



**Epilepsy Support Network**  
of Orange County

# REACHING OUT

**ESNOC NOVEMBER 2012**



THE ADULT EDUCATIONAL SUPPORT GROUP IS COMMITTED TO LEARNING AND MAKING CONNECTIONS.

ESNOC's Facilitators, Jim and Joan Ashlock, along with many of our active adult members brainstormed on how we could better serve the needs of adults with epilepsy. The adult focus group from May's meeting reported a strong interest in epilepsy specific education, such as: neuropsychology, endocrinology, sleep medicine, employment, financial planning, medical insurance, independent living, recreation and transportation.

ESNOC is appreciative of our member's investment of their time and input so that we may bring the desired epilepsy specific information and knowledge necessary to better control seizures and improve the quality of life for all attendees.

Orange County Transportation Authority (OCTA) – ACCESS Service is a shared-ride paratransit service that is available to qualified applicants whose physical or cognitive limitations prevent them from utilizing OCTA's regular fixed route bus service.

An Eligibility Contractor 714-560-5956, ext 2, will schedule and make transportation arrangements for your in-person assessment.

If you are a member who has difficulty navigating the regular bus system because you become confused, anxious or experience memory issues due to uncontrolled seizures, emphasize these barriers during your assessment. We want you to be active, independent and seizure free as you travel to your destinations. Remember, if declined, you have 60 days to make an appeal.

Call 714-916-0456 for more information.

June's Adult Educational Support Group presented Dr. Valeh Karimkhani, D.O. to a roomful of attentive listeners. Dr. Ks informal discussion on the issues Is Anxiety or Depression Affecting Your Life? is always a concern when considering Quality of Life (QOL) issues for adults with epilepsy

## THANK YOU

ESNOC is proud to highlight these outstanding members in our network...



The CHOC Children's Comprehensive Epilepsy Program achieved recognition by the National Association of Epilepsy Centers (NAEC) as a Level 4 epilepsy center. Level 4 epilepsy centers are recognized for having the professional expertise and facilities to provide the highest level of medical and surgical evaluation and treatment for patients with complex epilepsy. CHOC is the only free-standing children's hospital in California to be named a Level 4 epilepsy center.

### GRANTS AT WORK

#### Seizure Recognition & First Aid Presentations

Most people can identify tonic clonic (convulsive) movements, as seizure activity. Less familiar are the many other pediatric and non-convulsive seizures that aren't so obvious. ESNOC is raising awareness and advocating for children in schools and adults in the workplace, through our no-cost Seizure Recognition & First Aid community presentations.

#### EWOC raised 94K!

##### Top Five Fundraisers

Marena Flores  
Maddy Weizoerick  
Kaylyn Clemons  
Joan and Jim Ashlock  
Heidi and Vince Bester



##### Champion Corporate Sponsors

Allen and Suzanne Duemey  
CHOC, Children's Neuroscience Institute

##### Accepting sponsors for May 18, 2013!

##### Third Party Fundraisers

Swiss Restaurant and Bar, Santa Maria  
Kiwanis International, Huntington Beach  
Colby and Emma Marsh, Lemonade Stand  
Renee Burke, Support Group Raffles

##### Grants and Program Donations

Disney VolunTEARS Community Fund  
North Yorba Linda Mom's Club  
Kiwanas of HB  
Lundbeck

Second year recipients of the Disney VolunTEARS Community Fund grant supporting our outstanding Community Education Programs.

The goal of this presentation is to raise awareness about epilepsy by teaching attendees how to identify seizures so they can quickly and confidently administer first aid. With the assistance of our seizure medical mannequin, Walt, we can demonstrate first aid for a seizure. Our presenter explains the importance of getting immediate medical care for a person

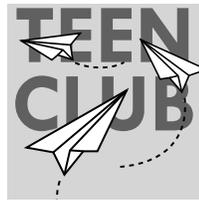


Epilepsy Support Network of Orange County is making the most of our time with the children in our Friday Friends Club

and the teenagers in the Teen Club.

Our experienced special needs child care staff, Temre Marsh and Jackie Wilson are paying close attention to what the Director of Psychiatry at CHOC, Hoang D. Nguyen, M.D., emphasized in the July Parents Educational Support Group meeting, "The significance of early friendships can greatly reduce anxiety and depression in children and teens."

