



“ Believe you can and
you're halfway there. ”

- Theodore Roosevelt, our 26th President who had epilepsy

Thank you for joining us in the fight to END EPILEPSY.



**EPILEPSY
FOUNDATION®**
GREATER LOS ANGELES

REPORT 2011-2012

END-EPILEPSY®.org

Director's Message

Three weeks before my father passed away, my brother and I lay on either side of my father as he seized through the night. It gave me an even deeper respect for the courage of children and adults who live with epilepsy. They inspire and influence our purpose -- to lead the fight to END EPILEPSY.

When I wear my END EPILEPSY button, people ask me:

Why END EPILEPSY?

Because anyone can have a seizure at any time. Epilepsy affects about 60 million people, worldwide. Each year, about 50,000 people die early as a result of epilepsy. In our region, alone, almost 160,000 people have epilepsy and about 21,000 more are diagnosed each year.

What is END EPILEPSY?

For individuals, END EPILEPSY guides and inspires actions in a personal battle against epilepsy.

For our organization, it focuses our attention on care, advocacy, research and education.

For our community, it is about joining forces to promote awareness, combat ignorance, and advocate for more care and research for cures.

Thank you for joining the fight to END EPILEPSY,



Susan Pietsch-Escueta, MPH
Executive Director



with our staff team at Epilepsy Foundation of Greater Los Angeles

CARE - SPECIALTY

Epilepsy can dramatically alter a child's life. The outcome can be worse if the child cannot access specialty care or if care is delayed. There are too few pediatric neurology-epilepsy specialists in our region and this leads to long wait times, insufficient specialty treatments, and still no cures for the epilepsies. Thus, specialty care has become a focus area of our organization.

The vision was to raise significant funds to increase the number of doctors in pediatric neurology-epilepsy so that no child has to wait to see a specialist, to ensure access to more specialty treatments, such as dietary therapies and surgery for children with epilepsy, with a commitment to expand the treatment options as research in the epilepsy diseases are advanced.

Pediatric Dietary Therapy

A grant from our local Epilepsy Foundation, with help from The Charlie Foundation, supported the re-establishment of the Dietary Therapy Program at UCLA Mattel Children's Hospital, and committed a similar grant to USC/LA County/Rancho Medical Center.

Pediatric Epilepsy Surgery

Our support has strengthened the pediatric epilepsy surgery program at USC/LA County/Rancho Medical Center. Children who did not previously have the option of surgical treatment for epilepsy, now have that option.

Pediatric Epilepsy Fellows

Past and current commitments from our local Epilepsy Foundation support the training and work of nine pediatric epilepsy fellows or faculty. (continued on next page)



A BENEFIT TO **END EPILEPSY** IN CHILDREN

To address these great needs in our region and make these solutions a reality, it was clear something big had to be done. The parents of three children with epilepsy (Camille, Ari and Chloe) stepped up to the plate. Steve & Julie DesJardins with help from Mark Borman & Karen Hermelin and Andrew & Nicole Gumpert launched the first two fundraisers. Mark and Andrew and their wives and friends have continued to take this event to the next level

the last three years. Between 2006-2011, the five Benefits which have come to be called "Care and Cure - A Benefit to End Epilepsy in Children" have raised \$3.56 million gross.

The 2011 Care and Cure Benefit, co-chaired by Mark Borman and Andrew Gumpert, was held at the Beverly Wilshire Hotel on June 14th. The event's success was due in part to the support of Honoree Bryan Lourd, Managing Partner at Creative Arts Agency, and other entertainment industry leaders on our Honorary Committee -- Amy Pascal, Todd Black, Jason Blumenthal, Steve Tisch and Brad Weston.



Mark Borman, Brad Weston, Bryan Lourd and Andrew Gumpert

“END EPILEPSY is a commitment to specialty care while investing in cures.”



