

# ANNUAL REPORT FY2024

#MyEpilepsyHero

Carter

## A Message from the President & CEO

Dear Friends and Supporters,

It is with heartfelt gratitude and a deep sense of purpose that I write to you as the new President & CEO of the Epilepsy Foundation. This role is one that carries both professional and personal meaning for me. I've been moved by the extraordinary resilience I've witnessed across this community.

Over the past year, I've met individuals and families who face the challenges of epilepsy with strength, compassion, and determination. That same spirit fuels the work of our staff, volunteers, and community partners each day, and it's what inspires me as we close our 2020-2025 strategic plan.

This has been a year of growth and renewed momentum. With **more than 3.4 million Americans living with epilepsy**, we continued to broaden our outreach and deliver programs that **advance health equity and accessibility**. In partnership with the Centers for Disease Control and Prevention (CDC), we launched the **Epilepsy Learning Portal for the Hispanic Community**—offering Spanish-language Seizure First Aid training and epilepsy education for families and caregivers. This is just one example of our commitment to inclusion and reaching underserved communities.

We also marked major advocacy wins, with **Seizure Safe Schools legislation** signed into law in Connecticut, Ohio, and Mississippi—ensuring that students living with epilepsy are better protected and supported in their learning environments. These milestones are a testament to the power of collaboration and community voice.

In November, during **National Epilepsy Awareness Month**, we launched “Change Our Epilepsy Story.” This campaign encourages individuals to share their lived experiences. Through storytelling, we are reducing stigma, building understanding, and creating connection across communities. Looking ahead, I am filled with optimism. We will be launching a new strategic plan that will guide our work and amplify our impact in the years to come. From expanding services and deepening partnerships to supporting groundbreaking research, this plan will keep us focused on what matters most: improving lives.

To our donors, partners, and advocates—you are the heart of this mission. Your belief in what we do makes it all possible. Thank you for walking with us, investing in progress, and helping to ensure that no one has to face this journey alone.

With gratitude and determination,



Bernice “Bee” Martin Lee

# Our Commitment, Our Momentum: Moving Forward Together

In a world still reshaping itself after social, economic, and public health upheaval, we have stayed true to one purpose: to be a steady, compassionate force for people living with epilepsy and their families. We've expanded our reach, deepened our partnerships, and sharpened our focus—delivering advocacy, education, direct services, and research initiatives that create lasting impact. While our journey is not without obstacles, each step forward has strengthened our resolve.

## Our Progress

**Increased Engagement:** Broadened our national and local impact, connecting with more individuals and families navigating epilepsy than ever before.

**Expanded Services:** Scaled programs addressing the emotional, physical, and economic toll of epilepsy—reaching underserved communities and confronting systemic inequities in care.

**Advocacy Achievements:** Amplified the voices of those affected by epilepsy, driving policy changes and increasing awareness to reduce stigma and improve access to treatment.

**Innovative Research Support:** Continued to fund and advocate for groundbreaking research focused not just on controlling seizures—but changing the course of the disease.

## Our Vision for the Future

We are not finished. As we close the chapter on our 2020–2025 Strategic Plan, the Five Pillars continue to guide us:



**Lead the conversation around epilepsy** to reduce stigma and empower voices.



**Shape the future of care** through research, innovation, and equity.



**Unite our network** to ensure no one feels isolated in their epilepsy journey.



**Diversify our funding** to sustain and grow mission-critical programs.



**Optimize through technology** to better serve every person, everywhere.

## Our Ongoing Promise

We know epilepsy can take a heavy toll—physically, emotionally, and financially. But we also see the courage, resilience, and hope that emerge when people come together to care, give, and advocate. Your support helps turn challenges into possibilities. With you, we are not just navigating change—we are helping thousands live fuller, safer, more empowered lives. **Thank you for standing with us.**

