiving EMDR therapy, and even now a psychologist is helping her to process her traumas,” says Marlous. “She doesn’t have white coat trauma, but she does have an anxious desire to know everything, and she is very wise for her age.” According to Marlous, Cécile has always had a feisty character. “That’s why we wanted to give her good guidance. Chris and I wrote her a letter in advance so that she could read later why we made this choice, based on the knowledge we had at the time. We also made a photo album of the entire process.” Before the procedure, Cécile and her parents read a picture book from Nevus Netwerk Nederland aloud in class, and they gave parents notes explaining what to expect.

Marlous: "This prevented questions and comments, because Cécile always found questions and comments about her birthmark very annoying."

Cécile was kept well informed. "She knows the expander is to help her move her mouth better and make the scar less visible." Each week, the balloon had to be filled in Rotterdam, thirteen times in total. "That was really tough," Marlous recalls. "But the team supported us incredibly well. I could always call or text with questions. And Cécile was amazing; she handled it so bravely. She wasn't allowed to do many things, such as rollerblading or climbing in gym class.

"That's why we made a list of fun things she could do. She was allowed to choose what she wanted to do and when."

Marlous and Chris also supported each other a lot, she says. "I took a step back at work to be with Cécile. In the evenings, Chris and I could cry it out together, because, gosh, what are you doing? We were both in survival mode, but in the end, we are so happy with the result."

Looking back

At the time of the interview, it had been three months since the balloon was removed. "That surgery took almost four hours," Marlous says, wide-eyed. "With the extra skin they created, they could

remove the scar tissue and the birthmark, and place the new scar along her jawline, where it's much less visible. We stayed one night in the hospital, but there were no complications." Because of her bad experiences with stitches, those had to be removed under anesthesia a week later. "Altogether, she had seven procedures in six years." Now Cécile is in second grade. "She's doing so well." When asked whether they ever had doubts during the process, Marlous replies: "Of course, constantly. But the excellent guidance got us through it. Once you've started, there's no turning back; just stopping is not an option." What advice would she give to other parents in a similar situation? "Take your time. Don't be swayed by what others say, but really listen to your own heart. No one can decide for you; it's up to you as a parent. Whatever choice you make, there is no right or wrong." Marlous concludes with some clear advice: "Take good care of yourself, because it's just really tough."

"Finally, you can
see what a beautiful
little boy Joep is."



Sandra | Joep

“The most difficult thing was that we had to make a decision for Joep. A decision that would largely determine the rest of his life. You constantly ask yourself: ‘How will he get through this?’ and ‘What will the consequences be for him?’”

Little Joep and his tissue expanders

When Joep Leenders was born at the local hospital in the Netherlands on May 19, 2013, the gynecologist noticed large dark spots on the back of his head. Something was wrong, but what? Mother Sandra Leenders: “The gynecologist didn’t really say anything about it and called in a pediatrician. The pediatrician thought it might be a port-wine stain combined with a nevus. He advised us to wait a few days. We were then referred to a center of expertise for hemangiomas and vascular malformations at the UMC Radboud in the Dutch city of Nijmegen. They have a multi-disciplinary team consisting of a radiologist, plastic surgeon, pediatric surgeon, and dermatologist. The dermatologist consulted a pediatric dermatologist, who quickly made the diagnosis: giant birthmarks. In hindsight, I am glad we got clarity so quickly, because from stories from other parents, it is now clear to me that they sometimes spend months or even a year in uncertainty. And uncertainty is like

concrete rot; it eats away at you.”

The family lives in Milheeze, near Helmond, in the south of the Netherlands. Joep has a little brother, Jelle, who is 3 years old. Sandra Leenders (34 years old) is a human resources officer. In that role, she is used to listening carefully and also acting as a mediator in conflicts or when difficult choices have to be made. No wonder she speaks calmly and gives measured answers, even about these sensitive private experiences. “From the moment the diagnosis was made, the search for information began. What does this diagnosis mean for Joep? What are the consequences and risks? Good, objective information was scarce, but the more we read about it, the more worried we became. It touches your soul when you read about your child’s increased risk of those nevi developing into skin cancer and the chance of neurological problems.” People with giant nevi have a more than fifty times* higher risk of skin cancer than the average Dutch person.

We ended up at the Amsterdam Medical Center, with Professor Van der Horst, professor and head of the Department of Pediatric Plastic Surgery. It soon became clear that there were two options: a passive, wait-and-see approach or active preventive intervention and surgery. Step by step, we went through the pros and cons

with Professor Van der Horst and plastic surgeon Dr. Lapid. First, an MRI scan had to determine whether there were also pigment cells in the meninges, brain, or spinal cord. If that were the case, surgery would be of little use, and we would have spared Joep this process. Fortunately, there was no evidence of growth on the 'inside.' I now believe that the MRI scan was the deciding factor in our decision to have Joep operated on. Due to the size of the nevus, tissue expanders were the only option for Joep as a 'removal method.'"

