



**European  
Patient  
Advocacy  
Group**

## **ePAG EpiCARE Newsletter January 2024**

It is our pleasure to announce that this year we will continue with our **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.

If you wish to disseminate the information about your association, projects, activities and events you are planning, please contact: [epag.epicare@gmail.com](mailto:epag.epicare@gmail.com)

### **AWARENESS DAYS**



**LIVING  
WITH  
AHC**

**TOGETHER, WE CAN MAKE A DIFFERENCE**  
JOIN US IN RAISING AWARENESS FOR  
ALTERNATING HEMIPLEGIA OF CHILDHOOD

#### **Alternating Hemiplegia of Childhood**

Join us in raising awareness for Alternating Hemiplegia of childhood (AHC) on this special day, January 18th, dedicated to shining a light on this rare and challenging neurological disorder.

##### **Understanding Alternating Hemiplegia of Childhood?**

AHC is an incredibly rare neurological disorder. Whilst plegia is the hallmark of the disease, AHC encompasses a vast and wide-ranging complex constellation of neurological symptoms, both paroxysmal and non-paroxysmal. Non-paroxysmal manifestations include mild to severe motor, cognitive and language impairment and sometimes regression.

##### **The Challenges Faced by Those with AHC**

Living with AHC presents a multitude of challenges for individuals and their families. The unpredictable nature of the main symptoms, coupled with the various associated symptoms, and comorbidities, significantly impacts daily

life, education, social interactions, and overall well-being.

#### **The Importance of Awareness and Support**

Raising awareness about AHC is crucial for early recognition, accurate diagnosis, and improved support for affected individuals and their families. By increasing understanding and knowledge within our communities, we can ensure that those living with AHC receive the necessary resources, healthcare, and support they deserve.

#### **Advocating for Research and Resources**

Advancements in research and increased resources are vital to better understand and manage AHC. Advocacy plays a pivotal role in encouraging further research, developing targeted therapies, and enhancing the quality of life for those affected by this rare condition.

#### **Final Thoughts**

On Alternating Hemiplegia of Childhood Awareness Day, let's come together to show support, spread awareness, and amplify the voices of individuals and families impacted by AHC. Together, we can make a difference by fostering a more inclusive and supportive environment for everyone affected by this rare neurological disorder.

To learn more about AHC have a look at [EpiCARE leaflets](#) and [Patient Journey](#).

## Events

### **ePAG webinar: Tools developed by patient organisations for improving physician-patient communication**



*Tools developed by patient organisations for improving physician-patient communication*

*Isabella Brambilla, Andrea Lodi, Irena Bibić*  
ePAG EpiCARE



On December 21st, ePAG EpiCARE held a webinar about tools developed by patient organisations for improving the communication between patients/caregivers and physicians.

Isabella Brambilla presented Dravet Diary, and app developed by Dravet Italia Onlus for tracking seizures, other symptoms, medical exams, therapy with the option to upload photo/video content and Emergency protocol, and taking direct emergency calls from the app.

Andrea Lodi, president of Associazione Italiana Glut1, presented KETONET app developed by the association and associates. This app is intended for facilitating ketogenic dietary therapy by preparing and sharing the recipes, and regular follow up of glucose and ketone levels and other symptoms. App also allows communication with the dietitians and physicians. Currently it is available in Italian, on request as it is necessary to ensure adequate monitoring during KDT.

Finally, Irena Bibić has presented Dravet Emergency protocol, a project initially developed by Dravet Syndrome European Federation's Scientific Advisory Board and patient representatives, and currently endorsed by EpiCARE ERN. It is a website that does not collect any data online, and it is used for generating the emergency certificate that is signed by a designated neurology specialist and shared with families. This document facilitates communication with the emergency room staff, and gives clear instructions on status treatment.

The webinar is available to view at: <https://epi-care.eu/past-webinars/>

## Save the date for European Dravet Syndrome Conference 2024

Fundación Síndrome de Dravet is organising a Dravet syndrome conference in 2024. Save 14th and 15th of March 2024 in your calendars and join the conference in Madrid.

[For preliminary program and registration, click here.](#)

## Meet the patients' associations

### PACS2 Research Foundation

Established in May 2022, our primary focus is advancing the development of treatments for ultra-rare epileptic encephalopathy, PACS2 syndrome, and to deepen our understanding of the disease mechanism of action. Currently, we are actively coordinating eight projects that span the spectrum from basic science to drug repurposing and exploration of RNA editing.



#### Collaboration

Both interdisciplinary and international is at the core of our approach, and we are proud to partner with institutions globally, to name a few: Warsaw Medical University (Poland), Oxford University (UK), and Northwestern University (US). For a comprehensive overview, visit [www.pacs2research.org/resources](http://www.pacs2research.org/resources). Having established connections with approximately 60-70 families out of the 100 diagnosed patients, we are now also planning a natural history study.

#### Activities

Anticipating our first PACS2 conference in May 2024, we look forward to creating a platform for knowledge exchange and fostering collaboration within the scientific community.

#### Social media

Facebook: <https://www.facebook.com/pacs2research>

LinkedIn: <https://www.linkedin.com/company/pacs2-research-foundation/>

For inquiries or further information, please feel free to reach out to us: [pacs2research@gmail.com](mailto:pacs2research@gmail.com).

### Association EURECAH



Accueil et accompagnements  
spécialisés auprès des  
personnes avec autisme

Since its creation in 1999, the association's actions have essentially been militant in nature. The aim was to advance a cause (that of people with autism spectrum disorders) and to act differently. This is why innovation has always been part of the association's culture, and why it has always positioned itself as a genuine collective action, sharing skills and ensuring real complementarity in the Loire region.

#### Highlighted project

For many years, EURECAH has been supporting people with services of varying intensity, tailored to the specific needs of the person and their carer, and to their short- and medium-term project. The association also allows for long-term interventions when these are the project that meets the free choice of the person or their loved ones, or interventions over a transitional period between two phases of the person's journey.

The question of modulation has been an integral part of the association's project since its creation, both in its institutional organization and in the responses it provides. Over the years, the association's service platform has developed into a truly modular system. The association's platform has no administrative status and is not an identity as such.

### Events

Recently, the EURECAH association, in partnership with the Vivre Et Travailler Autrement association and Groupe Despinasse, deployed an employment support program at AF FRAIS in La Talaudière.

The VETA model has proved its worth over a number of years with various companies, the first of which was the Andros group in Auneau. Thanks to VETA, people with ASD and intellectual disabilities have access to employment and support on the road to independence. The core of this project is to make companies aware of all the benefits that autistic employees can bring, and of the human stakes involved in such integration.

At the same time, EURECAH is continuing to roll out Shared Habitats in the Loire department.

In partnership with Loire Habitat and the town of Rive-de-Gier, the historic building on Rue Richarme in the heart of the town will be renovated to accommodate families, senior citizens and adults with disabilities.

5 adults with autism (intellectual disability) will soon be living in a shared apartment comprising private areas (bedrooms, bathroom, WC), including a studio, as well as communal areas (kitchen, living room, laundry room, social room) and a large terrace.

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