

RETHINK OUR APPROACH

FROM OUR PRESIDENT/CEO

Re-Imagining Our Efforts for Our Community

To say that this year was challenging is an understatement. However, this year also presented opportunities for us to rethink our approach and the way we serve our community during and post COVID. When our new fiscal year started, we were six months into the pandemic with no end in sight. COVID hit our community in so many ways — from people with epilepsy not knowing whether they'd have continued access to their anti-seizure medications, to employment challenges, to trying to ensure that students with epilepsy had their needs met during virtual school — people living with the epilepsies felt the impact, hard. Yet, our community was resilient and inspiring; our staff was nimble, tenacious, and bold. We recognized the urgency, embraced the challenge, and quickly set the wheels in motion to address these challenges by:

- Launching a COVID-19 section on our website to provide accurate and timely information regarding COVID and epilepsy.
- Adapting our programs to ensure our community had access to key services and support, such as our Seizure First Aid Recognition & Certification trainings.
- Advocating to ensure continued access to needed health care and treatments, paid leave, additional direct payments including for adult dependents and extension of unemployment benefits.
- Shifting our organizational model and changing the structure of our local teams to maximize efficiencies and deliver resources in areas where we did not have a physical office.
- Re-imagining our signature fundraising event, the nationwide Walk to END EPILEPSY®, into Walk Your Way events to give people the opportunity to participate in a virtual setting.
- Pivoting to a digital-first organization and finding new ways to reach our community where they are, through our social media channels, epilepsy.com and our Epilepsy 24/7

I am proud of what we accomplished this year. None of these achievements would have been possible without the support of our community, advocates, individual donors, and corporate partners.

Despite the continued uncertainty surrounding COVID -19, I am excited for this new era of the Epilepsy Foundation.



Laura Thrall
President & CEO



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We are on a mission

To lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.

Founded in 1968, the Epilepsy Foundation has a network of partners throughout the United States that work together to promote awareness, advocate for laws that matter to people with epilepsy, and advance the development of therapies and treatment for people with epilepsy. In collaboration with the Centers for Disease Control & Prevention, we have helped to improve access to care for people with epilepsy and trained people in seizure recognition and first aid.



THE EPILEPSIES BY THE NUMBERS IN THE U.S.A.



1 in 10
people will have a **seizure** over a lifetime



200,000
people are diagnosed with **epilepsy** each year



1 in 26
people will develop **epilepsy** over a lifetime



3,400,000
people live with **epilepsy**

EVERY NUMBER IS A REAL PERSON AND A REAL STORY –
REPRESENTING PEOPLE OF EVERY AGE, RACE, ETHNICITY, AND SOCIOECONOMIC GROUP



01

LEADING WITH ONE VOICE

The Epilepsy Foundation is made up of committed leaders that oversee a team of dedicated professionals who work tirelessly to create and implement efforts focused on education, advocacy, and research efforts.

In addition, we have a board of directors who help guide the Foundation's strategic plan; a professional advisory board composed of epilepsy experts who help execute on our success; and an editorial board comprised of renowned experts in the field of epilepsy treatment and research who develop content for epilepsy.com.

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Los Angeles, California

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Baltimore, Maryland

Douglas Nordli, Jr., MD

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Edward John Novotny, Jr., MD, FACNS, FAAN, FAES

Seattle, Washington

Cynthia Hudson

CNN en Español and Hispanic Strategy
for CNN/U.S.

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May Liang

Daniel Moore

LivaNova PLC

Jeffrey Parent

Gulf States Toyota

Steven Schachter

Consortia for Improving Medicine with
Innovation & Technology (CIMIT)

Howard Soule

Prostate Cancer Foundation

Rebekah Walker

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Idaho Comprehensive Epilepsy Center