Risks

"Another factor that played a role for us was that Joep will have no memories of what happened in his earliest years when he is older. If he had to undergo surgery later in life, it could leave him with traumatic memories. Moreover, his skin was still a lot thinner than that of adults, so it was easier to stretch. Then the waiting began. Joep's fontanelle had to close sufficiently first, and he had to gain some strength to be able to tolerate the anesthesia, for example. The expanders were inserted in mid-March." Four months later, in mid-July, the expanders were removed from Joep. "We were amazed at how well he was doing and how quickly he was recovering. It was wonderful to see how quickly children adapt to new

circumstances; it was incredible. It also must have been a relief for him, as he now had almost 800 ml less to carry on his head. They were able to remove more than half, unfortunately less than expected. But we knew in advance that a second procedure would be necessary, so that was not a problem. We involved Jelle in the process. Obviously not in all the details, but we didn't shield him from what was going on with his little brother. It was wonderful to see how calmly children deal with situations like this.

"All decisions about Joep were and are made together with my husband Dries. Fortunately, we were on the same page in this regard. That unity is a great support. We can talk about it together, although it is logical that sometimes one of us has a harder time with it than the other."

Photo

"When searching for information, we found a lot of outdated information and, above all, a lot of bad photos. Those images often look like something out of science fiction and are quite grim. I think those photos are bad publicity for tissue expanders: 'they create a false image of this treatment method and of children with this condition. That's why I'm so happy with Wanda Lemmers' photos.'" Wanda is a fellow member of

Nevus Netwerk Nederland and an avid amateur photographer. When talking about those photos, Sandra's maternal love comes to the fore. "Those photos are wonderful and moving. My mother reacted in the same way: 'Finally, you can see what a beautiful little boy Joep is.' People usually only see the condition or the balloons, not the beautiful child underneath.

"Nevus Netwerk Nederland has been extremely helpful with advice. It proved to be a source of objective information and valuable in connecting with other parents. In any case, those giant birthmarks on your baby don't leave you unmoved. It's intense, confrontational. Because I see how well Joep is developing and how comfortable he is in his own skin, the fear of complications is fading into the background, but it will never go away completely.

"What I want to impress upon other people is: don't forget to enjoy your newborn child. It may sound strange, but ultimately, we are 'grateful' that Joep has a condition that will not harm his further development. We keep a book, in words and pictures, about everything we experience. In this way, we are working on Joep's history so that later, when he is

grown up, he can look back in amazement at what he experienced as a baby".

"Ultimately, the question always remains: What will the future bring for him, physically and psychosocially? But whereas the diagnosis in his first year of life largely dominated our lives, that is no longer the case. That's because," she says, beaming and irresistible, "he's such a wonderful and cheerful little boy."

This story has been published before in print magazine *Huid en Haar* ("Skin and Hair") no. 3, 2014 of Huidfonds, the Dutch Skin Foundation.

* Outdated information.



PART 2

EXPERIENCES OF PEOPLE WITH CMN

"More than anything, I'm just glad I got my social life back and learned to appreciate it again."



Adri

Adri (36 years old) was born with one giant nevus on his back and countless satellite spots all over his body. He had the large nevus on his back removed when he was 24. Despite the serious complications that followed, he is still happy with the result.

Growing up with a giant nevus

“The nevus on my neck stretched all the way across my back,” Adri explains. “It was shaped like the continent of Africa. On top of that, I have literally countless satellite nevi all over my body, ranging from tiny dots to larger spots. I’ve tried counting them before, but I never managed to figure out how many there really are – there are just too many.”

Choose whether or not to remove

Adri didn’t get to make all the decisions himself. His first surgery took place when he was just 6 weeks old, followed by more than twenty operations on his neck. “The nevus on my neck was black when I was born. If you touched it, it immediately started bleeding. They removed it using a method called curettage. I always compare it to a cheese slicer – they cut away layer after layer of skin. Thirty-six years ago, the medical field wasn’t as advanced as it

is now, so that was the technique they used back then. The problem was that it left a huge scar, and scar tissue doesn’t grow with you. That meant I needed surgery throughout my entire childhood. Whenever I grew too much, doctors had to insert new skin into my neck so that I could keep growing properly.”

The decision to remove

By the time Adri went to secondary school, his doctors started talking about possibly removing or lasering the nevus on his back. “But at that time, I didn’t want to. I was fine with it as it was,” he recalls. About twelve years later, though, he changed his mind.

“I already knew about tissue expanders, because my doctor had explained the technique to me. But I only really started considering it after an appointment at Amsterdam UMC. The dermatologists there compared my photos to pictures they pulled from Google. That was the moment I thought: what am I doing here? If I want to compare my nevus to pictures on Google, I can do that at home. If I have it removed, then I won’t need these check-ups anymore – and I won’t be compared to random online images. After that, I had a detailed conversation with my doctor, who ex-

plained the entire process step by step. That's when I decided to go ahead with tissue expanders."

What are tissue expanders?

"With tissue expanders, they place one (or more) balloons under your skin," Adri explains. "Each week you go to the hospital, where the balloons are filled with fluid each time. The skin is gradually stretched to create extra skin. Once enough has formed, the birthmark is removed. The new skin is then pulled over the area where the birthmark used to be and stitched together. After that, the birthmark is gone."

Surgery and complications

The first step was a short procedure of about an hour, during which four expanders were placed under his skin. Two weeks later, once the wounds had healed, Adri went back weekly to have them filled. After a few weeks, when enough skin had been stretched, the main surgery was scheduled.

"The process went as planned at first," he says. "But after the main operation, I developed complications. I ended up spending two nights in the hospital. At the time, I was already living on my own, but I needed help, so I stayed with

my mom. One night, I woke up and the entire bed was soaked with blood. That was terrifying."

