

## Belgian League Against Epilepsy 2022 Report

### INTERNATIONAL EPILEPSY DAY

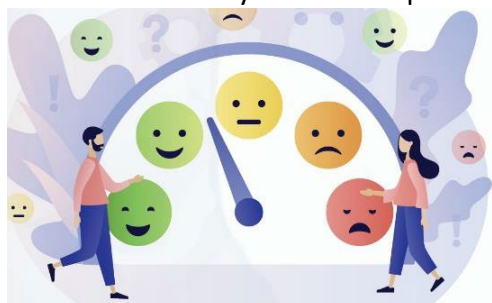
14 February 2022

- Facebook photo campaign in hospitals
- Theme: Spread some love



### FUTURE OF EPILEPSY LEAGUE SURVEY

Launched on 7 July 2022 to help determine our future goal, 525 people participated



### DE EPILEPSIE LIGA HEEFT JOUW HULP NODIG!

Met een korte enquête (+/- 5 minuten) willen we informeren naar jouw wensen over de taken van de Epilepsie Liga.

#### Main findings – general (patients and their communities)

- 25% do not know the League
- > 97% consider a patient organization important, only 37% are members of the League
- Website / social media is the most important portal
- Mainly demand for support / awareness

#### Main findings – professionals

- Know the league, but don't always use it
- Demand for guidelines, information, brochures
- Mainly demand for patient support, second place education

## **EEG COURSE CONTINUATION**

Start November 2021 - end May 2022

- EEG in epilepsy and consciousness disorders Dr. Annelies Van Dycke, 14 January 2022
- EEG in emergency care and intensive care Dr. Annelies Van Dycke, 4 February 2022
- EEG in children Prof. Dr. Lieven Lagae, 6 May 2022
- Epilepsy syndromes in childhood Prof. Dr. Anna Jansen, 18 February 2022
- Sleep diagnostics Prof. Dr. Paul Boon, 13 May 2022
- Neurophysiology of evoked potentials Dr. Kristof Verhoeven, 25 March 2022
- Demo 1: EEG and video EEG in children Dr. Lutgart Goossens, 22 April 2022
- Demo 2: EEG, VIDEO EEG, EP, PSG Prof. Dr. Alfred Meurs, 29 April 2022

## **MEETING DAYS**

- 4 June 2022 at 2:30 pm: IKAROS association walk and meeting in the nature reserve “Bourgoyen-Ossemeersen” te Mariakerke-Gent
- 1 October 2022 afternoon talk of IKAROS association: “Loss of your future plans for yourself, your partner, your child and how to give this a place in your life,” led by Gerd Claes, grief therapist
- 14 November 2022: Inform about “what is epilepsy,” KAASSE, 250 students

## **GENERAL ASSEMBLY MEETINGS**

- 17 January 2022, online – 17 attendees
- 14 June 2022, in person at One Tree Destelbergen – 15 attendees
- 21 November 2022, online – 15 attendees

## **BOARD OF DIRECTORS MEETINGS**

- 17 January 2022, online – 9 attendees
- 26 April 2022, in person at UZ Gent – 9 attendees
- 1 June 2022, online – 9 attendees
- 21 November 2022, online – 9 attendees

## **FUTURE OF EPILEPSY LEAGUE: INTERESTED PARTIES BRAINSTORMING**

14 October 2022, in person at Salons de Romrée, Grimbergen – 14 participants

## **WORKING GROUPS**

There were many meetings during November and December 2022 to work out ideas with members of the Board of Directors and the General Assembly.

- **Fundraising:** E. Carrette - E. Vancaester - B. Eichperger
  - Working out concrete actions to actively fundraise
  - Creation of a prize for masters
  - the idea should be finished by March 2023
  - KBS is interested in supporting this project financially

- **Website:** L. Seynaeve - A. Blomme - D. Beaudonck - B. Eichperger  
Working on a new website: launch December 2023
- **Courses:** A. Mertens - A. Meurs - K. Janssen - A. Schoonjans - A. Van Dycke  
Working on an Epilepsy course 2023-2024 (start 21 October 2023)
- **CGGs:** C. Van Daele - L. Coudenys - K. Janssen - S. Freson  
Seeking solutions to depleting collaboration with the CGGs
- **Special days:** R. Dorme - A. Blomme - L. Kalckman - B. Eichperger - P. Simons - L. Coudenys  
Organizing International Epilepsy Day on 13 February 2023: Contacting over 250 municipalities to participate by writing an article about epilepsy, post something on their socials or light up a building in purple, etc.

## PUBLICATIONS

The “Chronically Ill” campaign can be found in De Standaard and [nl.planet-health.be](https://nl.planet-health.be), article by Laura Seynaeve and Claudine Van Daele: “About 70% of epilepsy patients are seizure-free”, 7 September 2022

*Report submitted by xxx*