



Editorial

Stronger together – the Epilepsy Therapy Project and Epilepsy Foundation decide to merge. Our personal stories and reflections

Together

The Institute of Medicine (IOM) Report, “Epilepsy Across the Spectrum: Promoting Health and Understanding” contained many important findings for the field and reflected input from a range of advocates, patients, and families impacted by epilepsy. In particular, the IOM suggested that on the web, in the area of education and advocacy, the two leading voices in the epilepsy community, the Epilepsy Foundation (EF) and the Epilepsy Therapy Project (ETP) with its website epilepsy.com, could gain strength by joining together.

The Epilepsy Foundation and Epilepsy Therapy Project, after a successful almost decade-long partnership in the funding of new therapies, announced in October, 2012 a Memorandum of Understanding to merge. By coming together, we will operate more efficiently, with a stronger voice in education and awareness and with greater impact in pursuing ETP's mission of accelerating new therapies in a timeframe that matters and EF's broader mission of improving the lives of people with epilepsy.

We (EF CEO Phil Gattone and ETP Co-founder and Chairman Warren Lammert) and our families have both lived with epilepsy. As we reflect on the testimony provided in this issue of *Epilepsy & Behavior* by individuals who have shared that experience, we are in awe of the power of their words describing epilepsy and its impact in their lives and the lives of those they love. Here, we humbly offer our own personal perspectives as fathers of children living with epilepsy. We describe our journeys and how we came together in a decision to merge EF and ETP. We look forward to working together with these leaders and others who are striving to improve the care and therapies available to our children and the millions of other individuals living with seizures, side-effects, and all of the complications and challenges of epilepsy.

Warren's story

I was traveling on business in California on a November afternoon 14 years ago when I received a call from Sylvie's mom Kathy who told me that Sylvie, our until then healthy and robust 9-month-old daughter, had experienced a seizure. As I rushed to the airport to fly to Denver, Sylvie came home from Denver Children's Hospital only to experience a second seizure that afternoon. I landed that evening and arrived at the hospital just as Sylvie went into a prolonged status seizure. I held her that night as the doctors carried out a lumbar puncture to rule out meningitis. Sylvie is a strong, resilient girl, and a week later, she left behind intensive care and soon after the hospital, but not the seizures.

The seizures paused for some months but then restarted and continued and multiplied for Sylvie in kind and frequency: an arm stiffening progressing to a generalized tonic-clonic seizure lasting several minutes and subsiding into sleep and recovery; waking to an hour-long wave of unrelenting eye blinking and head movements; sporadic eye lid

movements and myoclonic jerks through the day and another wave of seizures starting in the early evening and only relenting over bedtime stories and into sleep; and perhaps weekly, another tonic-clonic seizure and its aftermath. Moreover, along with the seizures came visits to neurologists and one medicine and then another and one combination after another, and then the ketogenic diet, and an implanted medical device. However, the seizures continued.

As we struggled as a family to try and find answers, I looked to see what I could learn on the web and was frustrated. There was so little information available and none particularly relevant to a family facing the complexity and challenge of Sylvie's epilepsy. We wanted answers. We found a helpful book written by Sylvie's doctor Orrin Devinsky called “Epilepsy, a Patient and Family Guide,” but I had the idea that a comprehensive website about epilepsy and available therapies could synthesize still more experiences and might help our family and others like us.

Orrin Devinsky immediately grasped the potential of a dedicated information portal and community for epilepsy. He and his publisher generously contributed the contents of his book as a foundation for the site, and Orrin reached out for help from colleagues including Joyce Cramer and Steve Schachter and later Bob Fisher and Joe Sirven who individually over years and together in succession have helped to build epilepsy.com into a comprehensive resource for our community.