A small tear had formed where the different layers of skin were attached to each other, Adri explains. "The skin that they fold over your nevus has to reattach to the underside, to the other layers of your body. But because it was surgically removed, there was blood and fluid in between, which created a kind of waterbed effect; when you pressed on one side, the other side of the skin rose. That night, the first tear appeared, and all that blood and fluid leaked out. Then the tear spread all the way across".

"Then my skin shrank back to where it was before the balloons were placed," Adri continues. "As a result, the spot where my nevus used to be became an open wound. That was really painful. It took about eight weeks before it was completely torn apart.

Every wrong move I made tore it a little further and caused even more pain. In the end, I had to take quite strong medication to suppress the pain.

I was glad I was still with my mother; we rinsed the wound three times a day with running, lukewarm water.

The first few weeks, we waited for it to stop tearing so we could assess the damage. Only then could the doctors make a plan to fix it. So yes, that was unpleasant. I was just in a lot of pain.”

Adri had been warned about the risks beforehand, but the chance of it going so wrong was very small. “The doctors said we could try again. It would be a huge coincidence if it went wrong twice. Professor Van Der Horst said afterwards that she had performed many similar operations. She had never experienced anything as bad as what happened to me, and neither had the people she spoke to in her professional circle.

I was completely done with it after six months at home, so I wanted to have the wound closed and get out of there and never come back, so to speak.”

The solution

Adri and his doctors took some time to weigh up the various options. “Ultimately, the annoying, or wonderful, thing about our bodies is that if there is a very large wound somewhere, your body repairs it itself. We decided to wait until my body closed the large wound itself. The wound will close but you will not retain the beautiful natural skin since there

will always be a scar. But how long will that take? It is a very large wound. And in the meantime, I couldn’t do anything. I was 25 years old. I couldn’t go out with my friends. I couldn’t play soccer with my soccer team. I couldn’t exercise. I couldn’t go to the pub. I couldn’t work. My life consisted of the four walls of my mother’s house.

After a few weeks, I said: ‘I’m done with this. This has to stop.’ I decided with the doctors to do skin grafts. That meant I had to have another operation. They took strips of skin from my leg and put them in the wound. Within two or three weeks, the wound was closed. I still had a few tiny open spots, but I could do everything again. I was finally able to quit the medication. The painkillers were nice, but they were also really tough. I literally had hallucinations; I saw people walking in the garden who weren’t walking in the garden.”

Looking back

Adri now has a healed scar on his back. Only on his shoulder blade and neck is there still a small piece of nevus. Despite everything, he doesn’t regret his choice. “I’m not someone who looks back and regrets decisions. At the age of 24, I made this choice consciously.

And I still stand by it. The fact that things turned out differently than I had envisioned at the time is unfortunate and annoying. But there's nothing I can do about that. I can ask myself a hundred thousand times: why do I have nevi? Why did that operation fail?

The result isn't going to change. I'll always be someone with nevi and I'll always be someone with a big scar on my back, but I made a conscious choice. I made sure I was well informed. I'm also 100% certain that if I hadn't done it then, I would have done it five years later. In that sense, I don't look back on it negatively, except that that period was just unpleasant. I didn't mind that the operation failed, that the end result wasn't what I had hoped for, but I did mind that my life was confined to those four walls. Still, I would do it again without hesitation. I was apprehensive about many things, but until it started to tear, it wasn't as bad as I had imagined".

His initial motivation was to have as few nevi as possible. "Of course, there was also a cosmetic side to it, but mostly I wanted fewer nevi so I wouldn't need dermatology check-ups anymore. The fewer the nevi, the lower the risk of melanoma. And in that sense, I succeeded – I

got rid of about 90% of the nevus on my back. Of course, I would have preferred normal skin, but it's scar tissue now. The complications I faced were unusual, not what normally happens. It is what it is. More than anything, I'm just glad I got my social life back and learned to appreciate it again."



"Even though I'm happy
with the end result, it was
a long, hard process."



Angela

Until she was 18, Angela (35) had around 20 to 25 treatments to have her birthmarks lasered, making her one of the first children in the Netherlands to undergo this kind of treatment. When she decided she'd had enough, the treatments stopped. She shares her thoughts on her parents' choices, what the treatments were like, and how she feels about her birthmarks today.

"My back is almost completely covered by one giant birthmark, and about a third of my body is covered in satellite spots," Angela explains. "Sometimes it itches, but luckily not too badly." Her parents chose not to have the birthmarks surgically removed. "That wasn't very common back then," she says. "They could have had them scraped off, but they felt that was too extreme. If they'd done it, it would have had to be in my first weeks of life. My parents were already shocked when I was born with the birthmarks. You just don't know what the health risks are. But they felt that scraping was a step too far."

Laser treatments

"Since scraping wasn't an option, my parents searched for an alternative," Angela continues. "That's how they got in touch with a doctor in Rotterdam who

had a new experimental method: laser treatment. They pushed hard to have me treated with it. I believe I was even the first person in the Netherlands to be treated with a laser for birthmarks."

With the laser, the doctor could lighten the color of the giant birthmark on her back. "They used to be very dark brown, almost black. Now they're light brown." Angela was about 4 or 5 years old when the treatments began.

The plan was to treat her back in phases. "Since my whole back was covered, they wanted to laser small areas of about four by four inches at a time. What I remember most is that it was extremely painful as a child, even under local anesthesia. It was a pain similar to tattoo removal – I actually had one removed recently, so I can compare." Angela's face contorts as she talks about it. "Look, as an adult, you deal with it very differently, of course, but for a child, it's very intense."

