REN Rare Epilepsy Network

rareepilepsynetwork.org

2023 IMPACT REPORT

OUR MISSION

REN’s mission is to work across all rare epilepsy organizations with urgency to collaboratively improve outcomes of rare epilepsy patients and families by fostering patient-focused research and advocacy.

For 2023, REN set five overarching goals to fulfill its mission including:

- FOSTER PATIENT-FOCUSED RESEARCH AND ADVOCACY FOR EPILEPSIES
- IMPROVE ACCESS TO & CLINICAL CARE OF ALL PATIENTS AND FAMILIES *new*
- INCREASE PUBLIC AWARENESS OF THE RARE EPILEPSIES
- SUPPORT & EMPOWER REN MEMBERS
- BUILD & STRENGTHEN REN NETWORK

To achieve each goal, REN identified a number of strategies and tactics. Accomplishments across goals follow.

Foster Patient-Centered Research and Advocacy for the Epilepsies

REN facilitated a work group on Multi-Disciplinary Clinics (MDCs) which resulted in a journal submission; a digital toolkit will follow in 2024

- Led initiatives/work groups prioritized by REN's membership
- Endorsed Key Policies
- Promoted surveys and clinical trials from academia and industry
- Promoted Advocacy & Training Initiatives of Members and Stakeholders
- Cited in various publications/white papers and/or facilitated publications
- Facilitated new funding mechanisms and research grants
- Promoted Use of REN registry data on Rare Disease Cures Accelerator-Data and Analytics Platform (RDCA-DAP®)

Improve Access to Clinical Care for All Patients and Families *new*

- Advanced Professional Education via collaboration on first-ever Rare Epilepsy ECHO with Epilepsy Foundation and American Academy of Pediatrics
- Increased Clinical-Related Outreach and Partnerships

Increase Public Awareness of the Rare Epilepsies

- Organized Annual Membership Meeting at AES including clinicians and YIs
- Hosted Shared Booth at AES for REN Members
- Presented or participated in key national conferences
- Identified rare leaders to serve as speakers, advisors, and liaisons
- Maintained and grew public-facing communication channels
- Co-organized and recommended presenters for webinars

Subscribers Grew by **28%**

65% The Average Newsletter Open Rate

The REN Members Only List-Serve Grew By: **47%**

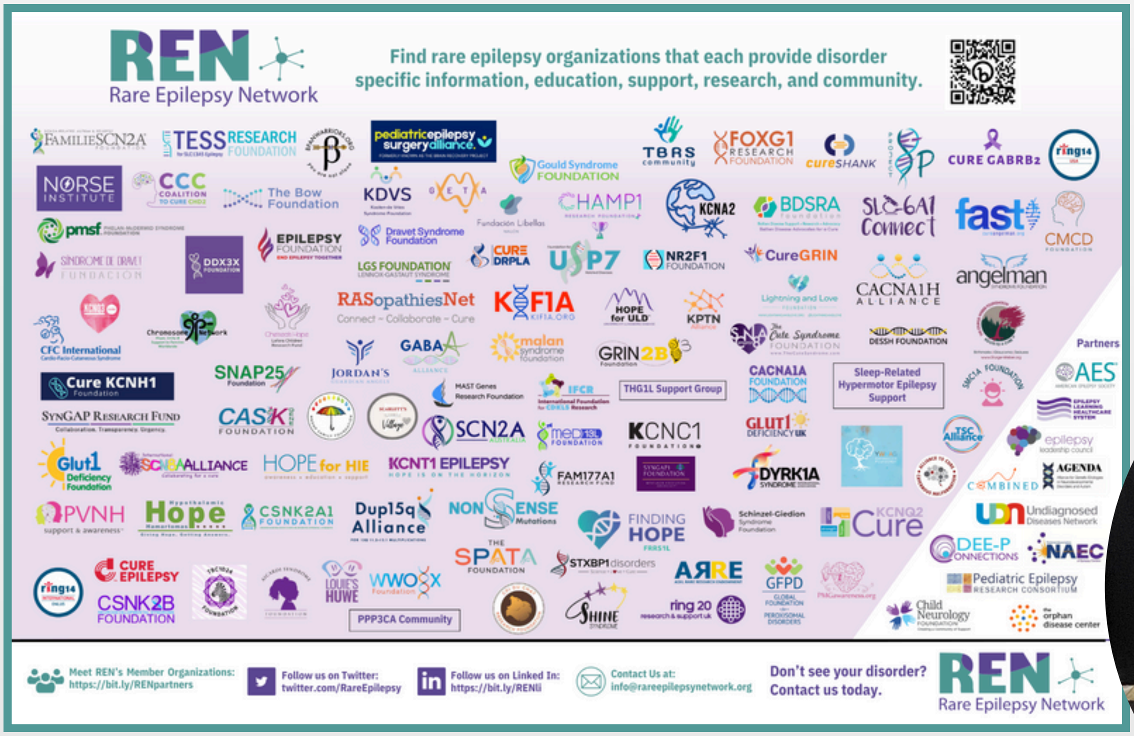
Support & Empower REN Partners & Members

- Organized Monthly Membership Meetings with 50 average attendance
- Operated Members Only actively engaged List-serve
- Managed Information & Referrals (I&R) from patients and HCPs
- Promoted Rare Epilepsy Awareness Days and related awareness days
- Recommended Members to present and lead webinars, attend conferences, and make presentations, etc.

Build and Strengthen Network

- Grew Membership by 28 percent and added two new partners
- Surveyed/Interviewed membership to understand priorities
- Conducted Timely Elections onboarding NEW strong leaders
- Strengthened Governance & Operational Practices
- Raised Funds to Support Mission and Operations
- Hired a Part-Time funded Director

In early 2023, REN disseminated a survey to its membership to identify priorities for the year. Based on the results, REN focused on the topic of "Clustering for research and collaboration". This topic was the focus on the 2023 breakfast with continued work on this topic planned for 2024.



REN Rare Epilepsy Network

Find rare epilepsy organizations that each provide disorder specific information, education, support, research, and community.

Partners

Meet REN's Member Organizations: https://bit.ly/RENpartners

Follow us on Twitter: twitter.com/RareEpilepsy

Follow us on Linked In: https://bit.ly/RENli

Contact Us at: info@rareepilepsynetwork.org

Don't see your disorder? Contact us today.

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About the Rare Epilepsy Network

Rare Epilepsy Network (REN) is a **one-of-a-kind consortium** comprised of 100 plus individual disorder organizations and partners. REN has doubled in size since 2020. REN's volunteer network works across the growing number of disorders to improve the lives lived of all persons touched by rare epilepsies and seizures. REN includes Members (rare epilepsy organizations) and Partners (broad epilepsy stakeholders) committed to this common mission. REN is led by a Coordinating Committee comprised of seven volunteer leaders and a Director.

REN began in 2013 with just ten rare epilepsy organizations fueled by a three million dollar Patient-Centered Outcomes Research Institute (PCORI) grant, managed by the Epilepsy Foundation (EF), and singularly focused on a project to build a patient-centered registry. By 2019, REN had grown to 32 organizations, launched a first-of-its-kind rare epilepsy registry, including 41 diseases with 1,500 patient and caregiver reported outcomes. The registry built a community across rare epilepsies and illuminated that although the underlying cause may differ, many of the comorbidities, as well as gaps and opportunities, were the same across disorders. In 2019, the registry project concluded. REN members reimagined the network, expanding its mission from a single focused project to a collaborative network fostering shared research and advocacy goals. American Epilepsy Society serves as REN's fiscal sponsor.

For more information, suggestions, and collaborations, contact: info@rareepilepsynetwork.org