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William Rosenfeld, MD

St. Louis, Missouri

Stephan Schuele, MD, MPH

Chicago, Illinois

Rebecca J. Schultz, PhD, RN, CPNP

Houston, Texas

Chris Shandera

Boise, Idaho

Beth Sheidley, MS, CGC

Boston, Massachusetts

Ivan Soltesz, PhD

Stanford, California

William Tatum, DO

Jacksonville, Florida

Sumeet Vadera, MD

Orange, California

Korwyn L. Williams, MD

Phoenix, Arizona

Richard S. Zimmerman, MD

Phoenix, Arizona

NON-VOTING LIAISONS

Severn B. Churn, PhD

Bethesda, Maryland

Pat Trudeau, R. EEG/T, CLTM

Marshfield, Wisconsin



02

≥ **100,000**
reach through
community awareness
day events, virtual
Walks, support groups
and educational
conferences across the
nation.

OUR UNITED NETWORK

This was a pivotal year for our local grassroots efforts. We restructured our local teams, Community Engagement and Partnership (CEP), all while delivering consistent, quality programs and services across state lines during the pandemic.

We also expanded our footprint by engaging volunteers around the country. Our Epilepsy Awareness Ambassadors are passionate volunteers who are building epilepsy awareness in their community. What was initially launched as an opportunity for volunteers to spread awareness despite the constraints posed by the COVID-19 pandemic, has now grown into a national and connected community of more than **214 Epilepsy Awareness Ambassadors nationwide**. The Ambassadors “choose their own adventure” based on their interests and availability and channel their passion, talents, and creativity to support our community. This year, the Ambassadors created their own Walk to END EPILEPSY® team and became the 6th highest fundraising team in the nation.

... a few highlights

Our team in the Mid-East Region conducted 52 live instructor-led seizure education webinars in Iowa with a total of 2,230 people, including staff from the Iowa Department of Public Health. In Oklahoma, we met with the Oklahoma State Department of Education (OSDE) and Oklahoma Department of Health to develop a strategy for integrating the **Epilepsy Foundation's seizure first aid trainings into the OSDE learning platform**. In addition, we grew our volunteer base tremendously in the region, and identified Epilepsy Advocacy Champions.



In the Great Lakes Region, local volunteers and supporters **raised more than \$100K** in the return of the **Ohio MUD Volleyball**, which had not taken place the previous year due to the pandemic.

We also planned and hosted the region's first virtual Seizure Education Conference.

The Mid-Atlantic Region team partnered with an internationally recognized neuroscientist who lives with epilepsy to host "**Sail for Epilepsy**" fundraiser in Annapolis.

Our CEP team in the Gulf-South Region worked closely with a level 4 epilepsy center in Alabama to gather enough signatures (and raise funds for epilepsy research) for what would become the **first epilepsy-specific license place** in the nation. In Mississippi, we planned a half-day camp for children with epilepsy, and in Louisiana, local ambassadors, educators, industry partners, and physicians came together to support local efforts.





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DELIVERING ON OUR MISSION

Although COVID-19 defined 2020, our mission of leading the fight to stop seizures, save lives, and find a cure remained the same. Our work didn't stop, it only got better. We were determined to effectively deliver on our mission. We expanded our education and seizure first aid trainings, grew our advocacy efforts, and continued to fund research for new therapies and devices.

MISSION OUTCOMES

Seizure First Aid Trainings

We expanded our Seizure Recognition & First Aid Certification program, training 15,184 individuals this year. In addition, we engaged with key partners, such as the National Hispanic Medical Association, American Heart Association, the Association of Asian Pacific Community Health Organizations, American Association of Neuroscience Nurses, and National Indian Health Board, providing outreach to ethnic and racial minority public health professionals. Furthermore, we hosted 28 Seizure First Aid live sessions and began working on an on-demand training course.

15,184

trained individuals through our Seizure Recognition & First Aid Certification program during FY 2021.

Information & Referrals



The Epilepsy & Seizures 24/7 Helpline responded to 13,063 inquiries, providing 11,112 referrals to those in need. Although the Helpline saw a 10.7% reduction in inquiries, we were able to identify 21 active suicide cases with only one requiring emergency intervention.