After that first treatment, her parents saw how much she was suffering and immediately searched for another option. They ended up in London (UK), where she underwent seven laser treatments under general anesthesia, until later on the same procedure became available in Utrecht. "My mom even convinced a

doctor to buy the same type of laser,” Angela says, laughing. In total, she was put under anesthesia around twenty times. Each session was followed by about six months of recovery. “At the time, I actually preferred being put under anesthesia because I didn’t feel the pain. But now I wonder if it was healthy – especially for a child.”

She stopped laser treatments around age 13. “I believe the doctor later stopped doing laser treatments under anesthesia altogether, because of the health risks. I agree with him now. I do wonder what the long-term effects of so many anesthetics might be.” When she was 17 or 18, she tried a few light-flash treatments. “But I didn’t have enough of those to really compare the results to the laser.”

A day in treatment

Angela can still vividly recall what a day of treatment was like. “Because we come from the south, we always had to leave early. It was a long drive to Utrecht in central The Netherlands. I also always had to fast. The doctors and nurses there were always very kind, which gave me good memories. And I actually liked the anesthesia compared to the pain of the first treatment without it.”

When they drove home after the treatment, her parents made a bed in the back seat with lots of pillows and blankets so she could lie on her stomach. “I wasn’t allowed to lie on my back, and sitting up was still very difficult after the treatment. The recovery period was tough, but that was part of it. Basically, you have one large burn on your back, because they burn your skin with that laser. It was especially painful when sleeping. When I wanted to lie on my back, the blanket stuck to my back. Recovery always took a few weeks. On the surface, it may look fine, but the subcutaneous tissue is particularly damaged.”

During her treatments, her parents took photos of her giant birthmark before, during, and after the treatments. “I still look at them sometimes, but for me it’s like looking back at normal childhood photos. It’s remarkable to see how it went from being a large, dark spot to being almost invisible. It’s nice to see.”

A different perspective

Like many teenagers, Angela sometimes struggled with her appearance during puberty. Even so, she looks back positively. “I think all teenagers have a hard time. Whether you have birthmarks or not, you’re ashamed of whatever makes you

different. I don't think my experience was much different from anyone else's." Nevertheless, that uncertainty was something her parents worried about, even when she was still a baby. "That's also why I had the treatments," she says. "They wanted me to have as normal a life as possible, without bullying and uncertainty. Meanwhile, society has changed so much that I have never felt treated differently. That was certainly not the case a hundred (maybe even fifty) years ago. Nowadays, you no longer fall outside the norm if you are different. Just look at the model Winnie [Harlow, ed., who has vitiligo]."

If she could decide today, knowing what she knows now, Angela wouldn't have chosen laser treatments. "Of course, it's easy to say that in hindsight. But I think I would have learned to live with my birthmark the way it was. Even though I'm happy with the end result, it was a long, hard process."

One of the reasons she feels that way is that the treatments were purely cosmetic. "Laser doesn't reduce the cancer risk, and that's the biggest risk with a giant birthmark. When I think about how painful and intense the treatments were, I ask myself: was it



"My back is almost completely covered by one giant birthmark."

worth it? Would I want to put my own child through that? No, I don't think so. I'd rather teach my child to love herself as she is, and to accept the birthmarks she was born with, instead of trying to change them."

"I've promised myself that this was the last round of treatments. The final step toward full self-acceptance."



Carine Westerweel

The story below is something I wrote when I was 23 years old. I recently added the last paragraph. In the photos of my arm, you can clearly see the results of different treatments: at the top of my arm, the much lighter color after dermabrasion (compared to the original dark brown patches you can still see in between); in the middle, the lighter “pulse” spots from the laser; and on my lower arm, the skin grafts – on the back of my hand a full-thickness graft, and on the palm side a split-skin graft.

My name is Carine Westerweel, I'm 23 years old, and like you, or your family member, I was also born with a congenital birthmark.

My entire right arm is covered (like a long sleeve), and I also had a satellite nevus on my back. After I was born, there was a lot of uncertainty about possible risks, the cause, and especially about treatment options. When I was five months old, doctors used a fairly new technique at the time dermabrasion, also called the “shave” technique. It made the spots noticeably lighter. The mark on my back always had fewer, finer, lighter hairs and became less visible after dermabrasion compared to the one on my arm.

When I was in elementary school and gym classes started, my parents and I wanted to make the nevus on my arm look less dark by removing the thick, black hairs. I found hair removal creams and epilating too painful, and perhaps those methods were also a little too aggressive for the skin. So, I started shaving my arm, which I still do regularly. Incidentally, the plastic surgeon who performed the operation and whom I visited annually for checkups at the time first gave me permission to shave when I was eight years old.

When sunbathing or swimming, I use sunscreen with a high SPF and often wear an elastic sleeve that matches my skin tone. It looks a bit like a therapeutic sleeve, which people are used to seeing, and at the same time it protects my arm from the sun.

My parents had agreed that once I reached adulthood, at the age of 18, I could decide whether I wanted to undergo treatment. Before that, they held off, which of course sometimes caused disagreements, especially during my adolescence. When I was 18, I had a trial treatment with a CO2 laser. According to the doctor, the results were unsatisfactory, so we didn't continue.