S. Hussain, UCLA



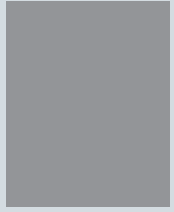
A. Partikian, USC



L. Rao, UCLA



N. Cobo, UCLA



TBN, CHLA



D. Millett, USC



J. Desai, CHLA



S. Javed-Ebeid, USC

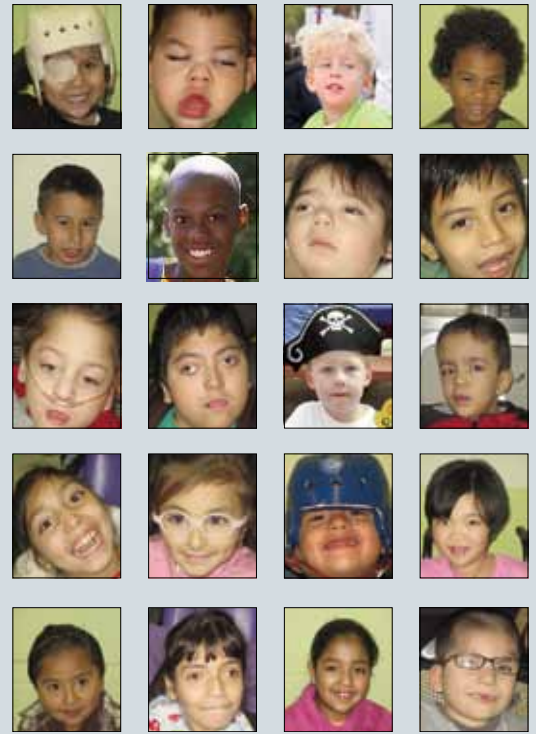


M. Porter, USC

Fellows (continued)

The Care and Cure Benefit makes its most direct, tangible impact in our community by supporting the training and work of pediatric neurology and epilepsy specialists, also known as our “Care and Cure Fellows or Faculty”, at major medical centers in our region -- Children’s Hospital of Los Angeles, Mattel Children’s Hospital at UCLA, and the USC/LA County/Rancho Medical Center.

As a result, more pediatric epilepsy fellows and faculty (left) are focused on providing specialty care for more children with epilepsy (right).

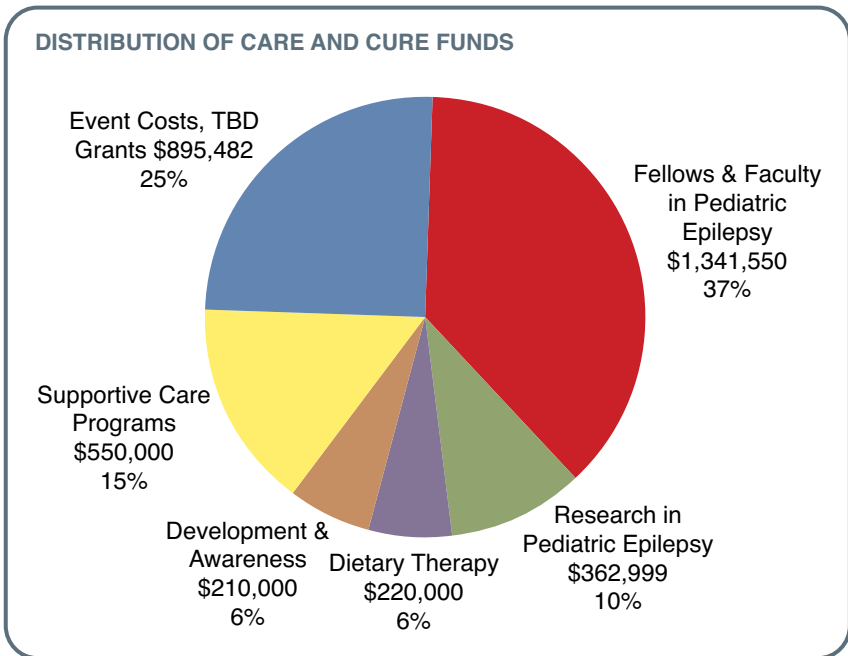


A few of the thousands of children with epilepsy who will benefit from specialty care

Distribution of Funds for Care and Cure Initiatives

All the Care and Cure Benefits, to-date, have raised almost 3.56 million dollars gross. As depicted in the chart below, these funds are supporting Care and Cure Initiatives in our region. As of 2011, grants have been given or commitments have been made to support nine fellows or faculty to optimize the care of children with epilepsy. Other grants have been provided or committed to establish two Pediatric Dietary Therapy Programs in our region. Other funds strengthen our supportive care programs (see Care-Supportive), support the awareness and growth agenda of the organization (see plans for 2012), and fund pediatric epilepsy research (see Research).

