EpiCARE

JANUARY 2023 NEWSLETTER

First of all, HAPPY NEW YEAR to all! We wish you all the best for 2023.

The goal of our newsletter is to keep you informed about actions related to the European Reference Network on rare and complex epilepsies, EpiCARE.

You will find information about our next events, educational and research activities and calls, but also news from the coordination team, our different members and our ePAG community.

NEXT WEBINARS

Learn more about rare and complex epilepsies every 2nd and 4th Thursday of the month

A new serie of webinars focusing on epilepsy in clinical trials will begin in 2023 !

This serie has been prepared by the Clinical Trials & Targeted Therapy and the Education & Training work groups.

February 2nd

PCOMS in clinical trials

Rima Nabbout
France
&
Isabella Brambilla
Italy

Register

February 16th
Contemporary scope of inborn errors of metabolism involving epilepsy or seizures

Birutė Tumienė
Lithuania
&
Co-speaker TBD

Register

You can check the programme of the upcoming webinars and register to the webinar mailing on the EpiCARE webinars webpage:

Webinars webpage

LATEST NEWS

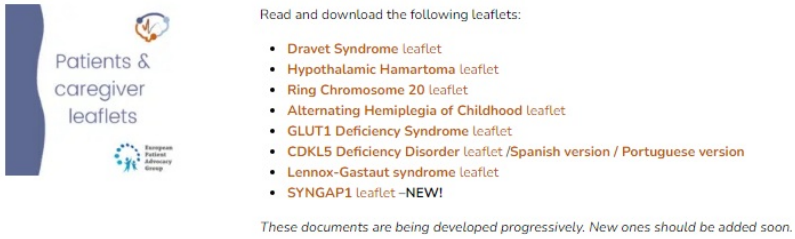
New e-learning case on Tuberous Sclerosis

We are happy to announce that a new e-learning case on Tuberous Sclerosis Complex, prepared with the ILAE Academy, has been published on the EpiCARE website !

There are now 9 patient-centred interactive e-learning modules on our website corresponding to diagnosis and management of some rare and complex epilepsies (Level 2 competencies according to the ILAE curriculum).

These cases were developped thanks to the CEF Telecom programme, and were co-funded by the European Agency INEA.

Leaflets on rare and complex epilepsies



Thanks to the collaboration between our ePAGs and clinicians members of EpiCARE, more and more leaflets about rare and complex epilepsies are written and translated everyday.

We now have a leaflet on SYNGAP1 (Thanks to Famiglie Syngap1 Italia APS for their work on providing information about SYNGAP1 together with physicians), and some translation in spanish, portuguese and soon in croatian!

Have a look to the newest leaflets here

EVENTS

EPIPED : treatment strategies in pediatric epilepsie - April 26-29

The aim of the 3 year cycle EPIPED Treatment is to reduce the geographical and knowledge gap by providing neurologists and child neurologists involved in epilepsy care the opportunity for a regular update on best treatment practices.

The concept of EPIPED is based on a 3 year cycle of independent annual training courses , developed specifically for child neurologists, physicians and epilepsy nurses caring for patients with epilepsy.

Topics treated are related to pharmacology, pharmacodynamics, pharmacokinetics, genetics, analysis of AED trials, design of clinical trials, pre surgical evaluation, optimal choice of AEDs,review of existing guidelines (ILAE, NICE, other), data on ketogenic diet, neurostimulation,indications for resective and palliative surgery, pharmacological treatments other than with AEDs, update on the development of targeted therapies.

This link gives you access to the full program of the 3 year cycle.

EPI-67069
Epilepsy Tagliacozzo

10th International Course on Drug Resistant Epilepsies - 30 April to 6 May

This course is clinically – oriented, targeted to specialists at the second and third level of epilepsy care and focused on comprehensive aspects of diagnosis and treatment of children and adults with epilepsy. It also includes the basic sciences in clinical epileptology issues, and comprehensive care of patients with epilepsy.
The faculty consists of leading International epileptologists. The faculty members give lectures and conduct interactive case discussions and/or tutorials on relevant aspects of epileptology.

See the preliminary programme here

EPNS Pre-congress symposium

“Drug-resistant epilepsy in the 21st century: From molecular mechanisms to precision therapies” will take place on Tuesday, 20 June 2023 in Prague, Czech Republic.
This exciting and unique one-day meeting will introduce and discuss in detail all the major developments including current clinical indications for Drug-resistant epilepsy in the 21st century. A broad faculty of international experts will bring you up-to-date with the history, practice and future developments in the rapidly developing field of drug-resistant epilepsy.

More information here.

