



## Activity Report 2019

### Structure and development

The Executive Board had three meetings in 2019

25.01.-27.01.2019 in Bockenem

13.04.2019 in Pforzheim

13.09-15.09.2019 in Bockenem

At the conference in Pforzheim 2019 a new board was elected. The board consists of Gesa Bressel, Nina Kiventidou as well as Camille and Olivier Raguin and Kerstin Rabe. Rick Pasman and Cindy de Klerk said goodbye to the board but will support the new board in the background. Gero Bressel is serving as treasurer.

We evaluated the results of the 2019 conference and have as an urgent task the revision of the membership database and data protection regulation on this.

The next conference will take place on 15.04.-18.04.2021 in Pforzheim.

### Internet

A YouTube channel for the network has been set up, where you can find the presentations and photos of the 2019 conference in four languages (English, German, Dutch and French).

Work on the homepage is continuing. The creation of the page is in the hands of the Bressel family. The Facebook page has proven to be a helpful communication tool between all European members. Work is being done on the presentation on Instagram.

### Our scientific advisors

We spoke to all the scientific advisors ( K. Paris, V. Dalm, S. Mayer, P. Grossfeld) at the conference in Pforzheim in April 2019.

S. Mayer presented on blood clotting disorder ber11-q syndrome, K. Paris and V. Dalm presented on immunology and P. Grossfeld presented on behaviour / cognitive ability of Jakobsen children and presented his cardiology research.

Fraser McLean told us about his life with Jacobsen Syndrome and how he has coped academically and work wise.

## **Finances**

At the conference in Pforzheim it was clearly stated that please all members should pay their membership fee of 20€. We have started to work on this in 2019. Financially, the situation has eased after the 2019 conference. Many donations have been received thanks to the work of the Raguin family and Aktion Mensch.

Due to the strong financial participation of the members in the conference and fortunate circumstances that led to speakers almost only with accommodation costs of the conference to load many, the total cost of the conference could be put at around 12000€.

Expenses for the work of the Executive Committee - mainly travel costs, as the accommodation was free of charge - amounted to about 1000€.

On the other hand, there were about 20,000€ in donations and 16,000€ in other subsidies, which more than covered the previous expenses.

## **The Board**

Gesa Bressel President, Nina Kiventidou, Camille Raguin, Oliver Raguin, Kerstin Rabe

Gero Bressel as Treasurer