Your continued support for these important initiatives can make the world of difference to children with epilepsy. Join us in helping to ensure children receive faster specialty care and ongoing supportive care TODAY, and invest in research and hope for TOMORROW.



“ END EPILEPSY is about making a difference for children. ”

“END EPILEPSY is an empowering attitude that ensures epilepsy won't define you or your loved one.”

CARE - SUPPORTIVE

The story of Dylan and his parents is one of a thousand stories in our region. They speak to the need for more supportive care for families and individuals with epilepsy.

All our supportive care programs are designed to help combat isolation and connect families affected by epilepsy to each other and to information.

Supportive care is provided through our Helpline, Picnics and Holiday socials, and Camps and Retreats.



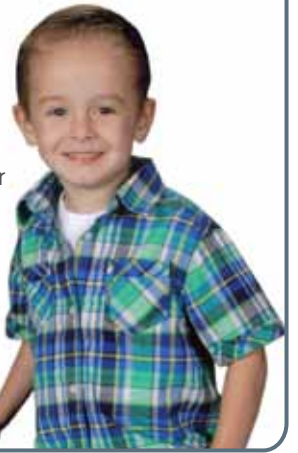
"March 27, 2010 started out as a typical Saturday night. Out of nowhere Dylan started making a weird noise and shaking in his highchair ... He was in full epileptic convulsion... For the longest two minutes of our lives we held his head, talking to him, praying this would stop. The fear of death washed over us ... The hospital had no answers ... There was no plan and we felt lost and alone.

The battle began ... My husband and I spent countless hours and sleepless nights researching ... which led us to finding the Epilepsy Foundation of Greater Los Angeles.

The first event I attended was their Epilepsy Brain Storm Summit in November 2010 ... The Summit was a huge eye opener and learning experience. I finally felt like there were others who understood ... and I finally got some explanations... It was a huge shock to see how bad it is for many ... and how little people know about it.

This is when I knew that I needed to start advocating to help other people like me who felt lost and alone. I have grown stronger and have a new mission in life - to help fight and find a cure. The 2011 Walk to End Epilepsy was our first time ever participating ... We didn't know anything about the epilepsy community before, but now that we are a part of it, we are going to make sure to spread the word and speak up!"

- Dylan's Mom and Captain of "Jones'n For a Cure" Team



“END EPILEPSY is about combating isolation and inaction.”

Camps and Retreats

While we had to discontinue our much loved Family Camp and our own Teen Retreat due to budgetary constraints, we are excited to still be able to host social outings and retreats for children and adults and partner with the other Epilepsy Foundations in California to offer a camp experience for children and teens near Yosemite.



Young Adult Retreat
Fourteen young adults joined us in Downtown Los Angeles on September 3-4. They took the metro to Universal City Walk, explored LA Live, went bowling, and socialized.



Adult Retreat
Twenty-four adults joined the Adults Retreat on March 13. They toured the Griffith Observatory, watched Love Letters, and dined at The Grove.



Camp Coelho
Nine adolescents, ranging from 9 to 15 years old, traveled to Yosemite Ridge to participate in this year's Camp Coelho and enjoy the great outdoors in and around Yosemite National Park.

“END EPILEPSY is a commitment to advocate and fight for awareness.”

ADVOCACY AND AWARENESS

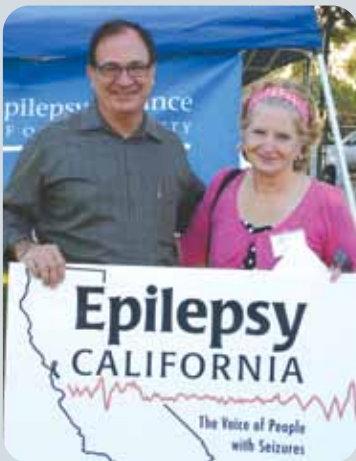
At its core, our organization is about advocacy and we are driven to promote understanding, fairness and access in order to create change and END EPILEPSY. Our advocacy and awareness efforts are closely linked. Through awareness we recruit new advocates and through our grassroots advocates we build awareness.

