

*The Epilepsy Foundation of Michigan leads the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.*



Metro Detroit Stroll for Epilepsy™ - Team Tristan Turtle Power

## MISSION ACTIVITIES *(Indicating the Strategic Planning Objective it supports)*

- ❖ The Foundation's annual Stroll for Epilepsy™ is a key event for the epilepsy community across Michigan, promoting unity and support. This year, we offered both in-person and virtual participation options, making the event accessible to everyone. One of the central features was our Interactive Wall, focusing on the "Challenge of the Year: Accessibility." Here, participants contributed their perspectives on accessibility, enhancing our understanding and dialogue within the community. Congratulations to everyone who participated in this quarter's Stroll for Epilepsy™ and thank you to those who raised funds.  
*(Objective 1, 3, 5)*
  - Traverse City Stroll raised a total of \$26,117.09 (9 teams, 126 people registered, \$6112.28 in Sponsorships)
  - Midland Stroll raised a total of \$24,062.77 (10 teams, 148 people registered, \$9,062.18 in Sponsorships)
  - Metro-Detroit Stroll raised \$153,499.47 (70 teams, 1,630 people registered, \$24,262.18 in Sponsorships)
- ❖ The 19th Annual Paul Neu Memorial Golf Classic was held on Monday, June 24<sup>th</sup>, at Railside Golf Club in Byron Center and brought together 145 golfers! Sponsorships totaled \$46,500, golfer registration and dinner-only tickets totaled \$22,290, \$9,739 came in through the day of raffle, 50/50 tickets, and donations totaled \$17,750. The event grossed a total of \$96,279 setting a new fundraising record while honoring the memory of Paul and his mother, Johanne Neu. *(Objective 1)*
- ❖ The Epilepsy Innovation Roundtable was held on April 27<sup>th</sup> at the Prince Conference Center in Grand Rapids. The program was designed with individuals and families affected by epilepsy in mind by providing valuable

insight, education and a glimpse into the latest advancements in the field. There were 65 individuals that registered for the roundtable. As a result of attending, over 91% of the participants made a connection to someone new through conversations providing practical information to better manage epilepsy or related issues. *(Objective 2)*

- ❖ The Epilepsy Foundation of Michigan welcomed thirty-five attendees to our office in Southfield for an **Open House** on April 11<sup>th</sup>. This event provided a valuable opportunity for community members affected by epilepsy, as well as supporters of our mission, to meet with our staff and connect with each other. Enhancing this year's gathering, we introduced a Seizure Recognition & First-Aid Training session immediately following the Open House, which attracted six participants. The evening was an enriching experience, fostering both community ties and educational growth. *(Objective 3)*
- ❖ As part of our **Strategic Plan**, the Foundation has created an annual internship for minority college students or recent college graduates, and we are pleased to share that Chaniqua Adams, a recent graduate of Michigan State University, has joined our team this summer to serve as our Disability Rights Intern. Chaniqua has a degree in Criminal Justice with a minor in Youth and Society. Her primary tasks this summer revolve around the 2024 Social Determinants of Health Mini-grant by creating a Legal Aid and Community Resource Guide. The guide can assist individuals and families on how to best advocate for someone who has been arrested during a seizure or post-ictal recovery to ensure they receive their medications in a timely manner. *(Objective 6)*
- ❖ During the quarter, we held an 8-week session of **Project UPLIFT**, our mental health, self-management program for people with epilepsy or functional seizures who additionally experience depression, anxiety, or high stress. The virtual program welcomed 8 participants. Participants finished the program with significantly lower depression and anxiety scores. *(Objective 2, 3)*
- ❖ Shannon Waid led a **Dearborn Public Library Staff Seizure Recognition and First Aid Training** on April 12<sup>th</sup>. Fifty-nine staff members from all three Dearborn Public Library branches were trained and certified through the training. *(Objective 2, 5)*
- ❖ On April 20<sup>th</sup>, Shannon Waid provided a presentation on Seizure Recognition and First Aid at the **Michigan PTA Conference** and hosted an exhibit booth. The event brought together parents, teachers, administrators, nurses, and students from across Michigan. Our training session had 10 attendees, and approximately 200 people visited our exhibit. *(Objective 2, 5)*
- ❖ On April 25<sup>th</sup>, the virtual **Book Club** was offered for people to discuss *The Sacred Disease: My Life with Epilepsy* by Kristin Seaborg, MD. Dr. Seaborg is a pediatric neurologist who lives with epilepsy herself, and 17 members of the epilepsy community attended. *(Objective 2, 5)*
- ❖ On May 7<sup>th</sup>, Nicole Fitzpatrick represented the Epilepsy Foundation of Michigan at the **Virtual Resource Fair**, in partnership with The Family Center for Children and Youth with Special Health Care Needs, Michigan Family to Family, and Michigan Family Voices. The event was held online with 122 people in attendance; afterward, it was shared with families across the state of Michigan. *(Objective 2, 5)*
- ❖ Renee Roederer provided a presentation about the Epilepsy Foundation of Michigan's success in launching our Chronic Disease Self-Management Program (CDSMP) on May 8, during the **Epilepsy Foundation of America - CDC Quarterly Update Call**. The positive impacts this program has had on participants and the 100% completion rate was shared with those attending. *(Objective 2)*
- ❖ On May 15<sup>th</sup> and May 16<sup>th</sup>, during the **Navigating Healthcare Training for Parents of Children with Epilepsy**, Nicole Fitzpatrick offered a two-part, in-depth training for parents who have children with epilepsy to create greater knowledge and ease in navigating the healthcare system. This training was offered in partnership with the Michigan Pediatric Epilepsy Project (MPEP), the Family Health Information Center, and the Family Center for Children and Youth with Special Health Care Needs. Six people were in attendance for the training. *(Objective 2)*