Shortly after that, I ended up at the Institute for Pigment Disorders at the Amsterdam Medical Center. There, the mole on my arm was treated several times with a pigment laser. With this method, only 1% of the body's surface area (about the size of a hand) can be treated each time, and often the same area needs to be treated twice. When I started studying in Maastricht, in the very south of the Netherlands near the Belgian border, I no longer had time to regularly take a day off to travel to Amsterdam and recover from the treatment, which was quite painful at times, so I stopped. However, I certainly don't rule out continuing with this treatment in the future.

During my clinical rotations (as part of my medical studies) last year, I worked with plastic surgeons in Maastricht. When I showed them my birthmarks, one suggested treating my arm with a new skin graft technique and removing the birthmark on my back in two stages. At birth, the spot on my back had been the size of a coin, but by then it had grown to about 10 centimeters across. The surgeon first considered using tissue expanders to stretch the "healthy" skin before removal, but in the end, the entire mark was successfully removed in one surgery. I was very relieved.

A few years ago, someone asked me what I would recommend for a newborn baby with a congenital birthmark. I've often thought about that question, and honestly, I still don't have a clear answer. Personally, I experience a kind of wave motion in which one moment I am willing to do anything to get rid of the spots, but the next moment I am relieved that it is only my arm and that I am otherwise healthy and do not want to take any risks. It's true that early treatment often gives better cosmetic results, but on the other hand, technology keeps improving. And the risk of malignancy doesn't seem as high as they thought it was when I was born.

Whenever I thought about "my answer," I kept coming back to the same word: acceptance. Only when the people around you accept your difference, do you as a child learn to accept it yourself. And when you see the nevus as part of yourself instead of something abnormal, others will see it that way too. I'm grateful my parents allowed some treatments when I was a baby, and that they've continued to support me in exploring new ones. But more importantly, I'm glad they never made a huge deal out of my birthmark. My congenital nevus has never been a major problem for me.

It's simply how I was born (things could have been much worse) and I don't need to be ashamed of it.

Reading this piece again now, what strikes me most is the last paragraph I wrote at 23, already saying that acceptance is the most important part of living with a congenital condition. Apparently, I hadn't fully reached that acceptance yet. After my partner and I had children and got through the baby years, I started wondering again about (new) possible treatments. I was referred to the team of Chantal van der Horst and Oren Lapid at the AMC hospital in Amsterdam. When they saw my belly (which was "a bit stretched out" after three pregnancies), they suggested a full-thickness skin graft from my belly to my forearm. The fact that this would be combined with a tummy tuck appealed to me ;-).

The surgery went well, the pain afterward wasn't too bad, and of course, I had to take it easy. Unfortunately, after two weeks, it turned out that the transplant had not fully "taken." Maybe I had done too much with that arm after all? In the end, half of the graft had to be removed, leaving me with an open wound for a few weeks, and then I



"Photos of my arm."

received a split-skin graft from my thigh. In the photos, you can clearly see the difference between the grafts.

Was it worth it? I think I've always (consciously or unconsciously) wanted to have a "normal" arm. The different procedures didn't give me that, but they did make the arm lighter and less noticeable. Now I wear three-quarter or even short sleeves more often. And I've promised myself that this was the last round of treatments. The final step toward full self-acceptance.

Author: Carine Westerweel

"I'm happy with who I am!"



Danique

My name is Danique, I'm 16 years old, and I have a giant birthmark. I see it as a part of me – this is who I am.

Some people are shocked when they see the size of my birthmark. They sometimes whisper, point, or nudge each other. These kinds of things often happen at the swimming pool, but fortunately not in everyday life. I used to find it annoying when someone looked at me strangely, made an unpleasant comment, or asked me again, "What's that on your neck?" It made me feel different when we went swimming. I wasn't ashamed, but I could see that other children thought what I had was strange. Nowadays, I don't have any problems with this anymore. When people look at me strangely or point, I like to explain that my nevus is nothing strange and that there's no need to be shocked. I easily ignore these looks. I am proud of who I am and how I look.

I couldn't imagine myself without my nevus anymore. I definitely wouldn't want my nevus to be gone. My friends sometimes say, "We don't re-

ally see your nevus anymore, it's just part of who you are and it's beautiful. You wouldn't be Danique without your nevus." When they first got to know me, they naturally noticed it, but no one ever gave me a nasty look or made a nasty comment when I moved from elementary school to high school. Most people didn't even ask about it and looked first at who I was inside, which of course makes me very happy.

Personally, I see my nevus as something that enriches me, something unique that makes me who I am. It's something special that I have and many others don't. Of course, my nevus does bother me from time to time, but these are only physical discomforts, like itching in winter when the skin gets dry, or overheating in summer because I can't sweat through that area. But I manage, and the people around me are understanding. I just say something when it's getting to much. I play field hockey, and during games it can be tough because it takes a lot of energy. Luckily, I have a supportive coach. Overall, I feel good about myself and I'm happy with who I am!

"I'm happy with the way
I look, I'm used to it"



Mirte (23 YEARS OLD)

Mirte was born with a giant nevus on her left cheek and part of her nose. Her parents chose to lighten the nevus with laser treatments, but they never had it removed. Mirte talks about her decision to not undergo removal surgery.

Early decisions

“My parents decided not to remove it when I was quite young, when I was still a baby, I think,” says Mirte. “If you do want to remove it, it’s easier to do so at a young age. Of course, as an infant, I was unaware of this choice.”

