

&CTH ANNIVERSARY

A Look Back As We Head To The Future.



1946

Eighty years ago, a small group of individuals with a desire to help those struggling with epilepsy came together and started something big. While the organization that began its existence as the Illinois Epilepsy League has clearly evolved, its original mission is still a vital aspect of the Epilepsy Foundation of Greater Chicago today: to provide guidance to those with epilepsy, as well as increased awareness and understanding in the general public. The group of founding mothers and fathers didn't want people with epilepsy to feel alone.

In 1946—the year of its formation—the Illinois Epilepsy League was run by a small Board of Directors who knew it would be challenging to bring epilepsy into the public eye, however, new scientific discoveries and treatments helped get them started on the right foot. Dr. Frederic Gibbs, who worked in collaboration with the League while heading the University of Illinois's epilepsy consultation clinic, had pioneered the use of the electro-encephalo-graph (EEG), a device that records the fluctuation of the electric currents of the brain. This development greatly advanced the treatment of epilepsy and gave the Illinois Epilepsy League something significant to talk about. They distributed printed materials to broaden epilepsy awareness and referring those in need to available medical facilities.

In 1966, the Illinois Epilepsy League received funding from the government, and thus had the financial ability to hire their first employee who was tasked with expanding the League's services. Additional staff members were brought on to provide counseling, employment services, a residential program, and support groups. As the years passed by, the support groups kept growing, with as many as twenty up and running in the League's service area.

In the early 1970s, the Illinois Epilepsy League became the Chicago Metropolitan Chapter of the Epilepsy Foundation of America and in 1988, it was renamed the Epilepsy Foundation of Greater Chicago, a more accurate reflection of who they intended to provide services to, metropolitan Chicago and its suburbs. With an increasingly strong support network, the Foundation not only improved local services, but was able to tackle epilepsy on a much broader scale. There was a bigger picture to examine: improving the quality of life for people with epilepsy by advocating for the rights they deserved yet were often denied.

The importance of this advocacy work was made very apparent when the negative consequences that the Americans with Disabilities Act (ADA) had on the epilepsy community unfolded. In order to aid the hearing impaired, the ADA required that strobe lights be used in conjunction with fire alarms, a potential seizure trigger for people with photosensitive epilepsy. The Foundation quickly became involved in an enormous lobbying effort that spanned the nation. Staff traveled to Washington, DC to testify in front of the ADA Committee, resulting in a successful revision of the Act itself.

In the 2000s, New initiatives were developed to tailor to specific communities, such as the Hispanic Epilepsy Community Health Outreach Program, Studio E: the Epilepsy Art Therapy Program, and the Kids & Teens Club. These gave people living with epilepsy the chance to come together in social settings, outside of support groups, to form friendships while engaging in activities that they gave them a sense of community. The Foundation also continued with the expansion of its outreach efforts. Two Suburban Outreach Clinics were opened, which provided clinical consultation with a case manager and a neurologist. An EFGC staff member was available to provide Seizure First Aid Trainings to any school or organization in the greater Chicago area.

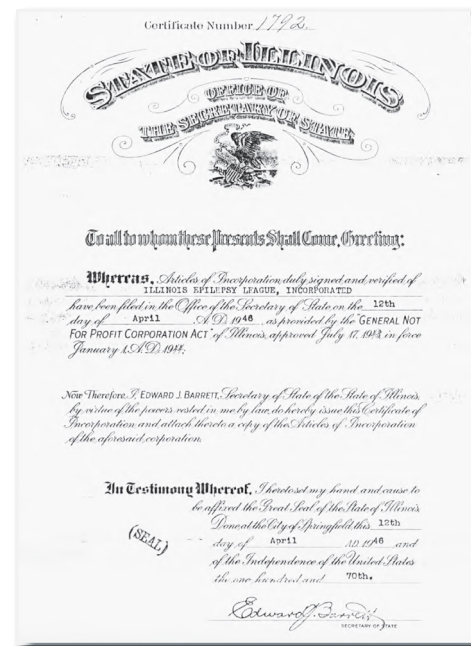
In the 2010s, the Foundation expanded its efforts to educate and advocate for people with epilepsy. It created two annual conferences, one held in English and one in Spanish. Each year hundreds of individuals attend these conferences to learn about the latest topics impacting the epilepsy community from expert medical professionals. The Education Department grew to include two additional staff that were dedicated to providing the Seizure First Aid trainings, educating thousands each year on how to properly respond when someone has a seizure. In 2018, the Foundation was instrumental in the passage of the Seizure Smart School Act, which requires all school personnel in Illinois to be trained in seizure first aid. Other advocacy efforts included guaranteeing access to all anti-epilepsy drugs, branded and generic, for all Illinois epilepsy patients on Medicaid and the availability of medical cannabis to reduce seizures.

During the COVID pandemic, the Foundation recognized a heightened need for enhanced mental health counseling for individuals living with epilepsy, in addition to the emotional strain caused by the global medical crisis. In response, a licensed clinician was hired to lead the Member Services Department, which included licensed therapists who still provide counseling sessions to support and improve the mental health of those the Foundation serves.

The Foundation's Education Department revised its name in 2023, becoming the Health Equity, Education & Advocacy Department. The intentional addition of health equity underscores its commitment to reaching underserved and underrepresented communities affected by epilepsy, ensuring our programs are accessible, culturally responsive, and inclusive. By integrating education with advocacy, it not only increases awareness and knowledge, but also works to remove barriers so people with epilepsy have the opportunity, support, and access to live their fullest lives.

Today, building off of the momentum created by those who came before her, EFGC President & CEO, Alison Ruble is enthusiastically looking toward the future:

"I am honored by the opportunity to serve as President & CEO of the Epilepsy Foundation of Greater Chicago and be a part of an incredible legacy of support for our epilepsy community. On this 80th anniversary, we pause to reflect on the compassion and dedicated service of many who have given so much over the years to ensure the needs of those living with epilepsy are met. There is still much work to do, but as we look to the future, we are heartened by the opportunity to grow our reach and impact through supporters and community partners that join us in our commitment that no one faces epilepsy alone."



Today