

Evolving and growing 2015

Introduction

2015 was the first full calendar year that BijnierNET (AdrenalNET) has been in operation. We had to spend a great deal of time designing and building up the network because, unfortunately, there were no blueprints available. The Board had it works cut out, and appointed a small but decisive executive team to cope with the frequent contacts with the many interested parties.

The year 2016 will see further ambitious growth towards better care and quality of life for people with an adrenal gland disorder.

In this context, BijnierNET will be focusing on three healthcare spearheads:

1. Improving the quality of specialist-led chronic care
2. Improving diagnosis
3. Improving care in emergency situations.

Various activities in these key areas have already been started and will continue during 2016 and on into 2017.

Improving the quality of specialist-led chronic care



By means of several bottleneck analyses in carried out in 2015, endocrinologists and other specialists in internal medicine made it clear that they feel that the quality of care provided to people with an adrenal gland disorder needs to be improved, and that they have concerns about the quality of life of people with such disorders.

BijnierNET is investing in improving healthcare in a number of ways:

1. Animated clips, mini-documentaries and infographics aimed at people with an adrenal gland disorder (and their families) to help them gain a better understanding of the complex array of symptoms involved.
2. The BijnierNET.nl website collects and provides information about the six disorders, not only for patients and their families but also for doctors and nurses.
3. Organising workshops and presentations about the latest knowledge and insights during refresher days for endocrinologists and other specialists in internal medicine.
4. Hosting blogs by more than 25 experts; each week there is a personal story about caring for someone with an adrenal gland disorder or living with such a disorder as a patient.
5. Organising mini-conferences to reach agreement that will ensure the continuity of supply of medication.
6. Taking advantage of new technologies: an electronic out-patient clinic and an App.
7. Working closely with other parties to develop relevant projects using the strength of the BijnierNET network. Projects will focus on illness, health and work and on encouraging transitional out-patient clinics.
8. Setting a Care Quality Standard for adrenal gland disorder. In the course of 2016, proposals will be made on the basis of the bottleneck analyses carried out in 2015. This Standard will define 'good care' from the perspective of the patient.

Our partners in all this include the Federation of Parent and Patient Organisations (VSOP), the teaching hospitals, Pharos (Expertise Centre for Refugees and Health), Royal Dutch Pharmaceutical Society (KNMP), other partners from the pharmaceutical world, patient associations such as the Dutch Adrenal Society (Bijnierverseniging) NVACP and various professional associations such as the Association for Internal Medicine (NIV), the Dutch Endocrine Society (NVE) and the National Working Group of Endocrine Nurses (LWEV).

Improving diagnosis



On average, it takes around 4.5 years from the onset of symptoms before an adrenal gland disorder is correctly diagnosed. Some patients even report diagnosis taking more than 10 years. What matters is early detection. Our aim is to help reduce this diagnostic delay, as it is often called, through our work. Previous research among patients who have suffered from Cushing's syndrome or Cushing's disease has shown that there is a positive correlation between the length of time prior to diagnosis and the residual 'damage' after treatment. From the start, BijnierNET has been engaged in research into the factors that play a role in this delay; in 2016 we will be developing film material to help patients find a diagnosis sooner and to draw more attention to rare disorders in general and make them better known. In addition, BijnierNET will be investing in standardised use of codes in hospitals, as a result of which it will be possible to collect data about the care of patients with adrenal gland disorders. Partners in this will be the Federation of Parent and Patient Organisations (VSOP), the national heredity information centre (Erfocentrum), data collection and processing centre DHD, National IT Institute for Healthcare NICTIZ, and the National Institute for Public Health and the Environment (RIVM).

Improving care in emergency situations



Approximately 40% of people who have an adrenal insufficiency have suffered one or more adrenal crises in

the last five years. For these people it is crucial that the stress instructions are followed precisely and immediately. Consensus was recently achieved on the subject of the stress instructions and it is the intention that once they have been approved by the Association for Internal Medicine (NIV) and the Dutch Endocrine Society (NVE) they will be implemented in all hospitals in the course of 2016. In order to ensure that healthcare practitioners, patients and informal carers are aware of these stress instructions, BijnierNET has collaborated with the Dutch Adrenal Society NVACP to develop some informative material that can be useful for patients in an emergency situation.

Procedures have been incorporated into the working processes of healthcare practitioners so that they are more quickly made aware that a person is dependent on hydrocortisone. In 2016, a special child's emergency card will be developed in collaboration with as many international adrenal gland organisations as possible. For further information, please visit the websites www.adrenals.eu and www.bijniergeenbijaak.nl

New funding

Further sources of funding will be necessary in and after 2017 to enable the BijnierNET to continue and to expand its work. The liquidity situation is sufficient for 2016, but further sources of funding need to be found for 2017 and beyond. Additional support, financial and otherwise, will be necessary for new projects such as the transitional out-patient clinic, improved coordination of ambulance and emergency room services, and research into the retention of appropriate work for people with an adrenal insufficiency.

Further information

If you have any questions about the work of BijnierNET or any suggestions as to how BijnierNET could achieve its objective, we invite you to get in touch with us, preferably by sending an email to info@bijnierNET.nl