Mirte hasn’t talked to her parents about that period for a while, so she doesn’t remember exactly what their considerations were at the time. “I think my parents found it quite difficult to make a decision for someone who wasn’t able to voice their own opinion.”

To remove or not?

“I’m happy with the way I look, I’m used to it,” Mirte says about keeping her nevus. “People I’m close to often say that they have never known me any other way, and that it would be very strange if I suddenly looked completely different. Also, if I had it removed, I would not have a ‘normal cheek,’ but rather a lot of scar tissue.

That seems much more disturbing to me, or at least more noticeable than the nevus that is there now, which everyone is already used to.” Mirte is also not keen on undergoing surgery: “You have multiple surgeries, as it has to be done in stages. After the first surgery, you need additional surgeries to make it look better or more attractive. That takes a lot of energy and time. Personally, I would undergo the surgery purely for cosmetic reasons. In that respect, I think: if it’s not necessary, then no need to do it.”

Thinking about the future

“During checkups, I always ask if there are new developments in available options,” says Mirte. “I have often discussed with my doctors what would happen if I wanted to have the nevus removed and what the effects of this would be. So, I have thought about it, but I have never chosen to do so. I don’t want to undergo the removal surgery, but I do want to stay informed about my options.” When asked if she would consider it if a method was developed in the future that would guarantee her a normal cheek, Mirte has to think for a moment. “Honestly, I don’t know. Probably not, now that you mention it. I don’t think so.

The doctors say that if I were to undergo removal surgery, the part of the nevus that is just below my eye and on my nose would remain anyway. At least, if I don't want to risk complications with my eye. So, I've never thought about what it would be like if my nevus was completely gone, but I don't think I would want that either. I don't know if my face would look much better if I had two 'normal cheeks,' as I don't know what that would look like. It's not like it's always easy now, but this is how I've learned to see myself.

"A nevus on your face is also very different from one on your leg or arm," Mirte continues. "Everyone sees it all the time. It's not like you only see it in the summer when you're wearing short sleeves or going to the pool. People see my nevus so often that I've been forced to get used to it, and so has everyone around me. I always say that it might be easier to have a nevus on your face than on your arm, even though you might not think so at first. Either way, I think it's easier to have a nevus without any additional complications. I'm lucky that I don't have any complications: no itching, no sweating issues, so I can do everything I want without problems."

Laser treatment

Mirte was one year old when she first underwent laser treatment. "I think I had about six surgeries. They weren't meant to remove my nevus, only to lighten it. That was my parents' decision, because I was too young to decide for myself. Eventually, I told them I didn't want to continue the treatments, so we stopped.

"I always found it quite strange that they decided on doing laser treatments, without knowing whether I wanted it or not. It's a strange feeling to think about those unpleasant surgeries, only to realize they weren't necessary. That's not to say that I don't understand why my parents made this decision, they wanted me to be happy. My parents thought that if my nevus would be less noticeable, it might be easier for me to make friends, or I might get fewer questions at school. I understand that you can't discuss this with someone who doesn't understand the consequences of this choice yet. The choice you make as a parent is always a gamble, because you don't know whether your child will be happier with or without the nevus. Personally, I'm really in favor of not performing surgeries if it's not necessary for health reasons. I believe that the choice

to intervene weighs more heavily than the choice to do nothing. That's why I'm very happy that my parents didn't have my nevus removed."

Living with her nevus

When asked how satisfied she is with her nevus now, Mirte replies with a smile: "I'm really glad we decided not to remove it. Even in a plain outfit, I still stand out because of my nevus and I like that. I find it quite boring when everyone looks the same. I think it's society's job to make sure people with a nevus can fully participate without being judged or limited. I think people should accept each other as they are. Removing a nevus for purely cosmetic reasons sends the complete opposite message. We should try to work towards a world where everyone belongs, nevus or no nevus."



Mirte was one year old when she first underwent laser treatment. "I think I had about six surgeries. They weren't meant to remove my nevus, just to lighten it."

"When I'm in my swimsuit, I still have to tell myself, "This is me, and people will just have to accept it."



Roland

My name is Roland, I'm retired, born in 1953. I worked for forty-two years for Rijkswaterstaat (the executive organization of the Dutch Ministry of Infrastructure and Water Management), in different roles, from IT specialist to safety expert. All my life, I have lived with the statement, "We don't know how old you can get with that skin," let alone whether I would reach retirement age. But as it turns out, you can do just fine with CMN. Other uncertainties were: Will the skin sag? How will the skin hold up over the years?

When I'm in my swimsuit, I still have to tell myself, "This is me, and people will just have to accept it."

I was born with the "swimming trunk" model: a nevus that stretches from halfway down my thighs up to the top of my pelvis, wrapping all the way around. There was also a complication. When I was born, the skin on my lower back wasn't closed. That meant surgery. This was done in eight operations, from my birth to the age of six. Each time, a piece of skin was removed, the rest stretched, and the wound closed with nylon. To close the 6 x 8 cm opening in my lower back, they used "diathermic wax." That patch still feels strange without

either sensation or blood vessels. Only the most severely affected skin was removed; most of the CMN skin was left intact. As a result, I still have the "swimming trunk" pattern. Doctors expected the remaining skin to lighten over time, and it did, though it's still brown.

