Iva

EGPA patient

Primary disease presentation:
Face

Day-to-day living

- Iva, 17 years old, lives in the Netherlands with her parents and is studying towards her high school exams
- Has an older brother and a sister
- Plays hockey and piano in her spare time, but at times is unable to walk and uses a wheelchair

Disease history

First symptoms: Became pale in the face and had less energy than before. Had an unexplained fever. GP carried out blood tests, but was unable to find anything

Hospitalisation: Lost control of some facial features, and mouth started to hang open. Was referred immediately to the regional hospital. Had multiple tests and scans, mainly to her head, but doctors could not work out the cause of her symptoms

Diagnosis: 5 months of uncertainty. Developed sensitivity to light, sound and smell during her stay in regional hospital. After a week and a half, was referred to a teaching hospital. Was diagnosed within 5–6 weeks of her referral to the teaching hospital. Iva's mother Birgitta slept in the hospital with her for months during rehabilitation

After hospital: Was discharged from teaching hospital to a rehabilitation centre. Returned to school. Has an adapted programme, with classes divided over 2 years so she can work half-days

Adapting to life with ANCA vasculitis: Felt very self-conscious about her facial weakness, especially when returning to school, until treatment helped her manage it. Takes part in sports, but now only plays half matches of hockey and has moved to a lower level team as she could not keep up. Is now in the year below, so has had to make new friends. When going on holiday it is important to choose countries that are familiar with the disease. She must take the risk of infection into account

The future: Doctors have said Iva can trial stopping her medication in July. Is uncertain about what to expect – whether the disease will come back or not, and whether her energy levels will ever fully recover

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“If I go out for a day where I have to run a lot, then I take the wheelchair.”

In her own words

Symptoms:

Birgitta – “When Iva was hospitalised, she had a lot of headaches and pain in her legs.”

Parents’ perspective:

Birgitta – “We’re very worried about her future. We worry whether she will be able to get a full-time job, whether the disease will come back… We always have worries in the back of our minds.”

Communicating with others:

Iva – “I made a report that explained very clearly what I have and how I feel about it. I’ve read the report to a lot of children and given copies to my hockey trainers, coaches and teachers. That has also already helped a lot.”

Coping with symptoms socially:

Iva – “In the rehabilitation center, it became worse and worse because I got to see people of my age again. Then, when I went back to school and saw a lot of old friends again, it really became difficult. Currently I have very little to no trouble with it, because we have several ways to counteract it – and consequently I’m more self-assured.”

Patient support groups:

Iva – “Part of my understanding of what ANCA associated vasculitis is, I found on the internet and part of it came from knowledge that I gained thanks to a day with Vasculitis Stichting.”

Personal goal:

Iva – “I still play hockey three times a week. I just do half matches. Sometimes I don’t have any energy left for training, so unfortunately then I cannot participate. And if I go out for a day where I have to run a lot, then I take the wheelchair.”

ANCA, anti-neutrophil cytoplasmic antibody; EGPA, eosinophilic granulomatosis with polyangiitis

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