Our Information Specialists were able to help the others identify ways to stay safe. In addition, we enrolled in the Alliance of Information & Referral Systems (AIRS) Enterprise Learning Management Platform for professional development, and expanded information & referral services within the Epilepsy Foundation's regional structure.



Telephone calls remain the primary method of contact for reaching the Helpline (62.67%). Email was second at 17.38%.



Medical-related topics were the number one reason people contacted the (Helpline 29.3%). Asking medical questions accounted for 6%, and requests for help finding a doctor or treatment center accounted for 5.4%, followed by questions about medication (4.5%).



Referred 522 contacts to Managing Epilepsy Well (MEW) programs.

ELHS Representation



13 U.S. states



14 clinical teams



18 community teams
(local Epilepsy Foundations,
Rare Epilepsy Network
organizations and advocacy
non-profits)



Seeking to improve upon

87%

Seizure Frequency
Documentation rate and to
include all network sites



35

current members
in new monthly
QI Journal Club

3000+

utilizations of ELHS Barriers
to Medication Adherence
and Telemedicine Toolkits

3 Quarterly
QI reports

2 virtual
Learning Sessions
involving
115+ attendees

9 Action Period
(AP) webinars

6+

total academic posters,
displayed at AAN, AES,
and CNS Conferences



Seeking to improve upon

56%

Intervention rate for
identified Barriers to
Medication Adherence and
to include all network sites

2 New Patient Toolkits:
Developmental &
Epileptic Encephalopathies
(DEE) and Difficult
to Treat Seizures



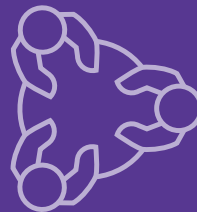
5,100+

visits to
ELHS website

3

new
publications

7



industry partners
in the QI Science
Leadership

1

Hearst Foundation
grant awarded



Social Engagement

208K

social media impressions

Collaboration with the Centers for Disease Control & Prevention

For decades, the Epilepsy Foundation has partnered with the Centers for Disease Control & Prevention (CDC) to improve the systems of care and support for people with epilepsy.

This was the last year of our current five-year cooperative agreement in which 12 different local offices across the country were awarded **25 grants to implement 34 virtual Managing Epilepsy Well programs**, including:

- Home Based Self-Management and Cognitive Training Changes Lives (HOBSCOTCH)
- Program for Active Consumer Engagement in Self-Management (PACES)
- Project Using Practice and Learning to Increase Favorable Thoughts (UPLIFT)

In addition, we successfully submitted and were awarded a new \$17.5M cooperative agreement for 2021-2026.

Sudden Unexpected Death in Epilepsy

The Epilepsy Foundation works to prevent sudden unexpected death in epilepsy (SUDEP) and support people bereaved by SUDEP and other epilepsy-related deaths. In September 2020, we hosted a two-day **SUDEP Coalition Summit** which was attended by **68 clinicians, researchers, community partners, people with epilepsy, and bereaved families**. The Summit produced a strategic plan and roadmap for what the SUDEP community needs to do in the next five years to end SUDEP. This year, we also began a monthly virtual support group for adults.



International Bureau for Epilepsy's Golden Light Award winner

Our very own Alison Kukla, senior program manager for programs and partnerships, was selected as the 2021 International Bureau for Epilepsy's Golden Light Award winner for the United States. This award recognizes the contributions of young people (ages 18-40) across the globe who living with epilepsy, or know someone who does, and are bringing "epilepsy out of the shadows and into the light."

Rare Epilepsies

- Established 40 partnerships with individual rare epilepsy organizations to expand our content library for rare epilepsies
- Secured funding from the CDC to launch a first-of-its kind Rare Epilepsy ECHO pilot initiative in 2022
- Published Developmental & Epileptic Encephalopathies content and a Toolkit for pediatrics and adults
- Hosted Facebook Lives and Rare Aware podcasts to bring awareness about rare epilepsies
- Introduced a Seizure First Aid training with content specific to rare epilepsies

Wellness Program

The Epilepsy Foundation was awarded a Robert Wood Johnson Foundation Employment and Empowerment Grant to create resources and training materials offered through our Epilepsy Learning Portal. Activities included an employment-focused Facebook Live focused on helping people with the epilepsies enhance their ability to get federal jobs. In addition, we hosted three live webinars with 191 participants, and produced three short videos for epilepsy.com.