Epilepsy California, the grassroots arm of our organization, is the recognized, unified voice of almost 400,000 people with epilepsy in California, represented by people with epilepsy, family members, volunteers, medical professionals, and partners such as Epilepsy Alliance of Orange County.

Awareness campaigns strengthen our advocacy. In 2011, our Foundation launched its END EPILEPSY Campaign through Public Service Announcements, produced for TV and radio by Women In Film (WIF), a new website and expanded social media presence.



“END EPILEPSY is making sure your voices are heard.”

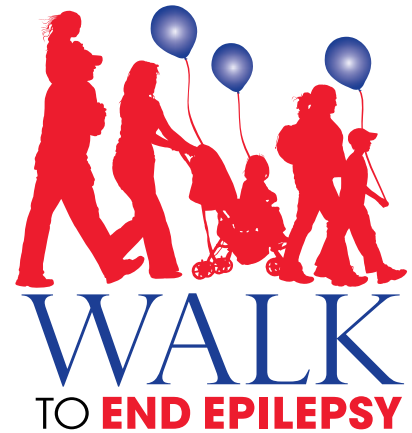


Successes of Epilepsy California in Sacramento

After nearly 3 years of tireless advocacy in Sacramento and California-wide, Governor Jerry Brown signed SB 161 (Senator Huff) into law on October 7, 2011. “This law will help to protect the lives of California children who require access to seizure rescue medication at school by authorizing volunteer, trained, non-medical personnel to administer emergency medication to students suffering from prolonged seizures.” said Ann Kinkor, Advocacy Coordinator for Epilepsy California.



Another success in Sacramento is the official designation of September as Students with Epilepsy Month Resolution (ACR 167), authored by Assembly Member Fiona Ma.



On a sunny Sunday in October 2011, the Epilepsy Foundation of Greater Los Angeles hosted its first ever Walk to End Epilepsy at the Rose Bowl Stadium in Pasadena, CA. The non-competitive 5K run/walk drew over 1,400 people and raised over \$160,000 in a much-needed show of support. This is a very important date and place to showcase support to END EPILEPSY.

The Walk provides a platform for the epilepsy community to increase awareness, raise money, strengthen advocacy skills, connect and encourage each other, and engage newcomers as advocates in the fight to END EPILEPSY.



RESEARCH

There are still no cures for the epilepsies. As a reflection of our commitment to research, our Epilepsy Foundation of Greater Los Angeles has been the largest affiliate sponsor of research for the past five years. In 2011, we donated \$33,300 to research projects funded through our national office. We also actively update our community about research advances, encourage them to participate in research studies in our region, and urge our members to advocate for more funding for research through the National Institutes of Health (NIH). We believe that everyone - not just scientists - has a role to play in accelerating research for cures.



Eduardo Pineda, one of our researchers

“END EPILEPSY is about research and hope.”

EDUCATION

Most people do not know about epilepsy even though it is the most common serious neurological disorder in the world, according to the World Health Organization. Our Foundation takes every opportunity to educate the newly diagnosed, school personnel, caregivers, and the general public about epilepsy and seizure first aid.

Epilepsy Brain Storm Summit

The annual Epilepsy Brain Storm Summit, an example of our Education programs, is typically a two-day regional conference (one day in English, one day in Spanish) held in November in Downtown Los Angeles. The purpose of the Summit is to provide individuals affected by epilepsy and their caregivers with the latest updates on epilepsy and related issues, workshops to discuss coping strategies for living with epilepsy, and a chance to explore community resources and a chance to meet others.

The 2010 Brain Storm Summit featured experts on diet therapies, fish oil therapy research, medication switching and side-effects, sudden unexplained death in epilepsy (SUDEP), and anti-seizure medications in development.



