REN
Rare Epilepsy Network

ANNUAL IMPACT REPORT

2024

WWW.RAREEPILEPSYNETWORK.ORG
INFO@RAREEPILEPSYNETWORK.ORG


REN WORKSHOP AT AES (2024)

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REN'S MISSION

To work with urgency to collaboratively improve outcomes of rare epilepsy patients and families by fostering patient-focused research and advocacy.

REN'S VISION

To support, grow, and maintain a network of rare epilepsy groups formed around a living overarching structure tasked with defining REN projects, in which REN groups are able to choose to participate.

ABOUT THE RARE EPILEPSY NETWORK

Rare Epilepsy Network (REN) is a one-of-a-kind consortium comprised of 150+ individual disorder organizations and partners, and has tripled in size since 2020. REN unites volunteer leaders across disorders to improve outcomes for those affected by rare epilepsies and seizures. It includes both Member organizations and broader epilepsy Partners, all working toward shared research, education, awareness, and advocacy goals.

Founded in 2013 with a $3M PCORI grant managed by the Epilepsy Foundation, REN began as a registry project with 10 organizations. By 2019, the registry included 41 disorders and 1,500 participants, revealing shared challenges across rare epilepsies. After the project concluded, REN expanded its mission and structure, now guided by a volunteer Coordinating Committee and Director, with the American Epilepsy Society as fiscal sponsor.

REN'S 2024 GOALS

Each year, the REN Coordinating Committee (CC) sets 3 to 5 strategic goals to guide the organization's priorities and activities. The goals established in 2023 were reaffirmed for 2024 and continued to shape REN's strategic direction.

FOSTER PATIENT-FOCUSED RESEARCH & ADVOCACY

IMPROVE ACCESS & CLINICAL CARE OF ALL PATIENTS /FAMILIES

INCREASE PUBLIC AWARENESS OF THE RARE EPILEPSIES

SUPPORT & EMPOWER REN MEMBERS

BUILD & STRENGTHEN REN NETWORK

This impact report outlines the five ongoing goals and the actions and deliverables that supported them, summarizing REN's key activities from the past year.

FOSTER PATIENT-FOCUSED ADVOCACY AND RESEARCH

2024 ACCOMPLISHMENTS

- Achieved record attendance at the **2024 AES REN Workshop**, marking a significant year-over-year growth.
- Partnered with DEE-P to co-lead an **FDA Listening Session** featuring eight rare epilepsy leaders sharing their lived experience.
- Promoted major **research funding mechanisms**, including: Rare As One, PCORI, NIH, AES, EF, AAP, CDC, NCATS, and more.
- Heightened awareness of the **RDCA-DAP Registry** including data for REN plus many other rare epilepsies and disorders including seizures - Angelman, CACNA1A, COL6-related; HNRP, KiF1A, Kleefstra, LGS, Prader-Willi, SCN2A, Sturgeon Weber and TSC.
- Collaborated with NINDS and ICARE to enhance **rare epilepsy data reporting and visibility via ICARE** and other national research efforts.
- Elevated participation in **caregiver and clinical research surveys** from AES, Yale, Boston Children's, Cleveland Clinic, ILAE, and others.
- Submitted **public comments** to AES/ILAE on disparities, joined Rare Disease Day/Week efforts, and engaged with national awareness campaigns.
- Participated in **Capitol Hill visits**, signed onto over a dozen federal funding and research advocacy letters, and supported epilepsy-specific budget priorities.
- Promoted **travel and junior faculty grants** from AES, EF, PERF, and ESCI to support REN member engagement and development.

2024 AES WORKSHOP

- 50 CLINICIANS AND RESEARCHERS
FROM 23 CENTERS;
-16 YOUNG INVESTIGATORS
FROM 13 CENTERS;
-73 PATIENT ADVOCACY LEADERS
FROM 43 INDIVIDUAL ORGANIZATIONS;
-LEADERS OF NINDS AND PCORI
-INDUSTRY & PHILANTHROPY

IMPROVE ACCESS TO AND CLINICAL CARE FOR PATIENTS AND FAMILIES

2024 ACCOMPLISHMENTS

- Shared lived experience **testimony at industry-sponsored events**, including OVID and Longboard Investors Day.
- Promoted **new rare epilepsy clinics,** including the launch of the first SCN2A multidisciplinary center at UTHealth Houston (FamiliesSCN2A Foundation).
- Amplified visibility of member **family and professional conferences** including CACNA1A, GRIN2B, STXBP1, LGS, CDKL5/IFCR, Sturge-Weber, Dravet, ARRE, Pediatric Epilepsy Surgery Alliance, TESS, SCN2A, HNRNP, and Jordan’s Guardian Angels.
- Elevated awareness of **Overgrowth-intellectual Disability Syndromes** collaboration by TBRS and Malan Syndrome Foundation via presentation and publication.
- Publicized **Dr. Devinsky’s seizure study work group** to advance trial readiness for SYNGAP1, Rett, CACNA1A, STXBP1, CDKL5, and KCNQ2.
- Advocated for **inclusion of ICD codes** - joining TESS and KCNQ2 in outreach to the CDC to support coding essential for clinical, research, and policy progress.
- Advanced **collaborations to strengthen clinical research, care models, and trial readiness**— work groups on clustering strategies across rare epilepsies and multidisciplinary clinics (draft publications pending).