Our Epilepsy Wellness team also developed Support Group Facilitator resources and best practices for Epilepsy Foundation staff facilitating and/or managing volunteer support group facilitators. This included on-demand training and updated volunteer resources on the Epilepsy Learning Portal.



A few highlights

3

Live Support Group Facilitator Trainings

40

individuals have participated in live Support Group Facilitator Trainings

1

Live Support Group Technical Assistance Call (in early 2021)

13

attended the support group TA call

1

Mental Health First Aid Training (in 2020)

9

completed Mental Health First Aid Training

Advocacy

Our **Seizure Safe Schools legislative** initiative saw great success this year! Passionate grassroots advocates, local Epilepsy Foundation offices and other epilepsy-related organizations worked together to help enact Seizure Safe Schools legislation in seven new states: Virginia, Washington, Oklahoma, Colorado, Alabama, Nebraska, and Minnesota — bringing the total to 12 states.

As part of our **Grassroots Engagement**, we trained more than 160 advocates representing 38 states, including 54 teen representatives and ambassadors living with the epilepsies. We also held more than 150 virtual meetings with congressional offices during our Virtual Teens Speak Up! & Public Policy Institute. Our Speak Up, Speak Out! grassroots network sent out more than 9,900 letters to their members of Congress and state-level officials about key policies impacting our community. We launched the **Epilepsy Advocacy Champions** program with 55 inaugural volunteer advocates who will strengthen relationships with members of Congress and more efficiently advance key federal policy priorities. We also rolled out the **Epilepsy Policy Advisory Committee** to provide input on our annual federal and state-level policy priorities.

Our **Jeanne A. Carpenter Legal Defense Fund** advised nearly 1,000 people with epilepsy and others in the community about their rights as it relates to employment, education, and access to care, and also connected them to resources. This was particularly important given the challenges that people with epilepsy faced through the COVID-19 pandemic, especially in the areas of employment and ensuring that the needs of students with disabilities were met in virtual learning. We also produced four webinars and two stand-alone technical assistance documents to help people with epilepsy gain and maintain employment.



12

states enacted Seizure Safe Schools legislation during FY 2021.



Other Policy Victories

- Rescission of a policy that would have restricted access to anti-seizure medications in Medicare by holding congressional and administration meetings and our advocates sending nearly 1,700 emails.
- Achieved a \$1M increase for the CDC's Epilepsy program, nearly \$4M increase for the VA Epilepsy Centers of Excellence, and a \$1.25B increase for the National Institutes of Health in the federal government's Fiscal Year 2021 budget.
- Enactment of federal legislation to end the practice of surprise medical billing, and enactment of several critical policies through the American Rescue Plan Act including: additional direct payments to Americans and for the first time, inclusion of adult dependents; dedicated funding for Medicaid home and community-based services; extension of emergency paid leave tax credits; extension and expansion of unemployment benefits; improved affordability of healthcare coverage and incentives for states that have not yet expanded Medicaid to expand coverage.
- Joined other patient advocacy organizations on an amicus curiae (friend-of-the-court) brief that was submitted to the U.S. Supreme Court in advance of oral arguments on the Affordable Care Act (ACA), discussing the law's importance in protecting people with pre-existing conditions like epilepsy.

In a 7-2 decision, the Supreme Court found no standing and dismissed the case, preserving the ACA and its protections.

Innovation

Research & New Therapies Grants (Shark Tank)

The 2021 Shark Tank competition was held on June 17 during the Antiepileptic Drug and Device Trials XVI Conference in Pennsylvania. We received 25 submissions from around the world and awarded a total of \$275,000 to two winners. Tobias Loddenkemper, MD, from Boston Children's Hospital, and Eric White from Miku, won the \$250,000 Investment Prize for their radar and video-based seizure monitoring system. Deborah Koltai, PhD, from Duke University School of Medicine, and Angelina Kakooza-Mwesige, MD, from Makerere University College of Health Sciences in Uganda, were awarded the \$25,000 Community Impact Award for their self-management and resilience app for adolescents with epilepsy.