Other upcoming events:

- 23 February - 25 June 2023: International Online Course on Pathogenesis of Epilepsy. More info
- 20-24 June: 15th congress of the European Paediatric Neurology Society. More info
- 1-4 July: 9th Congress of the European Academy of Neurology. More info

- 17-28 July : San Servolo Epilepsy Course "Early pediatric onset epilepsies: from syndrome and management to future perspectives". More info
- 2-6 Sept : 35th International Epilepsy Congress in Dublin, Ireland. More info.

EpiCARE SCIENTIFIC PUBLICATIONS

- Henshall, D. C., Arzimanoglou, A., Dedeurwaerdere, S., Guerrini, R., Jozwiak, S., Kokaia, M., Lerche, H., Pitkänen, A., Ryvlin, P., Simonato, M., & Sisodiya, S. M. (2023).
  Shaping the future of European epilepsy research: Final meeting report from EPICLUSTER. Epilepsy research, 189, 107068. Link.

- Nott, E., Behl, K. E., Brambilla, I., Green, T. E., Lucente, M., Vavassori, R., Watson, A., Dalla Bernardina, B., & Hildebrand, M. S. (2023).
  Rare. The importance of research, analysis, reporting and education in 'solving' the genetic epilepsies: A perspective from the European patient advocacy group for EpiCARE. European journal of medical genetics, 66(3), 104680. Advance online publication. Link.

You can consult recent publications on rare and complex epilepsies, epilepsy surgery and other topics on our scientific publications webpage.

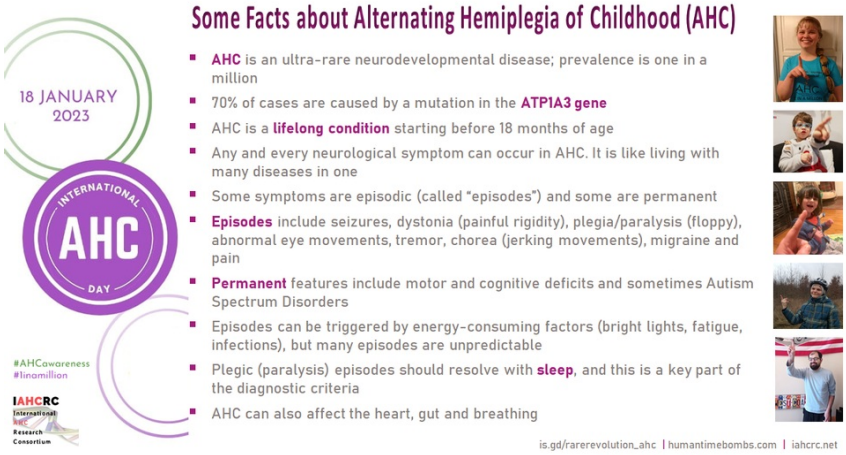
EpiCARE members: please remember to mention EpiCARE in your affiliations or in the acknowledgements / references when appropriate.

A word from our ePAGs

Alternating hemiplegia of childhood awareness day

AHC international awareness day was on 18th of January!

To learn more about AHC, check out our leaflets and Patient Journeys.



Members of ePAG EpiCARE and patient representatives joined forces in preparing and publishing an article titled: Rare. The importance of research, analysis, reporting and education in 'solving' the genetic epilepsies: A perspective from the European patient advocacy group for EpiCARE. Authors of the article are: Emma Nott (Hope for Hypothalamic Hamartomas), Katherine Behl (Alternating Hemiplegia of Childhood UK), Isabella Brambilla (Dravet Italia Onlus), Monica Lucente (Associazione Italiana GLUT1 Onlus, Rosaria Vavassori (International Alternating Hemiplegia of Childhood Research Consortium) and Allison Watson (Ring20 Research and Support UK) together with the physician: prof. Green, prod. Dalla Bernardina and prof. Hidelbrand.
Article was published in the European Journal for Medical Genetics, and highlights the transformative effect that early genetic diagnosis on the quality of life of individuals with epilepsy, discusses the significant gaps in knowledge and care that currently exist from the patient perspective, and describes some of the initiatives that patient-advocacy organisations have undertaken, and would promote, to fill those gaps

New newsletter coming out soon!

It is our pleasure to announce that this year we will start with a newsletter dedicated to patients' associations. It is our wish to connect and engage more with the wide community of rare and complex epilepsies and provide better support by disseminating relevant information.
The newsletter and related social media are the ideal tools to engage better among ourselves, physicians and broader public. The first edition will be disseminated on the 14th of February 2023.
If you wish to disseminate the information about your association, projects, activities and events you are planning, please contact: epag.epicare@gmail.com

ANYTHING TO SHARE?

Any news you would like to share, events planned, publications in the works?

Share with us any information you would like us to include in the next newsletter at a.robert@epi-care.eu

Follow us on social media!

Our mailing address is:

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You are receiving this email as you may work at one of the EpiCARE centres or you are taking part in one or more of EpiCARE expert groups or you may have attended one of our webinars.

See in browser