# Impact Highlights 2024

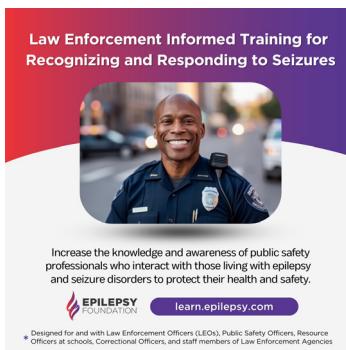
## MISSION OUTCOMES

# 27,419

people have been trained through our **Seizure Recognition & First Aid Certification** program

# 13,933

referrals made through the **Epilepsy & Seizures 24/7 Helpline** to connect people with vital support and services while **providing 16,055 referrals** to those in need



## Launch of the Law Enforcement Informed Training

during Public Health Institute

## RESEARCH

### Shark Tank

The Epilepsy Foundation awarded \$150,000 total to two innovators who competed in the Foundation's 2023 Shark Tank Competition held during the 17th Conference on Epilepsy Therapies and Diagnostics Development. The event was held June 12, 2023.

The awards included:

The \$100,000 prize was awarded to Dr. Angela Liedler, chief executive officer at Precisis GmbH, for EASEE™, a minimally invasive implant for bioelectrical treatment of epilepsy.

The \$50,000 prize was awarded to Paul Loomis, chief commercial officer at BrainCapture for its portable Electroencephalogram (EEG) device and platform to increase access to diagnostics tools for healthcare providers in underserved countries.

### Public Health Institute Conference

November 10-11, 2023, in Atlanta, GA

Focus: Addressing epilepsy inequities in Social Justice and Public Safety

### Epilepsy Learning Healthcare System

# 28k+

number of patients in the registry. Patient enrollment has increased by 600-700 patients monthly over the past year

# 70k+

number of new registered visits in the registry, averaging 2,300 new visits per month

### Epilepsy Learning System Portal

We launched the **Epilepsy Learning Portal for the Hispanic Community** on our Epilepsy Learning Portal

# 1,128,686

number of registered accounts on the platform



Worldwide renowned epilepsy expert, Jacqueline French, M.D., was honored with the 2023 Lifetime Accelerator Award at the Conference on Epilepsy Therapies and Diagnostics Development reception.

### Research Roundtable for Epilepsy

April 25-26, 2024 in Washington, D.C.

Focus: Drug Development to Address Non-Seizure Outcomes Associated with Epilepsy

## ADVOCACY



### Public Policy Institute

February 11-13, 2024 in Washington, DC



**75** number of advocates and local Epilepsy Foundation staff



**30** number of states represented



**105** number of congressional offices visited

## CHAPTERS OPERATIONS

**62**

local events and activities with more than

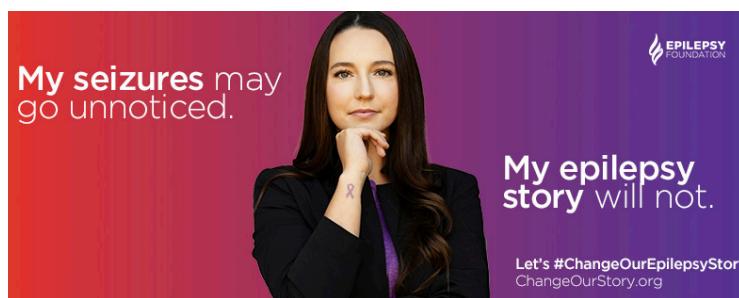
**88,000**

participants from

**28**

chapters throughout the country

## MARKETING & COMMUNICATIONS, DIGITAL STRATEGY



**| 653,679,872**

number of media impressions for Change Our Story campaign, in collaboration with CDC

**417**

eJourney Blog submissions

**| 6.6 million**

epilepsy.com total unique users

**| 13.7 million**

epilepsy.com page views

### Jeanne A. Carpenter Legal Defense Fund

Our **Jeanne A. Carpenter Legal Defense Fund** was established to help people with epilepsy and others in the community be informed about their rights as it relates to employment, education, and access to care, and connect them to the appropriate legal resources.



The Fund advised nearly **1,000** people.

