



ENCA meeting in Athens 2017



During the Paediatric Rheumatology Congress (PReS) in Athens 14-17 September 2017, ENCA had an independent program with different presentations. ENCA is getting stronger and from being a meeting of approx. 2-3 hours during PReS it has become a program of 2 full days.

It's amazing to be in the same room with parents / patient associations from 17 different countries; Denmark, Israel, Sweden, Germany, Italy, Spain, Greece, Scotland, United States, England, Ireland, Holland, Belgium, France, Cyprus, Slovenia and Latvia, as well as exchanging experience with each other.

ENCA has been working closely with PReS and this year, ENCA was for the first time ever on PReS's main program. It meant that 3 parents and 2 young people told their stories of how it is to be parents and adolescents with arthritis as a companion in life. This is the first time that the patient's perspective has been presented on the official program, which was welcomed by doctors, nurses and other health professionals who participated in the conference.

A short feedback was given on the SHARE project, a project that many parents associations in Europe has participated in, back in 2015. Here parents were given the opportunity to answer, through a questionnaire on how treatment of children with arthritis are going in different European countries and how they are organized. Some of the key



findings were that doctor-patient communication has to be improved, more references to physical therapy must be made, and patients need more information or assistance for support line (school, social worker, information about the associations and disease support groups)

On Friday, ENCA's program started with associations from different countries gave a representing of their association and their work.

Again this year, Lucy Wedderburn, Professor and Consultant of Paediatric Rheumatology from UCL Institute of Child Health in London, was also on the program. She still spoke very warmly about biomarkers and why they are so important in the field of research and that it is important that the doctors work- together to get clinical data. She also pointed out a number of challenges such as the classifications of arthritis are not respected. The different kinds of arthritis are gathered under one umbrella, which makes it difficult to study the genes. It is also not easy to collect biological material and clinical data because it is not standardized, so it is difficult for the doctors to share the information with each other.

Another topic that was on the ENCA program was about teenagers, alcohol, drugs and sex. Here, there were 2 young people who talked about how they had been through the teens, and a consultant from the Scottish Arthritis Care. The young people pointed out that it was important for them to have a network to talk about alcohol, drugs and sex and that most of their knowledge was from google, but that there is not enough information or research on the field. At the same time they also considered it important that the doctor gave clear information about alcohol, drugs and safe sex and that parents should be supporting about the talk.

Many young people are struggling with sex and especially the shame "of my body is not working well". Question like "What should I do if I'm intimate and I get a flare attack or suddenly get a painful joints?" Boys seem to have trouble getting condoms out of the packing. Young people also do not want to tell about their chronic disease.

The consultant told us, that one of the things she has learned from the young people is, that it is important that parents tell the teenagers that we always will be there for them, even if they make mistakes.

After that, Dutch rheumatologist Nico Wulffraat told us quite briefly about vaccine.

Unfortunately, there are only very few studies on children, but in these studies there was no tendency for flares. In comparison to the children who are on biological medicine, doctors want to do research in this field - the problem is just lack of capital. He also reported on a small study conducted on adults with Lupus for HPV vaccine that showed that the disease activity did not increase after HPV vaccination. There were some examples of flares, but these were considered to be random as it is most likely that some of the children would have a flare of arthritis. But as mentioned, it's only a small study and they are doing a big study in Brazil.

And the advice about vaccination is always consult with the rheumatologist.

In addition to the program with many different presentations, ENCA invited us all to eat, and it was very nice and gave all of us a chance to speak together across borders and languages.



Earlier this year ENCA also sent out a competition for children with arthritis - Fun with JIA. The competition was about making a short video showing that you can still have fun even if you have arthritis. The winners were awarded in Athens. The winners became 10-year-old Peteris Francis from Latvia and 16-year-old Axelle from France. Both videos can be viewed on Youtube.

All in all a very good conference, and I'am looking forward to see all of you next year in Lisbon, Portugal.

On behalf of ENCA
Mette H. Olesen, Denmark.
Elected board member

