

## **Dutch League Against Epilepsy**

### 2021-2022 Report

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*Officer Election Date: Changing Terms*

#### **ACTIVITIES AND ACCOMPLISHMENTS**

- **National Epilepsy Network**  
This gets the most specialized care and knowledge to the patient, but in the right place, if possible, at home, or in the regional hospital, if necessary, in a specialized epilepsy clinic. Epilepsy Centers as hubs and regional hospitals as spokes work together to deliver this care. In this setting, quarterly regional educational webinars are held with case discussions and microteaching, guided by experts from the epilepsy centers.
- **National platform for education and research in epilepsy**  
This constitutes an overview of all educational activities for all professionals who work in epilepsy care. This includes hand-on training as well as completely digital basic courses on epilepsy (which are currently under development).
- **Advisory activities for ministries**
  - **Ministry of Defense:** Patients with epilepsy are currently excluded from any professional activity in the police force. The Dutch League questions this practice for all patients with epilepsy and asked for a more differentiated approach, to reduce the stigma associated with epilepsy.
  - **Ministry of Health:** To prevent medication shortages (like those in end 2022 with clobazam), we have asked the Minister of Health for a more sustainable policy to prevent shortages.
- The [National Epilepsy Guideline](#) is a modular guideline, which is updated annually, and consists of modules, which enable a fast adaptation to the newest scientific insights. We are proud that it acquired European support for internship in modular guideline development.

## CHALLENGES FACED IN 2021 AND 2022

Financial support for the Dutch League changed in 2022, which caused a major change in income and expenses

## FUTURE PLANS FOR 2023

The national networks for patient care, education and research have our continuous support and attention. We keep a close eye on the policies to prevent medication shortages.

## RESEARCH AND PUBLISHED ARTICLES

[Current list \(website in Dutch\)](#)

- Non-coding DNA abnormalities in epilepsy. Principal investigators Dr. T.S.Barakat, Erasmus MC, Rotterdam
- How can we stop seizures? The usefulness of individualized models of brain networks to improve epilepsy surgery outcome. Principal investigators: Arjan Hillebrand, Amsterdam UMC
- Clinical, electro graphical, and metabolic markers in SCN1A-related epilepsy. Principal investigators: Floor Jansen en Eva Brilstra, UMC Utrecht
- Effects of radio frequent thermocoagulation on brain network activity in patients with epilepsy (CONTACT-studie). Principal investigators: Dr. S. Tousseyn, Academic Center for epileptology Kempenhaeghe/Maastricht UMC
- Better seizure detection: eSTAMP trial. Principal investigator: Roland Thijs, SEIN Heemstede
- Precision radiotherapy for epilepsy (PRECISION). Principal investigator: Daniëlle Eekers, Maastricht Clinic Maastricht
- EpiOPM: Portable MEG sensors to measure epileptiform activity. Principal investigators: Arjan Hillebrand, Amsterdam UMC
- Improving the accuracy of success prediction in patients undergoing epilepsy surgery. Principal investigators: Ilse van Straaten, Amsterdam UMC
- Damage to the Glycocalyx and cerebral microcirculation in patients with epilepsy. Principal investigators: Olaf Schijns, Academisch Center for Epileptology Kempenhaeghe/Maastricht UMC
- N-of-1 studies for precision treatment in monogenic epilepsy (GATOR1) Principal investigators: Dr. Floor Jansen en Dr. Eva Brilstra, UMC Utrecht
- New biomarkers to predict medication response (eCORTA trial) Principal Investigator: Roland Thijs, SEIN Heemstede

## MEETINGS

24 September 2021: Online Midwinter Meeting of the Scientific Section

*Report submitted by Rob Rouhl*