## Board of Directors

### Chair

**Jeff Parent**  
AutoNation

### Vice Chair

**Courtney Genosi Caputo**  
Parson Corporation

### Treasurer

**David Hawk**  
Hawk Investments

### Secretary

**Mark Theeuwes**  
Reunion Neurosciences

### Ex Officio

**Bernice (Bee) Martin Lee**  
President & CEO, Epilepsy Foundation

### Members

**Camila Coelho**  
elaluz

**Abraham Glaser**  
Sliverleaf Wealth Management

**Elizabeth Corbett**  
Affirm, Inc.

**Joshua Golden**  
Quad

**Curtis Deprey**  
Midwest Select Insurance Group, LLC

**Ali Heron**  
Petal

**Sarah Klein**  
Epilepsy Foundation CO & WY

**Michael McDonnell**  
Kutak Rock, LLP

**Wasim Q. Malik, PhD**  
Iaso Ventures

**David B. Moore, MD**  
McFarland Clinic

**Greg Mayes**  
Reunion Neurosciences

**Noah Richmond**  
Verily Life Sciences

**James J. McAlpin, Jr.**  
Bryan Cave Leighton Paisner, LLP

**Angelica Roiz**  
Grant Thornton, LLP

**Matt Tifft**  
Live Fast Motorsports, Inc.

**Mary Weldon**  
Stacy Gallo Casting

## Professional Advisory Board (Medical)

**Nicholas Abend, MD**  
Philadelphia, PA

**Sasha Alick-Lindstrom, MD, FAAN,**

**FACNS, FAES**

Dallas, TX

**Deepti Anbarasan, MD**

New York, NY

**Amir Arain, MD**

Salt Lake City, UT

**Michelle Bell, MD**

New York, NY

**Carrin Brandt, MFT**

Washington, DC

**Mark Callow, MD**

Cincinnati, OH

**Stephanie Chen, MSN, MPH**

Saint Paul, MN

**Kathryn Davis, MD, MS, FAES**

Philadelphia, Pennsylvania

**Severn B. Churn, PhD**

McLean, VA

**Dennis Drugos, MD, MSCE**

Media, Pennsylvania

**Julia Doss, PsyD, LP**

St. Paul, Minnesota

**Robert Doss, PsyD, LP, ABPP-CN**

St. Paul, Minnesota

**Daniel Fain, MD, FAAN**

Grand Rapids, Michigan

**Patrick Forcelli, PhD**

Washington, DC

**L. John Greenfield, MD, PhD**

Simsbury, CT

**Monisha Goyal, MD**

Birmingham, AL

**Sanjeet Grewal, MD**

Jacksonville, FL

**Susan T. Herman, MD**

Phoenix, AZ

**Lawrence Hirsch, MD**

Greenwich, CT

**Jennifer Hopp, MD**

Fulton, MD

**Aatif Husain, MD**

Durham, NC

**David King-Stephens, MD**

New Haven, CT

**Linda Leary, MD**

San Antonio, TX

**Samden, Lhatoo, MD**

Houston, TX

**Thomas J. McCarrier, Reg EMT-Intermediate**

Stevens Point, Wisconsin

**Danielle McDermott, MD, MS, FAES**

Denver, CO

**William McMullen, MD, PhD, ABCN, ABPP**

San Francisco, CA

**Wendy Miller, PhD, RN, CCRN**

Indianapolis, Indiana

**Mary Nasuta, RN, MS, NCSN**

Bel Air, MD

**Lorraine Newborn-Palmer, DNP, RN, ACNS-BC, CNRN, CBIS, FAES**

Baltimore, MD

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

Seattle, Washington

**Joffre Olaya, MD**

Orange, CA

**Alison Pack, MD, MPH**

New York, New York

**Archana Pasupuleti, MD**

Washington, District of Columbia

**Patricia Penovich, MD**

Saint Paul, MN

