



Yannick and Jerome

Hello! My name is Yannick Urbaniak. I am nearly 9 years old.

At the age of 2 and a half my parents and me were in the Turkey . The holiday began well. Everything was very fine, the hotel, the country, the people and finally the weather. Then it happened: The weather was great. It was warm, blue sky, the sun was shining unlimited. It couldn't be better. My parents went with me to the doctor, because I felt bad. The sun was hurting me, it hurt so badly. I got cortison injections, antihistaminica and my parents got the order, not to go out with me in the sun between (12 am - 3 pm). It should be a kind of sun allergy

Ok.

The holiday, ended somehow with many visits at the doctors'.

Since this holiday my parents went to the doctor, many, different doctors every time in the summer months, when I felt bad.

There was no understanding. No possibility to understand.

Because when we had an appointment with the doc, I felt most much better, but I tried to say it in my own words, if we got an appointment when it was acute, when the sun hurts me, none could see anything on my skin. Today it's the same, the sun hurts me, she hurts me bad, but nothing is visible, no changes on my skin. Still, no one can understand it. Almost anyone know this disease, one try to describe it, with having the feeling that no one believe what you tell about this symptoms.

So what?

The doctors only have one diagnosis: Maybe a sun allergy, or a kind of nettle addiction. I got different medications. But the fact is: If you haven't got acute symptoms, you haven't got anything to show, that's bad.

Again if it would be acute, but I haven't got nothing to show, and can't show it till today. It wasn't and isn't viewable for the eye.

So the years went by. Ok not so many years. In summer 2000 my brother Jerome was born. We have a caravan on Fehmarn (a German island). Often we stay there from early April till the end of September.

When Jerome was 2 years old, the disease started.

There was great summer weather on Fehmarn, everything was fine.

Jerome and I were only crying and screaming. My mom and dad were at the end of their strength.

What's wrong with our kids? Is Jerome only an imitator of his brother? But which child throws his head against a wall only caused by liking. The absolute nightmare begins....for the parents too.

As the mother of Yannick and Jerome I can say, it is the worst to see your own kids suffering, in a kind of way to have no understanding, to be helpless, because you can't help them.

But then the autumn begins and everything is ok, you can live your life like other people. How fast you can forget. Till next April.

When the disease started by Jerome, we were in procession by a doctor who knows a disease called EPP. The decisive for this doctor was that Jerome had the same symptoms like me. That was very obvious. The results of the blood tests were the reason why we were referred to a special clinic in Hannover . There my mom got the final diagnosis. EPP!

The doctors were honestly, they could not say much about this disease. The only thing that was known, were that it was really rare. But the chance to survive was big. WOW! Unprepared, cool, and heavy....for our mom. Jesus, what a diagnosis.

With this diagnosis we went back to our doc. He told us to go to Prof. Dr. Hölzle in Oldenburg . He is a specialist of this rare disease.

In May 2003 Jerome, me and our mom stayed in the hospital for 3 days. Many, many explorations were following. The specialist for our disease we only saw once. My mom thought he was not really interested. That was sad, especially for a specialist.

We didn't hear anything new, not even a detailed explanation about EPP.

The only positive fact is that we got our medicine, like beta carotin, eucerin and microban30plus.

Continued soon...