- ❖ The Foundation participated in the **Michigan Association of School Nurses Conference** on May 19<sup>th</sup> providing information on its programs and services. Approximately, 150 school nurses from around the state attended the conference. *(Objective 2, 5)*
  - ❖ On June 13<sup>th</sup>, Renee Roederer and Maanya Tarnal, former Public Health Intern, attended **Community Unity Day** at the Meijer LPGA Classic by Simply Give, expanding the Foundation's Diversity, Equity & Inclusion efforts. *(Objective 6)*
  - ❖ On June 19<sup>th</sup>, **The Critical Role of Rescue Medications Webinar** took place with Ryan Keating, DO, Epileptologist at Michigan State University-Sparrow, leading a presentation. The webinar focused on the important role of rescue medications in epilepsy care and was followed by a facilitated discussion with Nicole Fitzpatrick. Ten people attended the webinar. Additionally, in the third quarter, the Foundation has plans to send this recorded webinar to partners in the Upper Peninsula and additional rural areas in Michigan. *(Objective 2, 5)*
  - ❖ On June 29<sup>th</sup>, the Foundation held its first **Young Adults Retreat**. Renee Roederer led 8 young adults with epilepsy in a retreat experience that involved games, friendship building, time to ask questions about epilepsy, and a facilitated discussion about healthcare transition. This retreat was funded by the Michigan Pediatric Epilepsy Project (MPEP) and was held in Ann Arbor at Disability Network (Washtenaw Monroe Livingston). Afterward, family members were invited to join the young adults at Washtenaw Dairy for Ice Cream. *(Objective 2, 3)*
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- ❖ The **Individual Advocacy Program** assisted with 17 interactions made on behalf of 14 people with epilepsy and their family members. *(Objective 2)*
  - ❖ The **Call & Connect Network** included five different groups in the quarter. **Adults with Epilepsy**, which is phone-based, brought together 13 participants in this weekly discussion group. There were 13 calls with the average number of participants per call being 7. The **Young Adult Group**, which takes place via Zoom, brought together 14 participants in this bi-weekly group. There were 6 meetings with an average of 8 participants per meeting. The **Parent Group**, which takes place via Zoom, brought together 16 participants in this bi-weekly group. There were 12 meetings with an average of 4 participants per meeting. The **Older Adult & Caregiver Group**, which takes place via Zoom, brought together 8 participants in this weekly group. There were 11 meetings with an average of 5 participants per meeting. The **Teen Group**, which takes place via Zoom, brought together 4 participants in this monthly group. There were 2 meetings with an average of 3 participants per meeting. *(Objective 3)*
  - ❖ During the quarter, in partnership with Andrea Thomas, MA, LLP, Psychologist at Henry Ford Comprehensive Epilepsy Center, the Foundation held three sessions of the **Mindfulness Moments initiative**. There were 24 people attending with an average of 13 participants per session. This is a monthly opportunity for epilepsy community members to meet one another and practice mindfulness and meditation together. *(Objective 3)*
  - ❖ The **Here for You Helpline** assisted the epilepsy community with 321 contacts during the quarter. Contacts during the quarter resulted in 112 hours of staff time being contributed with an average call time of 21 minutes per contact. Lucy Zeiler started this quarter as our Helpline Assistant, and her presence has added great care and allowed the Foundation to increase the average call time per contact. *(Objective 2, 3, 4, 5)*
  - ❖ **Seizure Recognition & First Aid Trainings (Objective 5):**
    - **MICHIGAN:** Seizure First Aid ⇒ 8 presentations to approximately 170 School Staff/Students/First Responders/Health & Human Professionals or Company Employees