Save the Date for the next Summit
February 25-26, 2012



BRAIN STORM
SUMMIT

A REGIONAL CONFERENCE TO **END EPILEPSY**

10 Ways We Connect with Our Region

- 1. END EPILEPSY Helpline**
Our toll-free Helpline is open to those affected by epilepsy. New callers receive a packet (English or Spanish) with information, resources, a seizure alert bracelet (if requested), and event invites.
- 2. Social Media**
Less than a year after launching, our Facebook Page now has over 6,700 Fans and our Twitter has 1,600+ followers. Through these platforms, we reach and mobilize the epilepsy community and receive valuable feedback.
- 3. Community Presentations and Outreach**
In 2011, we conducted more than 33 trainings to educate over 1,200 people about seizure recognition, first aid and safety. These trainings to Veterans and in schools help quell myths about epilepsy and educate about seizure recognition and first aid.
- 4. Enews**
Our digital e-newsletter, full of news and media topics, research, advocacy alerts, inspiring stories, community resources, and Foundation updates, reaches 3,000+ homes monthly.
- 5. Scholarships (Saft Fund) and Emergency Help (Freedman Fund)**
Children and adults with epilepsy received camp/retreat scholarships from the Sitomer Memorial Fund and Lizzie Saft Fund, school/training scholarships from Lizzie Saft Fund, and families received assistance from Freedman Family Fund.
- 6. Partnerships**
Our community partnerships with Children Hospital Los Angeles, USC/LA County/Rancho Medical Center, UCLA Medical Center, West LA VA Medical Center, Art of Elysium, The Charlie Foundation and The Epilepsy Alliance of Orange County, and others help us expand our outreach and service.
- 7. Clinic Outreach**
Our team made close to 50 visits to neurology and epilepsy clinics as part of our outreach to epilepsy patients in our region.
- 8. Regular Events**
We host monthly Second Saturday Seminars and End Epilepsy Groups, seasonal events, such as the Picnic and Holiday Party, which altogether provide supportive and therapeutic services for hundreds of individuals affected by epilepsy.
- 9. Brian Alan Sitomer Memorial Resource Center**
This web-based and physical Resource Center provides referral, information and resources. The Center was established with support from Steve Sitomer in memory of his son, Brian Alan.
- 10. You.** We are here to support your efforts to speak up.
When YOU speak up, one more person knows epilepsy. Your example inspires others to join the fight to END EPILEPSY.

“END EPILEPSY is about pursuing freedom from seizures.”

OUR PLANS

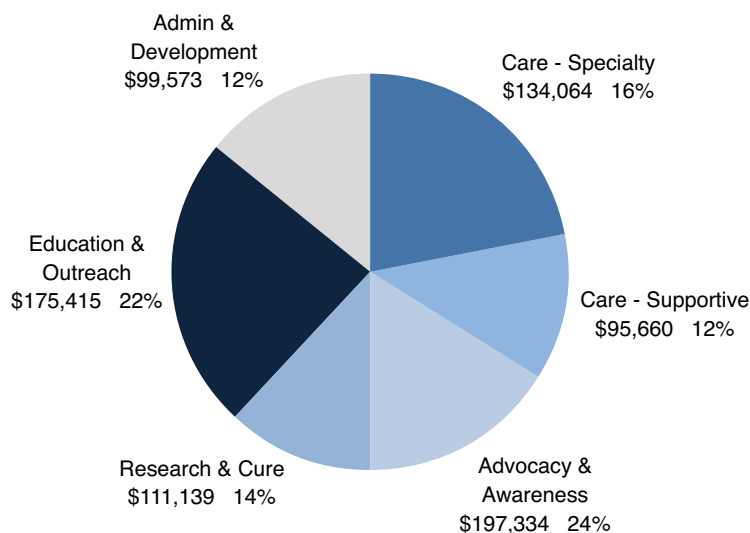
The Epilepsy Foundation of Greater Los Angeles is expanding our awareness and outreach efforts to reflect our seriousness about END EPILEPSY. Here are some examples of what you can expect from us.

- Maintain and improve our supportive programs - for children, teens, families, adults, and siblings - to connect you to us, to each other, and inspire others to join the fight.
- Continue to provide bring rich, meaningful opportunities to learn (Summit, Second Saturday Seminars, webinars) and improve access to care (Care and Cure),
- Conduct trainings so your school personnel know how to respond to seizures and better understand the impact of epilepsy and treatments on children
- Partner with others in our community to expand our reach
- Create opportunities for YOU to start your own fundraisers and awareness events
- Increase our media and public relations efforts - staying engaged with you, more than ever, with our enews, facebook, twitter, youtube, etc
- Share opportunities for advocacy and for participating in research with you.
- Literally and figuratively "run" Greater Los Angeles year-round, through both the Marathon and our Walk to END EPILEPSY.

