

# ROUND UP

An newsletter of the Rare Epilepsy Network (REN)

**December Alas.** As we race to the end of the year, we want to take a brief moment to say thank you! We are grateful for this community of rare epilepsy organizations. Although our journeys are diverse, we are aligned in our mission to cure these diseases and care for our communities.

In this ROUND UP, we encourage you to promote your research grants on the ERC, spread Infantile Spasm awareness, and continue to promote the REN Registry. Plus read about REN members' journeys. Stay abreast of key conferences. Access key resources.

Share this newsletter with your researchers, industry partners, clinicians, and others.

## Promote Your Research on the Epilepsy Research Connection

The **Epilepsy Research Connection (ERC)** is a repository of epilepsy research funding opportunities from non-profit and government organizations. Investigators can also register to receive new funding announcements. If your organization is interested in posting a grant notice on the Epilepsy Research Connection, please contact [info@epirc.org](mailto:info@epirc.org) for instructions.



## Help Spread the Word about Infantile Spasms



Infantile Spasms (IS) are a medical emergency. Please help raise awareness of this rare but serious type of seizure and participate in **Infantile Spasms Awareness Week (ISAW)**, December 1-7, 2020. Download the social media kit for easy to use graphics and messages. Plus ISAW video ISAW video available in [English](#) and [Spanish](#).

*PS. Is your rare epilepsy awareness campaign on the list?*

## Promote the REN Registry to Researchers & Clinicians

**Are you Rare Aware?**  
Compare top medications used in rare epilepsies.

**Access data for 1,459 rare epilepsy patients across 40 diagnoses at [bit.ly/RENData](http://bit.ly/RENData).**

The REN registry includes data for 1459 patients across 40 diseases! Help promote the REN registry data to your researchers and clinicians. Your outreach is important whether your disease participated in the original registry or not. Download the [Registry Tool Kit](#) and [images](#) and help spread the word via email, newsletters and social media!

## Get To Know REN Member Journeys

TBC1D24  
FOUNDATION

SÍNDROME DE DRAVET  
FUNDACIÓN  
[www.dravetfoundation.eu](http://www.dravetfoundation.eu)

Bridge the Gap  
SYNGAP  
Education & Research Foundation

Fundación Libellas  
NALCN

STBP1 Disorders

Be sure to introduce your rare epilepsy org [here](#).  
Shout out to STXP1 Foundation for a great blog post by parent Jennifer Clatterback on [EF's Journeys](#).

Also read a heartfelt story by Luke Rosen of KIF1A in [medium.com](#) titled [The Firestorm of Rare Epilepsy: Our Girl's Dreamless Nights](#).

Stories in the news? Please share!

## Stay Abreast of Key Conferences

- 12/4-8 **American Epilepsy Society Annual Meeting**. Be sure to check out REN's slides and slides for many REN members in rotation before the FREE Hoyer lecture on 12/4 @ 2:15 EST. Live streamed via the [AES website](#) and AES Facebook Live.
- And don't miss the [Partners Against Mortality in Epilepsy](#) Mtg on 12/7 @ 2:30. Live streamed for families.
- Check out REN's advice on [How to Get the Most out of AES](#) [here](#).
- 1/4-1/6 [Curing the Epilepsies 2021](#) (registration information coming soon).



## Check Out REN's New Resource Page + Other Resources

### Resources

for DATA SEEKERS	for RESEARCHERS	for RARE ORGS	for PARENTS
 <b>GET DATA</b> Visit <a href="#">REN registry</a> : 1459 patients across 40 rare epilepsy diagnoses. Read <a href="#">Rare Epilepsy Landscape Analysis &amp; Appendix</a> overviewing challenges and opportunities for 44 rare epilepsy organizations. Visit <a href="#">REN members' websites</a> to learn more about individual disease registries, research, and other resources.	 <b>FIND GRANTS &amp; FUNDING</b> Visit our <a href="#">members' websites</a> to find grants. Visit <a href="#">Epilepsy Research Connection (ERC)</a> to find grants across organizations. Visit <a href="#">ICARE</a> to see historical funding across government and patient organizations.	 <b>JOIN REN</b> Become a Member and join our listserve to stay abreast of information, meetings and news. Get tools to start a Rare Epilepsy Org. Meet REN collaborators.	 <b>GET INFO &amp; SUPPORT</b> Visit our <a href="#">members' websites</a> for info, support and community. Contact <a href="#">Epilepsy Foundation's 24/7 Helpline</a> . Find <a href="#">clinical trials</a> . Contact <a href="#">REN</a> with new diagnosis.

Visit REN [resource pages](#) including information about starting a nonprofit. Any suggestions for additional resources, please send them our way.

We are fans of Beyond the Ion Channel Blog post. The latest article "[Make data speak in rare childhood epilepsies.](#)"

Check out NORD's Report on the [Barriers to Rare Disease Diagnosis, Care and Treatment](#)

Did you miss CNF's talk on Shortening the Diagnostic Odyssey? Listen [here](#).

Thanks to Glenna Steele (Glut1) for tips about the [Rare Genomes Project](#). See if your families qualify to join a patient-driven research study aimed at discovering genes underlying rare disease within a family.

Shout Out to Epilepsy Foundation for the new column dedicated to rare epilepsies titled [Rare Aware](#).

Great advice shared by FoxG1 & Gould during NORD's Rare Launch Research Ready panel.

**Other resources you covet? Share!**

Keep In Touch | Become a [REN Member](#) | Join our [Listserve](#)  
Share news and more to [info@rareepilepsynetwork.org](mailto:info@rareepilepsynetwork.org)

Rare Epilepsy Network (REN) working with urgency to collaboratively improve outcomes of rare epilepsy patients and families by fostering patient-focused research and advocacy.

Visit: [www.rareepilepsynetwork.org](http://www.rareepilepsynetwork.org)