INCREASE PUBLIC AWARENESS OF THE RARE EPILEPSIES

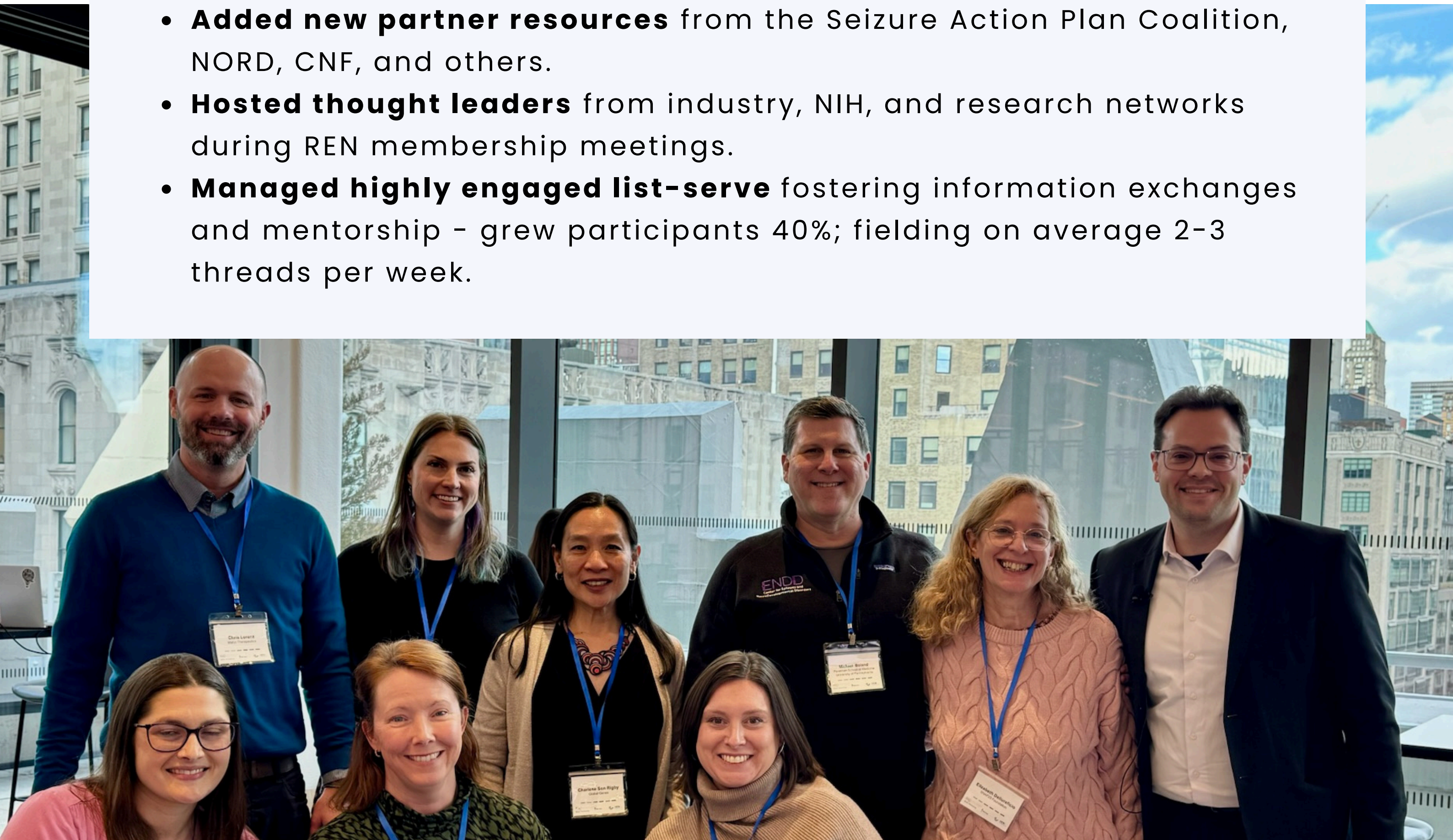
2024 ACCOMPLISHMENTS

- **Increased awareness of rare epilepsies, REN and its Members** with booths, presentations, and Ambassadors at major institutional, regional, national, and international conferences.
- **Published 12 monthly REN newsletters** with a growing reach - avg open rate is 60%+; grew subscribers 43%; Click rate is average 17% with up to 27%
- **Co-hosted and promoted key webinars** with partners (e.g., CURE Epilepsy on genetics, DEE-P on DEE clinical trials, RDCAP on rare epilepsy data).
- **Promoted member-specific and national awareness days** (e.g., Rare Disease Day, Seizure Action Plan Day, NEAM) throughout the year.
- **Shared new member videos and blog intros** across REN's website and social channels increasing awareness of disorders and resources.
- **Celebrated REN leaders** featured on TV, podcasts, in magazines (including People), invited to the White House, and presenting to federal agencies.
- **Boosted podcasts featuring rare epilepsy leaders and topics**, including Seizing Life, Epilepsy Sparks, Once Upon a Gene, What the EF, and Sharpwaves.
- **Promoted standout blogs** like TESS's #ScienceSimplified and thought leaders like Dennis Lal's Beyond the Ion Channel.
- **Praised REN and member leaders nominated for national award**s eg Global Genes Rare Champion and other honors.

SUPPORT & EMPOWER REN MEMBERS

2024 ACCOMPLISHMENTS

- **Recommended REN Leaders as keynotes, panelists, and facilitators** at major meetings.
- Collaborated with Global Genes to host a **Rare Advocacy Development (RAD) Workshop** with 28 rare epilepsy organizations.
- **Launched and managed multiple workgroups with partners**, driven by REN member priorities including: REN & PAME - SUDEP & Mortality Work Group; FDA Listening Session (collaboration with DEE-P); Cost of Rare Epilepsies; Clustering Across Rares; Data Sharing & Oversight; Research Grants and more
- **Fielded information and referral (I&R) requests** from patients, caregivers, industry, clinicians, and researchers on a wide range of conditions (including Kleefstra, Ohtahara, Prickle1, Sunflower Syndrome, Jeavons Syndrome, DEE-SWAS, LGS, KCNQ5, Pyridoxine Dependency Epilepsy, NKH, FoxP1, GNAO1, CYFIP2, KCNK4, UGDH, DLG4, YWHAG, Doose Syndrome, GNAI1, SETD1B) and referred to appropriate member orgs, Centers, and resources.
- **Added new partner resources** from the Seizure Action Plan Coalition, NORD, CNF, and others.
- **Hosted thought leaders** from industry, NIH, and research networks during REN membership meetings.
- **Managed highly engaged list-serve** fostering information exchanges and mentorship - grew participants 40%; fielding on average 2-3 threads per week.



BUILD & STRENGTHEN REN NETWORK

2024 ACCOMPLISHMENTS

- **Welcomed 38 new members and partners**, expanding REN's reach across rare epilepsies and related disorders. This was a 34% increase.
