

**Anke: assistant in organizing the international PTHS Congress**

*Meeting and getting to know families having a child with Pitt-Hopkins syndrome is central to the PTHS World Congress 2018. The goal is to draw up "Better guidelines" for people who are involved with the syndrome. The congress takes place on Friday, May 25th to Sunday, May 27, 2018. Anke Peters is helping our Stichting to organize this congress.*



Companies, associations and other organizations often struggle to set up a congress. The Pitt Hopkins Stichting Board is no different. What needs to be done to organize an international congress? Can we do that with such a small Stichting as ours? What is involved? It would be much easier if there was someone to assist to help organise the congress.

By coincidence, Ingrid Benoist, a Board member, knows someone locally who runs their own company called deCongresbalie / Conference Desk. What could be better?

Anke Peters is the sole proprietor of Conference Desk which is based in Oosterhout. Anke has run her business since 1997. She organizes all kinds of conferences, mainly for government and non-profit organizations.

Usually she works with clients who have a clear goal and are familiar with organizing a conference. The collaboration with the Stichting Board is different: Anke comments "Normally during the day, I'm very busy. Sometimes things have to be done very quickly and that is possible nowadays because of modern means of communication. When I work for the Stichting, it is usually on a Tuesday night because that is when the Board members are available. The members are working during the day. As a result, it can take a little longer before things are arranged. Precisely because it is all volunteer work, time is often limited. Fortunately, the organization of the congress started on time and the cooperation with the Board works well."

For the Board, the organization of a conference is a big challenge. There is little experience. Fortunately, we know what we want.

The Board presented the objectives and ideas for a PTHS congress to Anke and asked her to help set it up. Meeting and getting to know families having a child with Pitt-Hopkins syndrome is central. Gathering knowledge about Pitt-Hopkins syndrome from people from around the world is also an important objective. Professor Raoul Hennekam, from The Netherlands, is leading this research/project. The Congress should make a major contribution to these objectives.

Much knowledge about Pitt-Hopkins syndrome has been gathered by the Dutch Stichting. In many countries, this has not been possible. It is precisely families in those countries that we want to reach. Anke, working with the Board, has built the congress website in Dutch and English, to make as many people as possible aware of it.

Prof. Raoul Hennekam has used his professional network to use and share knowledge with doctors abroad to contribute to the Guidelines and the Congress.

A large part of the work for the Congress has already been completed. People who have a role at the Congress know what is expected of them. At the Congress, Anke will be the link between the participants and the facilities needed. Anke commented: "An important aspect of a congress is the location. The location must be designed to ensure that the objectives and wishes of the client can be achieved. For the PTHS Congress, I proposed to hold the congress at the Van der Valk Hotel in Sassenheim. This location is easily accessible from Schiphol airport. It has a variety of rooms where the different activities of the Congress can take place. In addition, there is also a lot on the site: catering, the auditorium and audio-visual equipment. Moreover, the accommodation has sufficient, well-equipped and spacious rooms for the participants."

May will soon be on us. Anke will be there every day, all day. Anke commented: "I make sure everything runs smoothly. I am the contact person for the Stichting, the guests and the hotel manager to ensure that matters are coordinated. Everyone can also contact me for complaints and wishes. I am convinced that we are going to an inspiring and successful Congress. See you there!"