As Sylvie went from one therapy to the next without finding an answer for her seizures, I came to understand that perhaps, one-third of those with epilepsy similarly had no therapy that would control their seizures. I understood a bit more about epilepsy and the existing therapies, and I came to learn that for many, there were no satisfactory answers: many live with uncontrolled seizures, and many others live with unacceptable side-effects from their medicines. In recent decades, important progress has been made on side-effects and seizure control, even bringing seizure freedom for some few. These gains matter, but I was, nevertheless, shocked and upset to learn that progress against uncontrolled seizures has been so limited. Seizures in about one-third were uncontrolled fifty years ago, and seizures in about one-third continue to be uncontrolled today: a profound failure.

Sylvie, despite all of this and with amazing support from her brothers Jack and James and sister Sarah as well as her mom and grandparents, is a bright, energetic, friendly, and outgoing individual. We had to do more, and like many families facing serious medical challenges, we turned again to Sylvie's doctor Orrin Devinsky and supported research and care at NYU through the NYU-affiliated Finding a Cure for Epilepsy and Seizures (FACES). However, Orrin thought outside the box about how to invest to have further impact beyond the important work at NYU. Epilepsy is broadly underfunded and especially so the translation of research insights into new therapies. He

suggested that we should take a broad lens and support the best new therapy ideas we could find anywhere in the world. Thus, together with Orrin and a long list of amazing parents, friends, and professionals, I helped create the Epilepsy Therapy Project, an organization dedicated to “accelerating ideas into therapies for people living with epilepsy.”

Epilepsy Therapy Project has not worked alone. In addition to contributions from families affected by epilepsy and their friends, partnerships with other organizations focused on improving the lives of people with epilepsy have been critical to ETP's ability to fund new therapies and have impact. These include critical funding and support from the Milken Family Foundation, from NYU/FACES, and also from unrestricted educational grants from industry to support the development of content on epilepsy.com. However, our most important partnership has been our 50/50 funding of our New Therapy Grants program with EF.

Together with EF and with our other foundation partners, ETP has provided funding for 38 of the 85 therapies in active development for epilepsy identified now in the epilepsy pipeline. Epilepsy Therapy Project solely funded grants and investments bring the total impact to 45 of the 85. Most exciting is that in the last year, 3 of our EF/ETP funded projects have made it to patients: the Visualase MR guided laser system for epilepsy surgery; the SmartWatch seizure detection and caregiver notification device; and most recently, the non-invasive NeuroSigma eTns stimulator for control of seizures. The NeuroSigma device has been approved in Europe but not in the US. In the US, the regulatory approval path for devices currently overweighs the risk against the benefits of innovation and underweights the burden and human cost of the status quo. Currently, there are two clinically proven medical device therapies for people with uncontrolled epilepsy that have for too long been held hostage in the regulatory process.

After pursuing this successful partnership in funding new therapies together with EF for close to a decade, we saw an opportunity to create a single organization with greater economy and greater impact. Nonetheless, it was over lunch in late June, following the publication of the IOM report on epilepsy, and on the eve of the important first Partner's Against Mortality in Epilepsy Conference in Chicago, where those plans began to take shape. I sat down with Phil and his wife Jill Gattone to discuss a possible partnership between ETP and EF around our epilepsy.com website, respecting both the IOM's suggestions and the urgings of our ETP board. Phil and Jill's sincerity and dedication as parents and advocates were immediately evident. Phil made it clear that he was excited to pursue a partnership around our websites. However, he also indicated that he felt that our ETP mission of new therapies in a timeframe that matters was a natural extension of EF's focus on improving the lives of people with epilepsy and was interested in having a broader conversation. At ETP, partnership had always been a core value, and we recognized that we needed greater scale and reach to have more significant impact in our mission to accelerate new therapies. Partnership is embedded in Phil's DNA, and he brings a passion and capacity for leadership that I feel will be transformative for EF and ETP and the epilepsy community.

