



The Candlelighter

Education • Information • Research
Support • Advocacy

Serving individuals and families affected by epilepsy since 1953

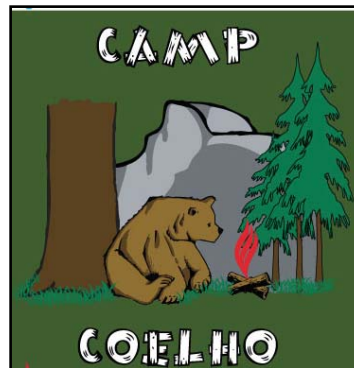
Camp Coelho 2008!

The third year of Camp Coelho in Yosemite was amazing! This year we raised enough funds for 35 campers to attend from all over California. The weather was perfect for the activities which included: archery, a ropes course and rock wall, Geocaching (a scavenger hunt with GPS units), swimming, a visit from a service dog, and more!

Besides having fun, campers were able to learn more about epilepsy and build their confidence and independence. Camp is such a unique experience that enables these children to meet others who have epilepsy, just like them.

A tremendous thank you to our medical staff who all did an excellent job and without whom camp would not be possible!

If you are interested in donating for camp in 2009 please see pg. 5 and keep an eye on our website for 2009 dates!



Camp would not have been possible without our incredible staff. A special thank you to:

Dr. Joe Sullivan, Dr. Rosemary Vega, Dr. Rachel Kuperman, Dr. David King-Stephens, Maritza Lopez, R.N., Cheryl Lockhart, R.N., Beverly Wilson, R.N., Yosemite Ridge, Brian Bieller, Dion Wells, Janey Michaelsen, Robert Rosetti, and Jennifer Sweeney!

What the campers say:

- “This was really fun. I hope it will be just as fun next year.”
- “I enjoyed having fun and I will always remember that having fun is always the first rule.”
- In answer to what could be changed:
 - “Make it longer!”
 - “I don’t think I would change anything. It was hecka fun.”

From a parent:

- “I’m so glad [my son] had the opportunity to go to this camp! He is more comfortable going places now, and doesn’t feel so awkward about his “diagnosis.” He wants to now participate in our local teen epilepsy activities (he wanted to shy away from everything before.)”

Thank you!
Thank you!
Thank you!

Executive Director's Note



I am proud to be associated with the Epilepsy Foundation of Northern California. Our continual expansion of programs and increased community presence is attributable to you. Thank you for attending our conferences, support groups, fundraising events, or for writing

letters to your legislators, sponsoring children to attend camp, and for being involved, even if involvement solely consists of reading this newsletter.

EFNC continues to expand our presence in the policy arena. SB 1394 is a legislative bill sponsored by the Epilepsy Foundation and aims to modify the mandatory physician reporting law for Lapses of Consciousness. Last February, EFNC, in partnership with the Los Angeles and San Diego County Epilepsy Foundations and Children's Hospital Los Angeles, hosted the 2008 Epilepsy State Forum in Sacramento. This was the first epilepsy State Forum since 1992 and provided the opportunity for various stakeholders to meet in-person to discuss existing barriers to care and to collaborate in identifying potential solutions.

Although Camp Coelho 2008 has just ended we have already begun raising funds for next year. Did you know that if each of the 140,000 people living with epilepsy in Northern California donated \$1 to the Foundation we could pay for Camp Coelho for 3 years?! It is a perfect example of 'every little bit helps.' As I often say – curing Epilepsy is possible, please continue to battle with us.

Neva Hirschhorn

Shining Stars

At the Epilepsy Foundation of Northern California we know that kids with epilepsy are special, in fact we think they're Shining Stars! The Shining Stars program recognizes all kids with epilepsy and encourages them to maintain communication by participating in this special program.

If you know a Shining Star.... Why not make it official and send in an application to be named a Shining Star! For more information contact Veronica at veronicaz@epilepsynorcal.org.



Thank You - Key Donors 2007

President's Circle

Abbott Neuroscience
Lane Auten
Community Health Charities
Epilepsy Foundation
GlaxoSmithKline
Heidi E. Kirsch, M.D. and Louis Green – Green Charitable Foundation
UCB Inc.
Yosemite Ridge

Benefactors

Cyberonics, Inc.
Melissa Lozano
PACE (Parents Against Childhood Epilepsy)
Shire US, Inc.
Valeant Pharmaceuticals International

Patrons

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Impax Pharmaceuticals
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Sutter Neuroscience Institute
University of California, Davis
University of California, San Francisco
Chuck and Beverly Wilson - Linear Options, Inc.

As of November 2007



Fundraising Can Start at Age 1!



