



Activity report 2017/2018

Foundation

The PedNet Haemophilia Research Foundation is a non-for profit foundation and was established on December 16th 2016 in Amsterdam, the Netherlands.

The foundation's objectives are to promote scientific research relating to haemophilia and to promote international cooperation between centres specialising in treating children with haemophilia given the fact that haemophilia is a rare disease.

Study staff & board

The study staff consisted at that time of the director Dr H. Marijke van den Berg, a senior study coordinator Ella van Hardeveld MANP and a research assistant Marloes de Kovel MSc. In November 2017 an epidemiologist was employed for 1 year Dr. Evangelia Antoniou.

The foundation board met in 2017 during 2 teleconferences and had 2 face-to-face meetings in July at the ISTH congress in Berlin, Germany and in September at the Annual PedNet meeting in Amsterdam, The Netherlands.

In 2018 the foundation board met during 2 teleconferences and had 2 face-to-face meetings in January at the office in Baarn, The Netherlands and in September at the Annual PedNet meeting in Frankfurt, Germany.

In January 2018 the Research Program 2018-2020 was accepted by the board. In this program all scientific research projects that have been approved by the board are described. All articles that were published by or on behalf of the PedNet group can be found on the website www.pednet.eu/publications

Members & participating centres

On January 1st 2017 the PedNet group consisted of 31 centres in 16 countries. In 2017 2 new centres were added Porto, Portugal and Oslo, Norway. In 2017/2018 two centres left the group; Seville, Spain and Edinburgh, UK.

Meetings & workshops

The annual meeting for members of the PedNet group in 2017 took place in September in Amsterdam, The Netherlands. 23 members and local investigators from 21 participating centres attended this meeting.

In September 2018 the meeting for members of the PedNet group was held in Frankfurt, Germany. The meeting was attended by 25 members & local investigators from 22 participating centres.

The objective of the annual meeting for members is to inform the PedNet group on the status of the PedNet Haemophilia Registry, on the progress of the research projects and to discuss the administrative and financial status of the foundation. During the meeting new members of the board and of the Scientific advisory council were elected.

In January 2018 a meeting & workshop for data registrars from the participating centres was organised in Barcelona, Spain. The purpose of this meeting was to inform the data registrars about the aims of the foundations and the scientific projects and to exchange experiences on data collection. During the workshop participants were trained on certain aspects of the data capture system that is used for the PedNet Haemophilia Registry.

In April 2018 a Writers week was organised for investigators from the participating centres. During 4 days 14 investigators from 12 participating centres worked on 5 research projects. The results of these projects are aimed to be ready for publications in 2019.

ANBI status

In June 2018 the foundation was recognised by the Netherlands tax authority as an official non-for-profit organisation (algemeen nut beogende instelling (ANBI))

The financial report 2017 of the foundation was accepted by the PedNet board and members and is published on our website; www.pednet.eu/foundation/anbi