Phil's story

When my wife Jill and I put our son Philip to bed on April 10, 1991, we said goodnight to a four-year-old boy who seemed healthy in every way. When we found him in his bedroom the next morning, he was on the floor fully immersed in a generalized tonic-clonic seizure, his lips were blue, and his eyes were wide open and deviating to the left. Paramedics were unable to stop the seizure, which eventually ended an hour later in the local hospital emergency room, thanks to a heavy dose of medication, which caused respiratory arrest and left Philip in intensive care for a week.

The hospital staff informed us that, although Philip had a long seizure that resulted in status epilepticus, this may be the only seizure he would have, as 1 in 10 Americans will have a single seizure at some point in their lifetime. We took that hope with us, but we were

devastated when within only a few weeks, multiple seizures per day were occurring, and we were left with no path to take, no understanding with which to build a plan.

We read what little we could find in the library and sought advice from every doctor we knew of to get answers, but all the while Philip's epilepsy persisted, increasing both in frequency and severity. Within months, he began having atypical absence seizures and complex partial seizures that secondarily generalized. Philip eventually experienced hundreds of brief seizures each day, the source of the seizures causing him great difficulty with receptive and expressive language and an inability to process simple instructions and remember basic information. We were losing our son right before our eyes. Philip, who at age four had met all developmental milestones, at age five could not tell us he wanted to go play, could not understand us, and could no longer read the words we were so proud that he knew a year earlier. We were losing hope. Our anger and frustration at the destruction of his brain caused us to ask ourselves, “Where are the resources we need? Were we the only ones going through this excruciating experience of helplessly watching our child suffer so much pain?”

Our family, supporting us in every way, discovered an epilepsy parent support group, run by the Epilepsy Foundation. We attended our first meeting, where we met Jan Buelow, an epilepsy advanced practice nurse, who had volunteered her time to teach us about different seizure types. It was at this meeting that we learned that there were epilepsy centers – seven of them to be exact – right in our backyard in Chicago. We found more than a resource that night—we found hope in a group of parents who, like us, were not victims, but people determined to find answers, including a nurse clinician who cared enough to volunteer to teach.

Through a series of assessments at a local epilepsy center, Philip's epilepsy specialist, Michael Smith, MD, discovered that Philip's seizures appeared to be focused in one area of the brain. Dr. Smith developed a plan together with us that included trials of medication and diet therapy. After a year of unsuccessful attempts to control seizures, and with Philip's cognitive skills continuing to decline, we eventually made the heart-wrenching decision to have Philip undergo resective surgery, which along with medication, helped to better control Philip's seizures.

The lack of understanding during Philip's elementary and middle school years was evident, and education was certainly needed but not readily available. We knew that, although a few close friends were willing to learn about epilepsy, many were not prepared to accept our son. Stigma was obvious as Philip's friends stopped calling him to play and inviting him to their birthday parties. Philip thankfully has three siblings who all supported him through difficult times. Michael, Jonathan, and Rebecca have been impacted by epilepsy, watching as we attended to Philip's immediate needs, often at their expense. Their friendship toward their brother has been nothing short of inspirational.

Today, after many years of therapy, classroom aides, and meetings to discuss Philip's individualized education program, our son is not only talking again and understanding what we are saying to him, but he is also living independently. He was able to complete high school, and he graduated from college. He is married and employed. Despite the fact that he continues to have simple partial seizures, he is by all accounts one of the lucky ones. Jill and I have a motivation to serve based upon the belief that people with epilepsy shouldn't have to be lucky to find and receive good care.

Through it all, I have seen great people do amazing things for my son and for many others fighting epilepsy. I was privileged to lead the Chicago Epilepsy Foundation affiliate and witnessed how affiliates across the country help thousands of people every day to overcome the challenges created by seizure disorders. Our partners at the American Epilepsy Society and our support from the Centers for Disease Control and Prevention and the Health Resources and Services Administration have made it possible for us to reach more underserved populations than ever before. Despite all our efforts, it has become

abundantly clear to me as a father and as an advocate that the unmet need for epilepsy education, epilepsy awareness, research, and access to practical therapies that can help families is far too great to remain in its current state. In my new role as CEO of the Epilepsy Foundation, I am privileged to join with Warren Lammert and the Epilepsy Therapy Project team to change that. Our history of partnering together with ETP to fund new therapies provides a perfect backdrop to the development of a new platform for growth. Our merger will allow our nationwide network of affiliates to bring therapies directly to families in their communities in addition to providing much needed support for education, supportive care advocacy, and therapies. Our network of leaders, led by our Board Chair, Brien Smith, MD, is energized and prepared to move forward with this new and enhanced mission.