Caley was born on her actual due date March 22, 2007. She was born healthy and we lived a completely normal life as new parents for the first 6 weeks of her life. In May 2007, our lives were turned upside down. Caley displayed an unusual twitch of her right arm. Then she did it again about 15 minutes later. I called the hospital and we took our first of many trips to the emergency room. Caley continued to have seizures while being examined. The doctors loaded her up on Phenobarbital and admitted her into the hospital. The good news was while on heavy doses of Phenobarbital in the hospital, she went a week without another seizure. The doctors discharged us still not knowing the cause of the seizures. In addition to discharge papers we were given the option of getting Caley off the Phenobarbital hoping the seizures were just a random thing. We went home and started the process of weaning her off the drug. After the half-life wore off on the drug, her seizures reappeared more frequent and more intense.

Since then we have been admitted to the hospital a dozen times. We have been to different medical facilities, heard different opinions, have had all of the tests done, dozens of EEG's, and along the way managed to get Caley loaded up on six different anti-seizure medications all in the first year of her life. Even on all six of the drugs, Caley continued to have breakthrough seizures daily. The MRI's and other tests did not show anything out of the ordinary that would be causing her seizure activity. For now Caley has been diagnosed with intractable epilepsy.

Caley is significantly delayed in her development. On top of that she has vision impairment issues caused from the seizure activity. We have formed what we call "Team Caley". It consists of a huge, close, supportive and loving family, five different therapists, many different sub specialty doctors, a great neurologist and a dietician. Everyone is working so hard to make Caley the best Caley that she can be!

We recently got Caley on the Ketogenic Diet.

We have seen a difference in her seizure frequency and intensity. Although she still has a couple seizures a day, Caley is doing better and making progress in so many ways! We have got her down to four medications and our goal is to get her off as many meds as possible so she has a chance to develop without the side effects of the medications interfering.

We continue to have faith and hope that Caley will see someday and she will learn to sit up or crawl or even walk on her own! I have had to rewrite my "hope book" for Caley and learn that the smallest improvement and any progress is a gift and a sign of hope.

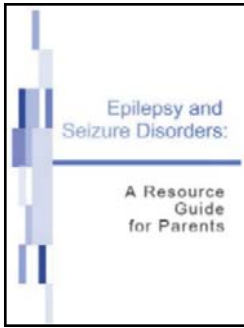
Caley's 1st birthday party was wonderful! So many people came out to celebrate her. Some have never even met her but made the trip out to catch a glimpse of her beautiful face and get to know her divine personality. We were very touched and taken back by everyone's love and support for Caley and for us.

-Beth Brown

In lieu of gifts the Brown family collected donations for Caley's 1st birthday and raised over \$3,000 for the Foundation! Many thanks to the Brown family, extended family, and friends for their generosity. **Thank you also to our other generous contributors who show support throughout the year. This is just one example of what fundraising can do.**

The donations will help fund our programs & services to better serve our community.





Parent Resource Guide

This guide was written with parents in mind. Inside, parents will find basic information, school forms, California specific resources, & a variety of other helpful tools & information. Download or order online at epilepsynorcal.org.

Meet Our Newest Staff Members!



Verónica Zárate
Administrative Assistant

Veronica began working in April 2008 and comes to us all the way from Ecuador! She is fluent in Spanish and is helping the Foundation reach out to the Latino community as well as updating the website and translating our most used brochures.



Stephanie Eistetter
Manager of Programs and Services

Stephanie has been with the Foundation since September 2007 and just successfully completed her first year as Director of Camp Coelho! She also works on the HOPE program, support groups, and the new Summer Social Series.

Did you know?

The Epilepsy Foundation of Northern California is a working partner of the national Epilepsy Foundation, yet each organization is independently supported by community gifts. A gift to the Epilepsy Foundation in Landover, Maryland is used for national projects. *Your gift to the Epilepsy Foundation of Northern California remains in our region and is used for local services.*

The Epilepsy Foundation of Northern California is a 501(c)3 charity, Federal Tax ID 94-6128891

In Memoriam

The following friends and volunteers of the Foundation will be greatly missed:

Divana Almora	Nancy Manning
Steve Barry	Mary Haxo Mansell
Wei-Jan Hsu Chang	Roy Mespelt
Daniel Coates	Jordan Nelson
Sophie Cvitanich	Robert Anthony Silva
Ernest DeBose	
Vivian Garcia	
Donna Lynn	

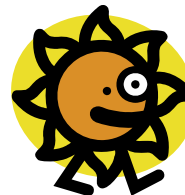
We Need Support Group Leaders!

If you're interested in starting a support group in your area, please contact Stephanie at stephaniee@epilepsynorcal.org or 800-632-3532. Groups can be open to all or focus on a certain population such as parents or teens.