Shark Tank Finalists

- Tim Buckinx from Epihunter for their real-time absence seizure tracker
- Nao Gamo, PhD, from NeuroSonics Medical for their minimally invasive focused ultrasound device to treat drug-resistant epilepsy
- Omid Kavehei from BrainConnect for their leadless sub-scalp electroencephalogram
- Richard Smith from Shower Belt for their shower safety system
- Matthew Speed from Partner for PSC for their video software to support people with photosensitivity

My Seizure Gauge Initiative

This is the final year of the My Seizure Gauge initiative, which was given an extension to build a minimally invasive seizure forecasting device. In conjunction with this project, the Epilepsy Foundation launched a data-sharing platform, EpilepsyEcosystem.org, for algorithm developers interested in seizure detection and forecasting.



Human Epilepsy Project

In 2021, we moved the Human Epilepsy Project from a multi-site study to a single site. This clinical study follows 157 individuals over 2 to 3 years with the goal of collecting valuable information to better understand why some individuals living with focal seizures respond, or do not respond, to medication. The study also seeks to gather history of treatment-resistant focal epilepsy and its co-morbidities. A study report will be completed in 2022.

Epilepsy Digital Experience Navigator (EDEN)

We established a collaboration with Eisai Inc. to develop a new platform — the Epilepsy Digital Experience Navigator (EDEN) — a personalized digital services platform for people with epilepsy and caregivers. Through a technology partner, Embleema, the platform can aggregate real-world data for thousands of people with epilepsy to improve therapeutic outcomes. Embleema will build patient-reported outcomes surveys, a seizure frequency check-in program, an onboarding experience where users share demographics and their epilepsy/treatment, and the ability to connect to both their FitBit device and their electronic medical record system.



2021 Accelerator Award

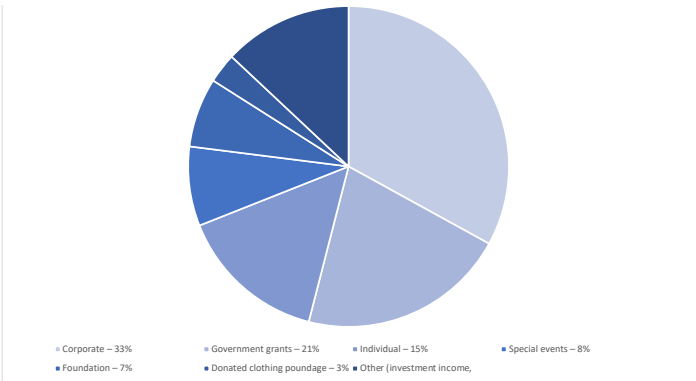
The 2021 winner of the Accelerator Award was Emilio Perucca, MD, PhD, who has spent his career determining the best therapy for people with epilepsy.

Development

Your Donations Help Fuel Our Mission

Each year, we diversify our revenue sources. In FY21, Epilepsy Foundation contributions by source included:

- Corporate – 33%
- Government grants – 21%
- Individual – 15%
- Special events – 8%
- Foundation – 7%
- Donated clothing poundage – 3%
- Other (investment income, miscellaneous revenue, affiliate fees): 13%



The **Walk to END EPILEPSY®** raised more than \$3.05M through nearly 100 events nationwide. This season we had approximately 20,000 participants and 2,200 teams throughout the country, coming together to walk to help fund epilepsy awareness in local communities.



STREAM FOR EPILEPSY

Launched in October 2020, our newest fundraising initiative, **Stream for Epilepsy**, had a very successful inaugural year! The campaign raised \$42K+ and we engaged 150 streamers in multiple streaming events throughout the year. We also have more than 30 ambassador volunteers focused on fundraising and helping the program grow to include more individuals in the streaming sphere.