I don't remember much pain, except for the compresses on my waist and lower abdomen. I don't even know why they were there. But I'll never forget the pain of having them removed to be replaced with clean ones. Even sixty-five years later, thinking about it gives me chills. The end result wasn't exactly pretty, and it still draws attention when I'm in swim trunks. That's when I have to remind myself again, "This is me, and people will just have to accept it." Joining a track and field club helped me accept it. At my first club, I never showered afterward. But at my second club, I finally dared to shower with everyone else. The first time I walked into the locker room, I thought, "Everyone's going to stop and stare." But after a few times, it just became normal—at least I think so.

Reaching out later in life

The hardest part was that no one ever talked about it. My parents probably knew very little. About twenty years

ago, I wanted to know what had really happened, so I contacted the Antoni van Leeuwenhoek hospital in Amsterdam, where I was treated as a child in the 1950s. I received a warm letter back from Dr. Van Coevorden. He remembered seeing me as a little boy when he had accompanied his father, who was a doctor there. I had been the only child patient in the whole hospital. He told me he was pleased I had reached out, "Back then, we had no idea how long you could live with this." They even looked up my original handwritten surgical records for me in the archives. They describe in very brief, sometimes cryptic, terms what had happened during eight operations, from my birth to my sixth year. The notes mention "nevus pilosus: very long hairs, dark brown skin, with some bluish spots." The reports are very brief, but they do show that a piece of skin was removed each time, after which the rest was stretched. The removed skin was "1 to 1.75 cm thick." Regarding the removed skin the notes say, "Histological examination of the removed material revealed nevus tissue with a strong neurogenic component with tactile corpuscles, but no signs of malignancy." The surgeries left scars on my lower back, pelvis, and right thigh. The skin on my left thigh,

right thigh (partly), lower stomach, and buttocks was left untouched. Doctors had expected that skin to lighten, and it did to some extent. The remaining CMN skin itself is quite thin, but I will discuss that later.

The operations were performed by Professor Van Slooten. When I think of him, I can still feel his soft, warm hands stroking my ravaged skin. A ray of light in those dark times. The checkups stopped when I was 12 because the situation remained stable, including my pimples, but more on that later.

I was never bullied at school, and my friends didn't seem to mind. They only saw the scar on my leg, because in gym class I always wore a shirt. Sometimes they asked what it was. Since I didn't really know, I would say, "I had an accident," and they believed me. I sometimes said the darker skin was a burn. My parents didn't let me join swimming lessons at school because of how I looked. That almost cost me my life later, when I nearly drowned in the North Sea. After that, I immediately signed up for adult swimming lessons. At the first swim club, they politely but firmly asked me to wear a T-shirt, because "your back is too shocking for the other swimmers."

I quit right away. Thankfully, the second club didn't mind at all, and I swam there in just my swim trunks.

My CMN skin has a number of disadvantages. First of all, CMN skin is quite thin and tears very easily. When I was seven, I bumped into the corner of a school desk, which tore my hip open and I had to go to the hospital to have it stitched up. And when I was eighteen, I was hit by a moped, which damaged the skin on my left and right thighs, even though my pants remained intact. That's why my parents have always been very careful with me, and I was no longer allowed to participate in gym class at secondary school. Later, when I was independent, I thought, "What the heck, I want to live," and started doing risky sports such as cycling and mountain climbing. Fortunately, I never suffered any injuries.

Another inconvenience is that I sometimes have deep itching, with nothing that helps. My skin is extremely sensitive, so that while caressing feels pleasant, clothing often irritates it. Once I start scratching, it's hard to stop. Finally, the operated skin has grooves in several areas where, if not cleaned properly, may accumulate bacteria, potentially developing into skin infections or blemishes over time. When deciding whether or not to have surgery, it is important to carefully consider the consequences.

For example, when I had excess skin (CMN) removed from my right buttock in 1993, I experienced the following:

- Massive bleeding during the operation requiring that I be given three liters of new blood
- An infection in my right leg the day after the operation, with a fever of 41 degrees

Since that operation, I can no longer go on long bike rides because after an hour, the skin around the scar in my groin tears slightly. Incidentally, that doesn't stop me from enjoying cycling. I'm happy to put up with the pain for that.

That's why I always say, "Think very carefully before choosing surgery. Scars can cause problems later and sometimes limit movement.

The bumps

Strangely enough, the little bumps on my CMN skin gave me more psychological trouble than the nevus itself. As a kid, I thought they were contagious. If I saw another child with bumps, I thought, "Did I infect them?" Because we never talked about it at home, my parents never corrected this belief. I even thought no one would ever want to

marry me, “Who would want someone with bumps? Luckily, I was wrong, and I’m very happy with my life partner (and she with me).

In 1993, I had excess skin removed from my right buttock because it hung down like a pouch, and once while running, I heard someone behind me say, “Look, he pooped his pants.” For me, that was the signal to do something about it. Unfortunately, the treating physician mentioned “excess skin in a patient with Recklinghausen’s disease.” Well, that was a bit of a shock. My GP immediately referred me to Leiden University Medical Center to have it checked, asking whether periodic check-ups were necessary. Strangely enough, I never heard the results afterwards, nor did I ask about them. I thought, “No news is good news.”

Later, another GP told me, “You know your body very well, even if you don’t realize it. You’ll notice right away if something changes.” So, I learned to live with uncertainty.

