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Dutch hemophilia patient registry and digital infusion log.

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Introduction

For rare diseases like hemophilia, with good though very expensive treatment available, a nationwide patient registry is essential to monitor and improve quality of care.

The aims of this project are:

- ❖ to develop a nationwide registry of Dutch patients with hemophilia and associated disorders
- ❖ to develop a digital infusion log (app) for patients
- ❖ to obtain data on number of patients, diagnoses, treatment intensity and outcomes
- ❖ benchmarking
- ❖ central registration of side effects of medication.

Methods

To the Dutch Hemophilia Treaters Society (NVHB) together with the Netherlands Hemophilia Patient Society (NVHP) a 2-year grant was awarded by the Netherlands Organization for Health Research and Development (ZonMw) to develop the registry.
The project – named HemoNED – started in December 2015 with the appointment of a project coordinator, dr. Geertje Goedhart.
For long-term continuation of the registry additional funding will be provided by pharmaceutical industries.

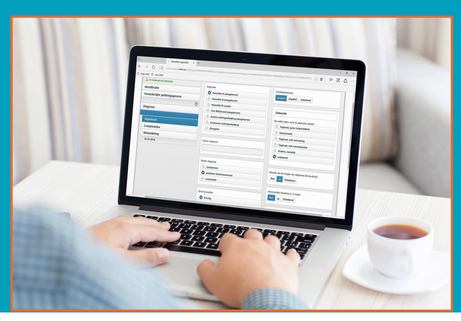
Board members of the HemoNED Foundation

Results

In October 2016, the HemoNED Foundation was established to manage the registry; the board consists of two NVHB and one NVHP member. A Steering Committee, including delegates from each hemophilia treatment center, the NVHP and the Dutch Hemophilia Nurses Society (NVHV), is responsible for appropriate use of the registry data as described in a Governance document. The protocol was evaluated by the Medical Ethical Committee of the Leiden University Medical Center. A company specialized in medical data management was contracted to build, host and support the registry and app.

Registry

The registry will include baseline data such as age, diagnosis, viral and inhibitor status, and prospective data including treatment, bleeds, side effects of treatment and - on the longer term - patient reported outcomes.
To minimalize registration burden, most data will be semi-automatically transferred from existing databases to the registry. Adverse events will be reported to the Dutch Pharmacovigilance Centre (Lareb) and the European Haemophilia Safety Surveillance program. The first patient data will be entered in the first quarter of 2017.



Digital infusion log (app)

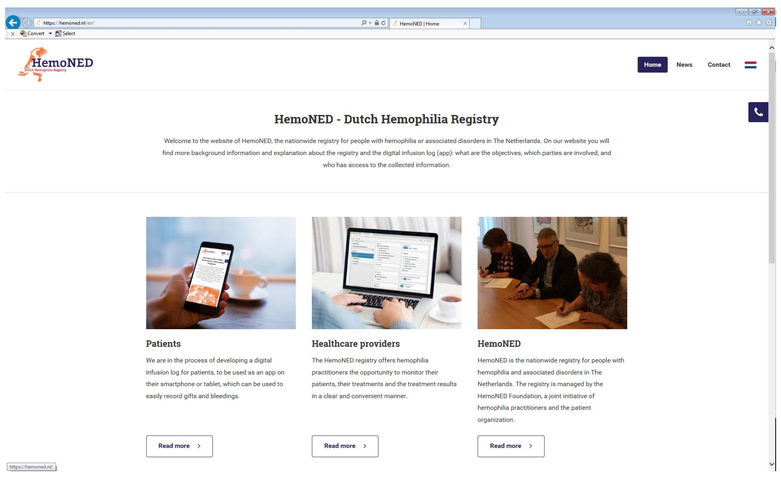
Patients will report infusions and bleeds via an app (web- and mobile version). The app data will be directly transferred to the registry via a secured internet connection. An overview of the app data is available for both patients and health care staff through a secured webpage, to be used in clinical practice during consultation.

Conclusion

This hemophilia patient registry (HemoNED) and digital infusion log, will generate

- ❖ data on the prevalence of hemophilia and associated disorders in The Netherlands,
- ❖ the efficacy and safety of treatment,
- ❖ the incidence of bleeds, and
- ❖ the incidence of side effects of treatment.

This is expected to improve the quality of patient care.



Have a look at our new website!

https://hemoned.nl

Participating Hemophilia Treatment Centers in The Netherlands

- ✓ AMC Amsterdam
- ✓ Erasmus MC Rotterdam
- ✓ LUMC Leiden / HagaZiekenhuis The Hague
- ✓ MUMC Maastricht / MMC Veldhoven
- ✓ Radboudumc Nijmegen
- ✓ UMC Groningen
- ✓ Van Creveld Clinic UMC Utrecht

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Netherlands Organization for Health Research and Development