**Angela Peters, MD**

Salt Lake City, UT

**Ignacio L. Pita Garcia, MD**

San Juan, PR

**Annapurna Poduri, MD, MPH**

Boston, Massachusetts

**John Schreiber, MD**

Washington, DC

**Stephan Schuele, MD, MPH**

Chicago, Illinois

**Chris Shandera**

Boise, ID

**Ashwini Sharan, MD**

Philadelphia, PA

**Beth Sheidley, MS, CGC**

Boston, Massachusetts

**Azara Singh, MBBS**

Charleston, WV

**David Spencer, MD**

Portland, OR

**Bethany Thomas**

Philadelphia, PA

**Pat Trudeau, R. EEG T., NA-CLTM, FASET**

Philadelphia, PA

**Sumeet Vadera, MD**

Orange, California

**Mary Zupanc, MD**

Madison, WI

# Financials

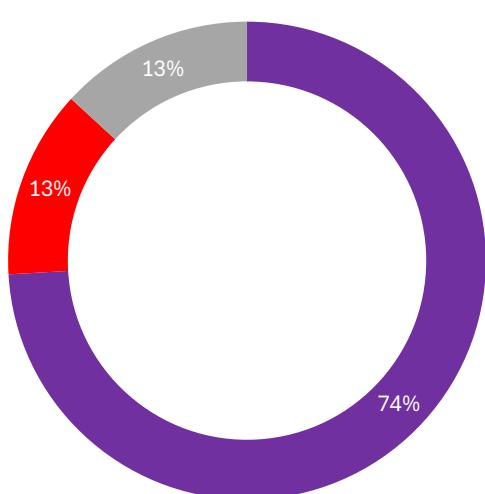
## Your Impact

### Epilepsy Foundation

#### Summary Consolidated Financial Statements

CONSOLIDATED STATEMENT OF FINANCIAL POSITION		As of June 30		CONSOLIDATED STATEMENT OF ACTIVITIES		For the year ended June 30	
ASSETS		2024	2023	REVENUE		2024	2023
Cash and cash equivalents		2,861,544	4,728,071	Contributions		8,886,477	11,114,908
Investments		13,684,009	11,730,731	Government grants		4,041,655	4,603,977
Receivables		646,555	907,986	Special Events, net		1,631,209	1,809,796
Prepaid expenses and Inventory		600,650	583,707	Affiliate fees		394,174	407,605
Property, net		27,525	73,450	ELHS memberships		200,024	295,976
Deferred rent asset		0	39	Donated clothing revenue		690,698	849,727
Beneficial interest in perpetual trusts and other assets		4,067,983	3,827,763	Investment income		1,039,536	737,539
		<u>21,888,266</u>	<u>21,851,708</u>	Change in value of beneficial interests in trusts		222,498	-91,845
<b>LIABILITIES AND NET ASSETS</b>				Loss/impairment on other investments		-104,946	-1,125,000
Accounts payable and accrued expenses		1,307,820	1,189,954	Other revenue		33,755	55,356
Deferred revenue		154,165	120,024	<b>TOTAL REVENUE</b>		<u>17,034,080</u>	<u>18,658,039</u>
Current maturities of operating lease liabilities		22,557	42,467	<b>EXPENSES</b>			
Operating lease liabilities, net		9,740	19,121	Program Services			
		<u>1,494,282</u>	<u>1,371,566</u>	Research, Innovations and New Therapies		1,172,588	1,207,690
				Public Health, Education, and Awareness		2,082,895	2,000,708
				Advocacy and Services for Individuals, Families and communities		9,427,124	9,310,993
				Supporting Services			
				Administrative		2,183,914	1,535,379
				Fundraising		2,253,747	2,272,777
				<b>TOTAL EXPENSES</b>		<u>17,120,238</u>	<u>16,327,547</u>

#### Spending Percentages - Fiscal Year Ending 2024



**74%**

Research, Innovation and New Therapies, Education, Awareness, Advocacy, and Services

**13%**

Fundraising

**13%**

Administrative



Visit [epilepsy.com/about/financial-information](http://epilepsy.com/about/financial-information)  
to visit financial reports and reports