

# What is BijnierNET ?



**Not every patient with an adrenal disorder is 'lucky' enough to be diagnosed quickly and correctly. Every year, even nowadays, doctors and patients are confronted with unnecessary human suffering simply because it sometimes takes ten or even twenty years before the correct diagnosis is made. That is hardly desirable: not for the patients in question, for their loved ones, for their healthcare practitioners, not for the healthcare service as a whole.**

BijnierNET is working to make *improvements to the care* provided to people with adrenal disorders in the following ways:

- Improved diagnostics in terms of promptness, adequacy and efficiency
- Better care in emergency situations, during triage, Better injection skills and training for non-professional carers
- Improved quality of specialized long-term care, with special attention for co-management and the development of quality standards.

BijnierNET was established on 19 December 2014 and is based on the principle *'the patient as partner'*.

## Mission

*BijnierNET helps adrenal gland patients, carers and healthcare practitioners find reliable and accessible information (both scientific and general), and offers a secure platform for the exchange of information so that together they can improve the care provided, from the diagnosis itself to the scheduling of care, all with a view to reinforcing the patient's management of his or her own life.*

## BijnierNET offers patients with adrenal gland disorders and their carers:

- the latest knowledge and information about the diagnosis and treatment of adrenal gland disorders, with the collaboration of all acknowledged experts in this domain
- the opportunity to ask general questions which are

answered by specialist healthcare practitioners

- the opportunity to share and exchange experiences between patients and carers, so that they can learn from each other.

## BijnierNET offers healthcare practitioners:

- the possibility to share knowledge and information with patients, non-professional carers and other healthcare practitioners
- a unique and innovative collaboration between all the University Medical Centers and with a number of other teaching hospitals in the Netherlands that specialize in adrenal gland disorders
- the possibility to establish uniform nation-wide care pathways, based on the Adrenal Gland Disorder Care Quality Standard that is currently being developed, so that patients with adrenal gland disorders will receive the same quality of care, no matter where they live
- support to carry out joint research, and better coordinated research, with a view to improving the care for patients with adrenal gland disorders.

## Board

BijnierNET is a non-profit foundation managed by a Board. The Board consists of representatives of the Dutch Adrenal Society NVACP, the Dutch Adrenal Fund, the University Medical Centers, the teaching hospitals, the National Working Group of Endocrine Nurses (LWEV) and the Dutch College of General Practitioners (NHG). This broad-based involvement ensures that all facets of caring for patients with adrenal gland disorders are represented. The executive board consists of two doctors (Ad Hermus of Radboud UMC and Anton Franken of Isala Hospital), two patients (Alida Noordzij and one vacancy), and the coordinator, Johan Beun. The executive board bears responsibility for the day-to-day operations of the foundation.

## Work activities

Another important employee of BijnierNET is Lisanne Smans, a specialist in internal medicine and endocrinology. Her main task is to draw up a Care Quality Standard for all

adrenal gland disorders. She provides the basic information about adrenal gland disorders that is available on the website. Jacqueline Neijenhuis takes care of communications, including the website and social media, the establishment and enlargement of the BijnierNET community and the progress reports. Lastly, the website and the house style are the domains of Marnix Bras and Wil Scholten.

## Projects

### Care Quality Standard for adrenal gland disorders

Development of a care quality standard for adrenal gland disorders, which describes best practices and can be included in the Dutch National Health Care Institute's quality register.



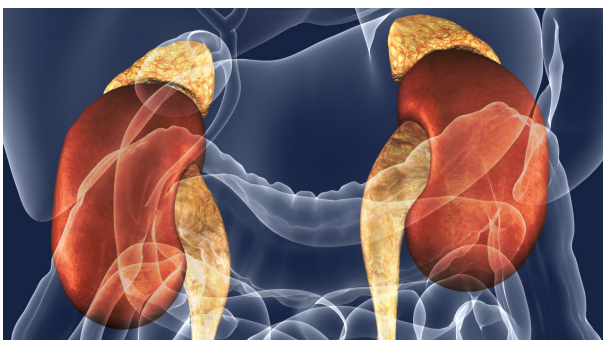
### Health education and information

Development of an extensive range of educational materials in an effort to satisfy the widely varying information needs of patients.



### Prevention of Addison crisis

Adrenal crisis is a life-threatening emergency that may occur in patients with chronic adrenal insufficiency, even under established replacement therapy.



The stress-related cortisol response is lacking in chronic adrenal insufficiency and has to be mimicked by the patient with a transient steroid dose increase above the standard replacement dosage.

### Digital care

Looking for ways to improve healthcare for people with an adrenal gland disorder with the aid of digital technologies. The format of contacts between patients and healthcare practitioners is set to change.



### Donors and sponsors

The work of BijnierNET is being made possible by various donors and sponsors, including: We have received financial support from:

- Nuts Ohra Fund
- SGS Spaarneland Healthcare fund
- Voorzorg Foundation
- ZonMW
- Dutch Adrenal Society NVACP
- Adrenal Fund

In addition, we received contributions in kind from UMC Radboud Nijmegen, UMC Utrecht, Isala hospital and others.

BijnierNET is also participating in two projects being carried out under the auspices of the Health Insurers' Innovation Fund.

## BijnierNET



### Information and contact details

For information about BijnierNET you can contact the coordinator, Johan Beun, by phone (+31 651 340 516) or send an email to [info@bijnierNET.nl](mailto:info@bijnierNET.nl)

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