For a list of existing support groups, please see the last page.

Summer Social Series

In an effort to get families and individuals together we would like to announce the 1st Annual Summer Social Series!



Series #1: Oakland A's vs. Texas Rangers

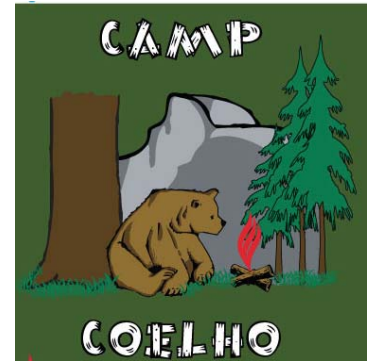
Date: Friday, Sept. 12
7:05 pm

Series #2: Fresno

For more information contact Stephanie at stephaniee@epilepsynorcal.org or 800-632-3532.

Please Help Us Open the Doors....

Camp is not possible without the generous support of our community. Your donation will help underwrite camp and will fund scholarships to give more children the opportunity to participate. The goals of Camp Coelho include gaining independence, building self-esteem, promoting self-confidence, and improving social interaction. With your help, and the support of your friends, we can open the doors to a new outlook on life.



Camp Coelho is the most important program offered by the Epilepsy Foundation of Northern California. Camp takes place in Yosemite National Park and for every camper that attends, we must raise \$750.00. In all, we need to collect more than \$50,000. Please consider donating and know that your gift will impact a child's life forever. We appreciate your contribution.



Sponsor a Child for Camp Coelho

It is my wish to sponsor _____ Child/Children:

- _____ x \$107 One Day
- _____ x \$ 375 Half Camp Session
- _____ x \$750 Full Session



Name

Address

Phone

Visa American Express

Master Card Discover

Check Enclosed

Card Number Exp Date

Signature

In partnership with Yosemite Ridge



Candlelight Gala 2007

Last November, Dr. Martha Morrell, Chief Medical Officer of NeuroPace, and Clinical Professor of



Neurology at Stanford University was honored with the Commitment to Progress Award. Dr. Morrell is an internationally recognized epileptologist and continues to impact the epilepsy community both locally and nationally.

Greg Mortenson, co-author of *Three Cups of Tea*, served as our keynote speaker and captivated the audience with his story of building schools for women and children in South Asia. Mortenson's sister experienced seizures and we were honored to have him share his story.

Save the Date! Candlelight Gala 2008

This year our featured keynote speaker will be Andy Grove, former Board Chairman and Co-founder of Intel Corporation. We will also honor Dr. Warwick J. Peacock, Professor Emeritus of Pediatric Neurological Surgery at UCSF, with our Commitment to Progress Award.

Join us for this year's Gala on Friday, November 14th, once again at the world famous Intercontinental Mark Hopkins Hotel in San Francisco! To become a sponsor or donate an auction item please contact Neva Hirschhorn at 800-632-3532 or nevah@epilepsynorcal.org



EPGP

The Epilepsy Phenome Genome Project

The Epilepsy Phenome Genome Project (www.epgp.org) is the largest study ever created to identify genes that influence the development of epilepsy and genes that affect the response to treatment. Drs. Daniel Lowenstein, Heidi Kirsch, Brian Alldredge, and Paul Garcia at University of California, San Francisco are collaborating with clinicians at 12 other major epilepsy centers around the United States on this project. The goal is to understand what causes epilepsy, which treatment will be effective, and why some families have multiple relatives with seizures.

Participation involves donating a blood sample and answering questionnaires. Participants will receive a \$25 gift card, and are not required to come to UCSF.

EPGP is looking for two types of participants:

1. People who have been diagnosed with epilepsy, **and also have a brother or sister with epilepsy.**
2. People who have been diagnosed with one of several types of rare epilepsy and both biological parents are willing to participate. These types of epilepsies include seizures due to: Infantile Spasms, Lennox-Gastaut Syndrome, Polymicrogyria, or Periventricular Nodular Heterotopia.

If you would like more information about the project please contact:

Maritza Lopez, RN
Toll-free Phone: 1-888-279-EPGP

E-mail: info@epgp.org
Website: www.epgp.org

The RAMPART Trial

Emergency Medicine Physicians and Neurologists at San Francisco General Hospital and Stanford are conducting a research study to determine the best treatment for a prolonged seizure called status epilepticus. The study will include San Mateo, Santa Clara, & San Francisco counties.

The GOAL of this study is to find out if giving one medication (midazolam) in the muscle works as well as giving another medication (lorazepam) in the vein.