Finally, in 2000, Dr. Van Coevorden at Antonie van Leeuwenhoek, the Netherlands, helped clarify things. I had told him about my suspicion of Reckling-

hausen’s disease, and after consulting with the pathologist at the Antonie van Leeuwenhoek hospital, he concluded that the pimples were “a type of mole, in which the nerve cells are overrepresented in various spots, causing a kind of skin lump to form. A benign condition that you can live with until a ripe old age.” And since Dr. Remco Van Doorn’s lecture at a Nevus Netwerk Nederland conference day, I know that the pimples are simply satellites of the CMN skin and therefore just part of it. Sometimes you just have to grow old to let everything fall into place. Join Nevus Netwerk Nederland!

"My birthmark is
simply part of who I am.
I'm proud of it."



Thirsa

Thirsa was born with a large birthmark on her upper left arm. She hasn't experienced any physical complications and has never had treatment for it. Now 23, she shares why she chose not to go through a removal process.

She doesn't have many negative memories about her giant birthmark, not even from when she was a child. "I was bullied a little when I was younger, but it usually wasn't about my birthmark. Sometimes people tried to make mean comments, but I was always pretty confident. Now I work as a swimming instructor, and kids are often more curious than anything else. I actually think it's beautiful that I have a giant birthmark," she says.

Remove it or not?

When Thirsa was a baby, her parents were sent to several different hospitals. "I was born with what looked like a big bruise on my arm, and that set off all the alarm bells. The doctors didn't know what it was. They had never seen anything like it. At first, they thought it should be removed." One doctor suggested trying dermabrasion, the so-called "cheese slicer method," but for that they had to go to yet another

hospital. "In Groningen, in the north of the Netherlands, a doctor there advised my parents not to remove it, but instead to leave the choice to me when I was older." Her parents followed that advice, and she never had treatment. The doctor who gave Thirsa's parents this advice remained her doctor until she was about ten years old. Unfortunately, he moved abroad, which meant she needed a new doctor.

"I didn't like the new doctor as much. She only asked how I was doing but didn't really examine my birthmark. For example, she never touched it to check for lumps. So, I went to another doctor in another hospital who did do that. I had checkups every six months until I turned eighteen, and then my doctor said that since the birthmark had been so stable, I could monitor it myself if I felt comfortable with that. If anything came up, of course I could always come back. So, since I turned 18, I've been doing the checkups myself."

Doubts about the decision

Thirsa fully supports her parents' decision not to have her birthmark removed. "If there had been a serious risk of complications, I would have understood if they had chosen surgery. But I'm glad

they didn't, because it shaped who I am. When I was younger, I sometimes avoided short sleeves in the summer because I didn't want people to see my birthmark. I had whole summers where I only wore long sleeves, even though I was boiling hot. At some point, something clicked. I thought, 'Why am I doing this? Why should I suffer in the heat just to hide it from other people?' Eventually I started wearing short sleeves, and it became less and less scary."

She has never really wanted her birthmark removed, except once in elementary school. "I remember saying, 'I'm done, I want it gone.' My parents asked, 'Are you sure? If you remove it, you'll have a scar instead, and you're already used to your birthmark. Do you really want that change?' I thought about it and decided not to go through with it. I still feel the same way now. If nothing's wrong, I'd rather just leave it as it is."

Living with a giant birthmark

Reactions to her birthmark were often amusing, but at times the remarks were quite annoying. "I really don't like it when people shout things at me, like: 'What happened to you?' or 'Did you roll in the mud?' Once a grown man even came up to me and asked if I was a

werewolf. That was too much. Of course I don't enjoy being insulted, and I'd rather not talk to people like that." Still, she understands that most people are just curious. "Before I turned 18, a lot of people asked if it was a tattoo. That was funny because underage tattoos aren't allowed. I didn't really mind. I was even in the newspaper once with the headline that I had a 'congenital tattoo,' ha-ha. And now you see black tattoo sleeves becoming trendy. Mine doesn't go all the way around, though. One time, someone said to me: 'Oh my god, you actually have a giant birthmark! I think people with harmless skin conditions are so cool.' I was completely speechless. I didn't know how to respond to that."

At Nevus Netwerk Nederland, where Thirsa has been a member since she was 4, she's also had many positive experiences. "I remember once during a game of farmers golf, my ball landed near a cow pat. I asked if I could move it because it was so close to the poop. And then someone else from the Nevus Network, who also has a birthmark, said: 'Come on, one more spot won't matter, no one will notice.' I thought that was hilarious."

For Thirsa, her giant birthmark has always felt like a lighthearted topic, so much so that it almost fades into the background now compared to a new diagnosis. “A year ago, I found out I have a gluten allergy, and honestly, that felt way heavier than having a birthmark. I feel like most people don’t really care about my birthmark one way or the other, since most of those around me have never known me without it. But with my gluten allergy, people definitely have opinions. I often hear things like: ‘Here she goes again with her gluten allergy’ or ‘That gluten allergy is always the topic of conversation.’ My birthmark is simply part of who I am. I’m proud of it. Other people might not think it’s beautiful, but for a so-called ‘condition,’ I think it’s actually a very beautiful one.”

SPECIAL THANKS TO

Marjolein van Kessel

Emile Petiet

TRANSLATION EDITOR

Susan Greenstein

AUTHORS

Sanne Roes

Indra Mobach

Frans Meulenberg

Roland van Staveren

Carine Westerweel

GRAPHIC DESIGN

Rick Schurink

PRINTING

Printx