We foster an evening filled with fun, laughter and bonding friendships. As part of our Friday Friends Club program, we develop monthly PLAY schedules designed to address the developmental and social needs of your children. Parents are encouraged to discuss any needed support by Temre and Jackie. Or ask questions regarding their child's developmental and social strengths during their stay in the Friday Friends Club.



We want our teens to soar so we offer this social skills group for moderately to mildly affected teens with epilepsy, 13-18 years, who would benefit from social skills instruction.

The goal of this program is to allow teens to practice and build on their social skills in a safe and supportive environment while our facilitator monitors the members for signs of anxiety and/or depression, the most common comorbidities for teens with epilepsy. We invite typical teens to participate in the club for appropriate social modeling. The teens participate in fun activities while focusing on issues such as: Self Awareness and Esteem issues, Building and Sustaining Friendships, Social Planning and Social Responsibility.

Our facilitator, Jennifer Leath is a Psy.D, Doctor of Psychology. This is an applied clinical doctorate degree that is one of the highest-level degrees available in the field of psychology.

In 2013 we will offer off-site activities for the teens to participate in, so they may strengthen the skills learned in this program.

GRANTS AT WORK – continued

experiencing a first time seizure. We provide sensitivity training for attendees to foster compassion toward parents, children, teens, adults and families who are facing an epilepsy diagnosis and especially for the 30-40% who continue to have seizures despite treatment.

As part of a Back-to-School campaign, we invited all Orange County School Districts



to schedule a SR&FA presentation for their teachers, health aides, nurses and staff. We would like parents to combine efforts with us. Visit our website for a link to the SR&FA letter to down-

load, print, or email asking your child/children's school principal or nurse to contact us for this effective, no cost presentation.

For more information, contact Janna Moore, MPA, [srfa@EpilepsySupportNet.org](mailto:srfa@EpilepsySupportNet.org) or call 714-916-0456.

"Do not let what you cannot do interfere with what you can do." - John Wooden



**Priorities In Pediatric Epilepsy Care: Changing Childrens Futures Today**

Sponsored by CURE and Ann & Robert H. Lurie Children's Hospital of Chicago

Janna Moore and Tracy Salazar attended the CURE-sponsored Pediatric Epilepsy Research Consortium (PERC) meeting in Chicago, October 22-24. The entire focus of PERC is to determine how we can improve pediatric patient care by focusing on what is most beneficial to patients and families. In order to change patient care, we must provide the necessary research and data that will get doctors to change the way they practice medicine. This exciting new coalition is

poised to make changes in the unstandardized care of newly diagnosed 0-3 pediatric patients with epilepsy.

Janna and Tracy spoke on behalf of our parents bringing knowledge of what many families go through during diagnosis and treatment. Earlier, accurate diagnosis and treatments are critical for best possible outcomes. Committee members attending the meeting were very interested in our unique and well attended programs. The meeting organizers were very appreciative of ESNOOC for sending out a representative to speak on behalf of parents.

**Eisai Epilepsy Medicine Wins U.S. Approval for Seizures**

Bloomberg Businessweek

Results from three clinical trials show improvement in seizure control in patients taking perampnol, to be known as Fycompa, the agency said in its statement. Among the

side effects were dizziness, tiredness, irritability, headaches and falls, according to results from a late-stage clinical trial released in April 2011. "Some people with epilepsy do not achieve satisfactory seizure control from treatments they are currently using," said Russell Katz, director of the Division of Neurology Products in the FDA's Center for Drug Evaluation and Research. "It is important to have a variety of treatment options available for patients with epilepsy."

**CHOC Children's Mission Hospital** now has 4 monitoring beds! This is an added convenience for those in South county.

**The American Epilepsy Society's Annual Meeting**

is the premiere meeting for epilepsy and other seizure disorders. The Annual Meeting is an international forum for the exchange of current findings in epilepsy research. ESNOOC Board of Director, Dr. Tracy Salazar will be reporting on the topics discussed at the American Epilepsy Society (AES) annual conference for our January 11, 2013 Educational meeting.

**MISSION STATEMENT** | Epilepsy Support Network of Orange County is a 501(c)(3) non-profit organization committed to building a community of support to improve the lives of those affected by epilepsy through education, support, and advocacy.

# CALENDAR

## Epilepsy Awareness Month

Nov 1 | **Lennox Gstaux Syndrome Awareness Day**

Nov 9 | **Friday, 6-8:45 pm**

**Emotional Support for Parents**, led by Phyllis Larkin, PsyD, she will help you put a positive spin on our emotional triggers.