- **Developed and disseminated an internal IRB-approved Member Needs Assessment Survey** to inform strategic planning and membership needs - NEW data for 87 Members - available to clinicians, researchers and other stakeholders.
- **Launched a new website** with interactive features and improved navigation - new calendaring, ICD codes, interactive map plus.
- **Expanded social media** to include LinkedIn and BlueSky.
- **Grew newsletter and social media followings.**
- **Published REN's first Annual Impact Report**
- **Hosted 8 monthly Member meetings** (avg. 60+ attendees) and special sessions with key partners on mortality, surgery, clinical trials, and REN updates.
- **Tracked and promoted publications** citing REN and REN leaders.
- **Managed six interns** to expose students to rare disease advocacy.
- **Implemented Asana and time tracking tools** to improve operations.

WEBSITE: 19,827 PAGE VIEWS | 10,134 SITE SESSIONS | 7,276 UNIQUE VISITORS | 50% RETURN RATE | AVG TIME 5 MIN 25 SECS | 272% ENGAGEMENT

CONCLUSION & FORWARD LOOKING STATEMENT

SUMMARY OF REPORT

In 2024, the Rare Epilepsy Network (REN) experienced significant growth and momentum, now representing over 150 member organizations and partners. REN advanced its five strategic goals through impactful collaborations and initiatives, including (but not limited to) a high-attendance workshop at AES, a co-hosted FDA Listening Session, and new efforts to foster patient-focused research and advocacy. REN strengthened its role in shaping national research conversations by promoting critical funding opportunities, expanding its research initiatives, and collaborating with a variety of rare epilepsy stakeholders. REN amplified public awareness through traditional and new media over a variety of platforms. Members were empowered through workgroups, monthly meetings, and new digital resources. REN also welcomed 38 new members and partners, launched a redesigned website, grew its communications platforms, managed six interns, and so much more.

As REN continues to evolve from a registry project to a dynamic, volunteer-powered network, it stands at a pivotal moment — ready to scale its impact, accelerate shared progress, and drive meaningful change for all those affected by rare epilepsies.

FORWARD-LOOKING STATEMENT

As the Rare Epilepsy Network (REN) continues to grow in reach and impact, 2025 marks the launch of a new chapter. REN will introduce a three-year strategic plan focused on building long-term capacity while continuing to advance the collaborative activities and strategies that define our work. This plan will guide REN through its next phase of development, ensuring we have the infrastructure, leadership, and resources to meet the evolving needs of our community and accelerate progress across the rare epilepsy landscape.

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