THE PROBLEM: 1) Eligible patients are unconscious and are therefore unable to give consent (permission) to participate in the study. 2) The study medication must be given very rapidly as this condition is a medical emergency.

THE SOLUTION: “Exception from Informed Consent” – this means that due to their illness, patients will not be able to give their permission or consent before being enrolled in the study. Because this involves a medical emergency, there is also not time to explain the study and obtain consent before study treatment. In order to conduct a study using “Exception from Informed Consent”, the State of California and the Federal Government regulations require that we discuss the study with the community to allow groups and individuals to ask questions and to determine if there is community support. Patients and/or their families will be notified and informed about the study after their arrival to the hospital by ambulance.

For more information about this study, contact Michele Meeker, RN, BSN at meekerm@neurosurg.ucsf.edu or by phone at 415-206-3220. OPT OUT BRACELETS WILL BE AVAILABLE FOR THOSE WHO DO NOT WISH TO PARTICIPATE. Please see the UCSF Committee on Human Research (CHR) web page at www.ucsf.edu/ora/chr for information on protection of human subjects. This site provides links to the FDA web site as well. You can also call the CHR at 415-476-1814.

This study is being funded by the National Institutes of Health through the Neurological Emergencies Treatment Trials Network (NETT)
www.nett.umich.edu/nett/community_members

Stroll for Epilepsy 2008!



The 16th Annual Stroll for Epilepsy was held on Saturday, May 17th, at Six Flags Discovery Kingdom in Vallejo. Nearly \$55,000 was raised by over 300 participants. Surpassing her record from last year, Melissa Lozano and Mission Michaela raised \$7,525 followed closely by Aimee Rubio and Aiden's Amazing 'E' Team and Nikki Farris with Amazing Grace. A great time was had by all!

Thank you to all of our participants and volunteers for promoting epilepsy awareness, raising funds, and walking for this shared cause. We hope to see all of you and more next year!

Expressions of Courage® Art Contest!

Who: Everyone!

What: Annual art contest sponsored by Ortho-McNeill

When: Deadline is August 29, 2008

Why: Allows people with epilepsy to showcase their talents and their perspectives of the world around them through art. In addition, the contest is designed to raise awareness and help eliminate the stigma of epilepsy.



To learn more about *Expressions of Courage*, please visit www.expressionsofcourage.com. Feel free to direct contest questions to the Contest Help Line at 800-224-4935 or contact our office.

Calendar of Events

Living With Epilepsy Conference
November 1, 2008
San Francisco

Taking Charge of Epilepsy
Conference
Pacific Epilepsy Program
November 8, 2008
Castro Valley

Candlelight Gala Dinner
November 14, 2008
San Francisco

Sacramento Epilepsy Update
Sutter Neurosciences Institute
*Check website for updates

People With Disabilities Fdtn.
Social Security Information
December 2008

17th Stroll For Epilepsy
May 2009
Vallejo, CA

Camp Coelho
June 2009

Active Support Groups

Please check our website for updates

Monterey, CA

1st Tuesday, 6:00 – 7:30 PM
Comm. Hospital of the
Monterey Peninsula
23625 Holman Hwy, Classroom 3
Monterey, CA 93940

Grass Valley

2nd Tuesday, 6:00 – 8:00 PM
FREED-Ctr. for Independent Living
154 Hughes Rd., Grass Valley

Sacramento

3rd Tuesday, 6:00 – 8:00 PM
Sutter Hospital-Conf. Room C
2801 L Street, Sacramento

San Francisco

3rd Wednesday, 7:00 – 9:00 PM
California Pacific Medical Center
Pacific Campus
Enright Room
2333 Buchanan Street,
San Francisco

Santa Cruz

Contact Phone: (831) 475-9110, to
verify times & location of upcoming
meetings.
Website: www.epilepsynetwork.org.

Mountain View

1st Thursday, 7:30 – 9:00 PM
El Camino Hospital Group,
YMCA Bldg. Basement Mtg. Room K
2500 Grant Road, Mountain View

Redding

Rowell Family Empowerment
at (877) 277-3471 to verify times &
location of upcoming meetings.

Vacaville

4th Wednesday, 6:00 – 7:30 PM
Vaca Valley Health Plaza
Annex Building
1010 Nut Tree Rd. Suite 290

Sonoma

2nd Tuesday, 6:30 – 8:00 PM
Sonoma Valley Hospital
347 Andrieux St., Central Conf. Rm
Sonoma, Ca 95476
First Meeting: August 12, 2008

Sonora

2nd Tuesday 6:00 – 7:30 PM
Sonora Regional Medical Center
1000 Greenley Road, Conf. Rm #3
Sonora, CA 95370



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www.epilepsynorcal.org

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