

BijnierNET in the starting blocks

Final preparations are now underway for the official founding of the BijnierNET Foundation on 19 December 2014. The years of groundwork have paid off, the essential starting grants have been promised: now we can really start to create a community for adrenal gland patients.

11 December 2014

In his opening words at the last meeting on december 11th 2014, Johan Beun, one of the initiators of BijnierNET, spoke of a historic moment. "It has been a long and difficult process, but we have finally arrived on the threshold of the founding of the BijnierNET Foundation."

It has been nearly two years since the various parties signed the 'Noordwijkerhout Declaration' in which they stated their intention to work together to create a national community for adrenal gland disorders and patients. The intention is that this online platform will evolve into a virtual nation-wide meeting place for patients, carers and healthcare practitioners alike. In combination with a standardization of care pathways, this platform - which offers an opportunity to exchange ideas and experience about the various disorders and what it is like to have them - will help raise the quality of care offered to adrenal gland patients.

Thanks to the grants provided by the Health Insurers' Innovation Fund, Agis Fund, NutsOHRA Fund, Adrenal gland Fund, SGS Fund, some of the University Medical Centers and other sponsors, the community can now really get off to a flying start. The BijnierNET Foundation will be responsible for stimulating, supporting and monitoring its progress. The first Chairman of the board of the BijnierNET Foundation will be Prof. Ad Hermus, professor of endocrinology at Radboud University Medical Center in Nijmegen.

Now that the BijnierNET Foundation's articles of association have been drawn up and the members of the executive board and governing board of the Foundation have been appointed, the ambitions of the BijnierNET will become clear from its well-filled list of priorities. Among them, practical matters such as the distribution of a European 'emergency card', plus a card holder that can be affixed to a bag or to the safety belt of a vehicle.

An important focal point for the coming year will be the development of national healthcare standards, partly based on international consensus papers. These healthcare standards describe the criteria that the quality of the care for people with an adrenal gland disorder should fulfil. It is the intention that hospitals that want to affiliate to the BijnierNET will work in accordance with such standards. Any healthcare institutions and/or healthcare practitioners who are unable or unwilling to uphold these healthcare standards should not be permitted to treat adrenal gland patients.

The development of the healthcare standards - an exercise which is being carried out in the context of the Care for Rare Disorders [*Zorg voor Zeldzaam*] project, of which BijnierNET also forms a part - will also provide the basis for the personal health records (PHR) that patients will later be able to manage via BijnierNET.

According to Dr Nick Guldenmond of Utrecht's University Medical Center, BijnierNET is part of a national and international trend in healthcare which will give patients (and their families) a greater say in what care they want and receive. He is following this development closely on behalf of the Dutch Federation of University Medical Centers (NFU) and he is encouraging the board of BijnierNET to make their experience with the establishment and use of the community and the digital platform known to the wider world and particularly to other organisations with similar ideas.

If you have any questions, please go to: www.bijniernet.nl or contact INFO@Bijniernet.nl