Marketing and Communications



eJourney

In November 2020, we successfully introduced our eJourney Community Blog. The idea came from a conversation with two of our board members, Camila Coelho and Cynthia Hudson, who suggested a new approach to sharing stories from our community. eJourney reflects the many stories of our epilepsy warriors and their journeys navigating the epilepsies. This is a way for our community to raise their voice and share their journey, wherever they are in the fight against epilepsy — the struggles and successes that come with being strong and never giving up.

13,996

Pageviews

11,587

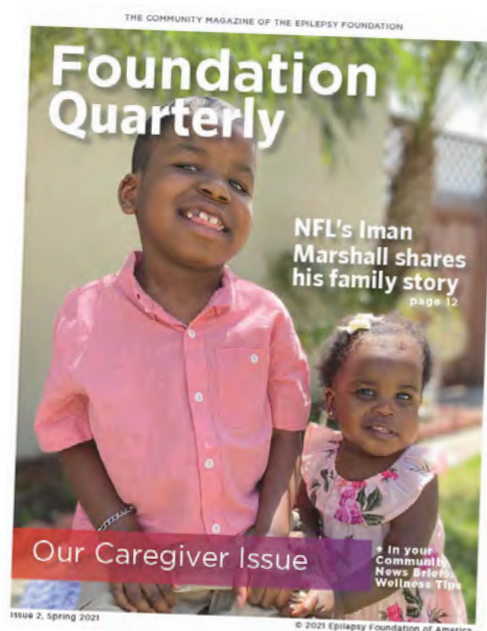
Unique pageviews

Top 3 Stories

Andra's Employment eJourney: 1,229

Lowell's Employment eJourney: 785

Mama Bear for Rare: 758



Foundation Quarterly

We also transformed our quarterly research publication into the Foundation Quarterly — a new, completely digital magazine format designed to inspire and inform our community and others about the amazing work we do at the Epilepsy Foundation. Issues throughout the year featured celebrities such as Iman Marshall, cornerback for the Baltimore Ravens, people with epilepsy, caregivers, school nurses and others who have been impacted by epilepsy.

Website

Moreover, epilepsy.com continues to be the largest and most comprehensive digital hub in the world for seizure information and education. The Epilepsy Foundation's social media channels are also a key communications and engagement platform for education and awareness with epilepsy, caregivers, school nurses, and others who have been impacted by epilepsy.

Our Digital Reach

Website

20,744,081
Page views

18,243,942
Unique page views

COVID-19 pages

420,092
Page views

341,481
Unique page views

Top Website Pages

1. Homepage 551,795
2. What Is Epilepsy 455,574
3. Types of Seizures 393,074
4. Absence Seizures 329,651
5. Seizure Medication List 236,444

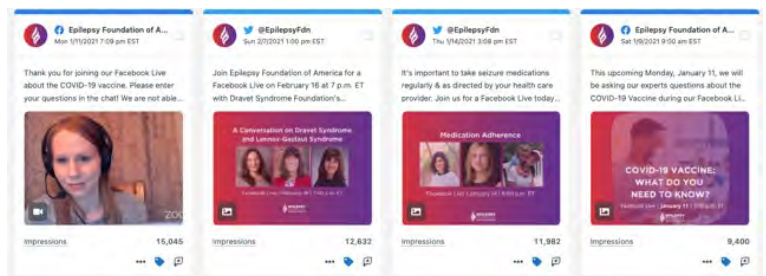
Our Social Channels

Instagram followers (net growth): 10,901
Facebook page likes (net growth): 4,377
Twitter followers gained: 1,611
Facebook Fundraisers: 41,509
Amount raised through FB fundraisers: \$1.4M+

Top FB Fundraiser

- o PurplePumpkinProject
- o Birthday Fundraiser
- o Memorial Fundraiser

Facebook Lives/Webinars: 21



Key campaigns generating most engagement

1. Seizure First Aid- Michael video campaign- 47,164
2. Seizure First Aid- 39,558
3. National Epilepsy Awareness Month- 35,500
4. Give26- 33,482
5. eJourney- 12,990