This and more you can expect from us.

The Epilepsy Foundation of Greater Los Angeles
is raising money to END EPILEPSY.

DISTRIBUTION OF EXPENSES



Most of our overhead costs are covered by our Garnier Trust Fund, so most of your donation supports programs and services. Our audited financial statement can be viewed at END-EPILEPSY.org

BOARD OF TRUSTEES

Executive Committee

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Mark Borman, Vice President
Earl Feldhorn, Treasurer
Brad Boyer, Secretary
Andrew Gumpert, Member at Large

Members

Hillary Booth
Matthew Howley
Christianne Heck
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President's Message

On behalf of the Trustees, thank you for joining the fight to END EPILEPSY. Our own experiences, as parents of a son with epilepsy, and the other stories in this report convey why we must fight.

So, how do we END EPILEPSY?

While we may rush to think this is only about "cures," which can only be done by doctors and researchers, END EPILEPSY also encompasses the collective role that each one of us plays as members of the epilepsy community and the general public.

As more and more of us learn more, volunteer, donate and speak up -- even more people will learn about epilepsy and be made aware of the need. As a result, more money will be allocated for epilepsy, more doctors will devote their lives to epilepsy specialty care, more researchers will focus on cures, more supportive services will be available, and the public's conversation about epilepsy will change from misunderstanding to understanding. All of this is critical to achieve our goal.

Thank you for your past, current and future generosity and participation, and please invite others to join you in our fight to END EPILEPSY.

Steve Baum
President

“END EPILEPSY is an attitude, action and aspiration. END EPILEPSY is how we approach today and how we view the future.”

“Getting involved with the Walk to End Epilepsy has taken away some of the feeling of helplessness. It was amazing to see the outpouring of support that we received from our friends and extended family. The Walk was almost exactly one year from the date of Josie’s diagnosis. The Walk was a way to tell more people about Josie’s epilepsy and when we did we found out others were dealing with the same issues among their friends or other family members! Finally the statistics of 1 in 10 and 1 in 100 made sense. Having no control over this mysterious disease, we felt the Walk was one way for us to fight back!”

- Josie’s Mom and Captain of “Team Wolfpack”



“ END EPILEPSY is about what you define ... ”

THANK YOU

The Epilepsy Foundation of Greater Los Angeles would like to acknowledge and thank all our donors and sponsors – those named here and many others. Your generosity and participation make our programs and initiatives possible.

Our Special Initiatives

PSAs for TV and radio - Women In Film
Social Media - Resnick Family Foundation
Dietary Therapy Program - The Charlie Foundation
Outreach to Veterans - West LA VA Medical Center

Our Care and Cure Sponsors

Escape Artists
Steve Tisch Family Foundation
Earl I. Feldhorn/Wedbusch Securities
Ivory Investment Management, L.P.
Rosenthal Family Foundation
Sony Pictures

Our Walk to End Epilepsy Teams and Sponsors

Our Programs Donors and Supporters

The Art of Elysium
Cyberonics
Lundbeck
Lawrence M. Daley Children’s Foundation
The Freedman Family Fund
Thomas and Dorothy Leavey Foundation
LA DWP Employees’ Association
The Milken Foundation
Lizzie Saft Fund
Sidney Stern Memorial Fund
Brian Alan Sitomer Memorial Fund
J.B. and Emily Van Nuys’ Charities
UCB, Inc.

GET INVOLVED!

We told you what END EPILEPSY means to us and a few of our friends and supporters. Now, it’s your turn to tell us how you want to fight to END EPILEPSY. Here are a few ideas:

- Speak up and advocate
- Attend our events and connect with others
- Volunteer and help spread awareness
- Sponsor events
- Request a seizure first aid presentation
- Donate
- Conduct your own fundraiser
- Learn more about epilepsy