Trusting that this merger would be the right next step in the evolution of the Epilepsy Foundation was easy after meeting with Warren Lammert. Warren is an amazing leader, whose talent is matched by his impeccable reputation, passion, and integrity. Warren's experience as a father of a daughter living with epilepsy has created a visible passion and energy that all who know Warren find contagious. As the Co-founder of the Epilepsy Therapy Project and epilepsy.com with Orrin Devinsky, Warren and Orrin have helped to build the premier portal for consumers and professionals in the field of epilepsy. Having an opportunity to create a single website to help people find the epilepsy resources they need is incredibly exciting. It is an honor to work together with Warren, Executive Director, Kim Macher, and their staff and board members in this important endeavor. I believe that this merger offers a new sense of inspiration and optimism for all our stakeholders to know that the new Epilepsy Foundation is doing more to improve the lives of people with epilepsy and doing so in a more powerful way than ever before.

Together

We are exceedingly grateful for the work of epilepsy advocates, clinicians, researchers, caregivers, individuals with epilepsy, families, donors, and those in industry who every day make a difference fighting epilepsy and supporting other individuals and families with epilepsy. Our varied temperaments, talents, and convictions, although diverse, are called upon now in this challenging time—summoned for a common and noble purpose. That purpose is to serve together whenever we are able, knowing we can do better in our effort to support people with epilepsy.

It was that phrase – we can do better – that served as motivation for ETP and EF to come together to more effectively serve individuals and families fighting epilepsy. That sense of purpose along with our recognition of opportunities to gain efficiency and drive our missions with greater scale and a shared voice has transformed our vision of partnership.

Together we will work to build a platform, based upon partnership and new possibilities, to change the status quo, and to realign our priorities. We are honored to take part in the building of a new epilepsy community, and we value the work and missions of individuals, of families, and of our many other partner organizations, philanthropic, commercial, academic and public. Epilepsy Therapy Project and Epilepsy Foundation are merging in full – in a manner that respects the priorities and missions of the two organizations. In the end, we see that these are interlinked and mutually supportive. With others, we will hope as well to find similar linkages and opportunities for collaboration or even leveraging of infrastructure where it advances our missions and ability to serve people with epilepsy.

As the IOM Report clearly indicates, we must be efficient and recognize the links that exist interdependently between us. Moreover, we recognize that at the same time, we must also respect our distinct roles, capacities, and missions. Our interconnections – our links to each other – as well as our diversity and independence help provide the passion, the fuel, and the strength to achieve our goals and to meet the needs of individuals and families with epilepsy.

Our new epilepsy community leads the fight by first recognizing that the enemy is the common threat of epilepsy and its consequences—cognitive impairment, unemployment, stigma and misunderstanding, loneliness and isolation, seizures, side-effects, injury, and death. Our new Epilepsy Foundation takes its vision and values and uses them to build strategic partnerships. There is something incredibly exciting happening in the epilepsy community as was evidenced at the Partners Against Mortality in Epilepsy conference this past summer. We firmly believe that our merger provides a unique opportunity to create a new direction that will deliver sustainable support for our community to build capacity and make a meaningful difference. We respect diversity, competition, and individual missions, but we also believe that we are less divided and more united than anyone has given us credit for. If we have the intelligence and the courage to reach out and fight together, we believe that we will change the future for people with epilepsy. We celebrate that new beginning. We are stronger together.

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