Financials

Your Impact

Epilepsy Foundation Summary Consolidated Financial Statements \$ In Thousands

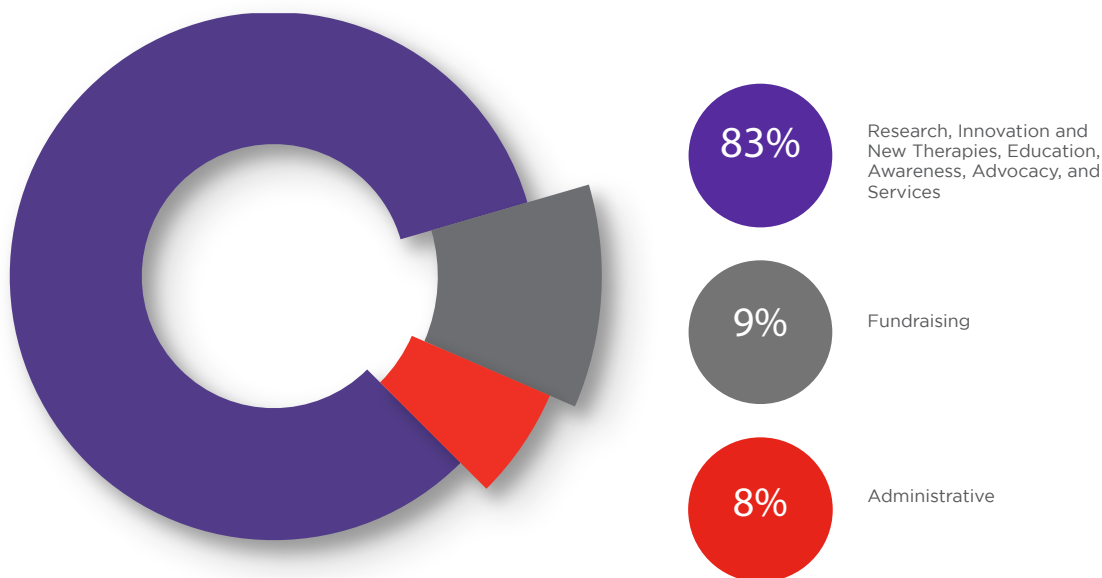
CONSOLIDATED STATEMENT OF FINANCIAL POSITION

	As of June 30	
ASSETS	2021	2020
Cash and cash equivalents	2,383	10,757
Investments	13,807	7,548
Receivables	1,446	1,644
Prepaid expenses and Inventory	194	402
Fixed assets, net	517	752
Deferred rent asset	0	39
Beneficial interest in perpetual trusts and other assets	3,763	5,161
	22,110	26,303
LIABILITIES AND NET ASSETS		
Accounts payable and accrued expenses	1,681	1,264
Grants payable	597	2,405
Deferred revenue and refundable advances	363	774
Paycheck Protection Loan Payable	2,001	2,001
	4,643	6,444
	17,467	19,860
TOTAL LIABILITIES & NET ASSETS	22,110	26,303

CONSOLIDATED STATEMENT OF ACTIVITIES

	For the year ended June 30	
REVENUE	2021	2020
Contributions	10,737	20,997
Government and other grants	4,041	4,057
Affiliate fees	386	351
Special events, net of direct cost	1,533	1,844
Investment Income	1,854	(13)
Change in value of beneficial interests in trusts	524	(158)
Other	245	168
TOTAL REVENUE	19,319	27,246
EXPENSES		
Program Services		
Research, Innovations and New Therapies	3,133	3,750
Education and Awareness	3,618	5,073
Advocacy and Services for Individuals, Families and communities	8,585	9,657
Supporting Services		
Administrative	1,650	1,769
Fundraising	1,658	2,596
TOTAL EXPENSES	18,643	22,845
Change in net assets	(2,392)	2775

Epilepsy Foundation Spending Percentages - Fiscal Year Ending 2021





epilepsy.com