**Talk with the Docs**, Three Epilepsy Hospitals in one place, this night. This open forum will allow attendees an opportunity to ask questions and get answers on the spot.

**Teen Club**, Jennifer Leath, PsyD will be back from maternity leave.

**Friday Friends Club**, Thanksgiving Celebration, 6-8:45 pm, ages 1-12 years

Dec 14 | **Friday, 6-9 pm**

**Holiday Party**, join us at First Presbyterian Church. 7702 Westminster Bl, Westminster/Beach Blvd. Reservations are required.

## 2012 Calendar 2nd Friday/Month

Meeting location:

### HOAG Hospital, Irvine

16200 Sand Canyon Avenue  
Irvine, CA, 92618

- Jan 13 Epilepsy in the New Year
- Feb 10 What is Your Epilepsy Diagnosis?
- Mar 9 March Medication Madness
- Apr 13 Identifying and Eliminating Seizure Triggers
- May 11 Individualized Education - Parents Focus Group - Adults
- Jun 8 Anxiety & Depression in Epilepsy
- Jul 13 Social Connectedness
- Aug 10 Latest in Epilepsy Research, An Overview with Dr. Salazar (rescheduled)
- Sept 14 Classification of Seizure Disorders
- Oct 12 Navigating the Epilepsy Road Map
- November is Epilepsy Awareness Month
- Nov 9 Talk with the Doc, Resource Fair
- Dec 14 Holiday Party
- Jan 11 AES, Epilepsy in the New Year

**Save the Date: May 18, 2013**

## Epilepsy Walk Orange County

Tewinkle Park, Costa Mesa

SIGN UP TO BE A CORPORATE SPONSOR

## Friday Night Drive

Is the idea of bumper to bumper traffic is keeping you from our meetings? Attending members report the drive isn't that bad and worth the effort. Try it so you don't miss important information that could provide improvements to your health and well-being.

### IT'S EASY TO ATTEND OUR MEETINGS...

Hoag Irvine Hospital has generously offered ESNOC meeting space for another year. This location offers a large auditorium for our professional speaker presentations and room for your kids in our Friday Friends Club and Teen Club. Come early for E101, Parent's Emotional Support Group or Adult's Social Hour. We always have finger foods and beverages for all attendees or there is a cafeteria for hungrier guests.



### A Wee Dragon

Jennifer Leath & Chad Nimmo would like to introduce their wee dragon, Declan Matthew Nimmo. Born on July 21 at 11:34 am; 8 lbs, 14 oz. and 21.5" tall.

### 2013 Navigate Your Epilepsy Roadmap | Monthly Topics for the Upcoming Year

We want to help you or your loved one understand how to Navigate the Epilepsy Roadmap to Seizure Control. Throughout the year we invite experts to speak on important topics. Our Educational and Support meetings will help members manage their health and well being in an informed and compassionate setting.

## GET TO KNOW US

### ESNOC Staff

Janna L. Moore, MPA, *Acting Executive Director*

Denise Wada, *Director of Marketing*

Temre Marsh, *Programs Assistant & Childcare Coordinator*

Jackie Wilson, *Childcare Provider*

Phyllis Larkin, PsyD, *Emotional Support Group Facilitator*

Jennifer Leath, PsyD, *Teen Club Facilitator*

### Volunteers

Jim & Joan M. Ashlock, *Adult Educational Support Group Facilitators*

Jill M. Foster, *On-line Support Group for Parents & Mom's Night Out Facilitator*

### Board of Directors

Jennifer Gunther, *President*

Wendy Crommelin-Tarvin, *Treasurer*

Joan M. Ashlock, *Secretary*

Jill M. Foster

Tracy J. Salazar, PhD,

### Advisory Board

Dr. Mary Zupanc, *Division Chief, PSF Neurology Medical Director, CHOC & UCI Pediatric Epilepsy Program*

Dr. Mona Sazgar, *Director of the UCI Irvine Comprehensive Epilepsy Program*

Tracy J. Salazar, PhD, *Post-Doctoral Fellow, UCSD; Research Review Board, CURE; Professional Advisory Board, LGS Foundation*

Dr. Richard Kim, *Medical Director, Hoag Epilepsy Center, Co-founder Brain and Spine Surgeons of Orange County, Co-director of CHOC's Epilepsy Center*

Phyllis Larkin, PsyD, *Individual and Family Psychotherapy, Private Practice*

## CONTACT US

Tel & Fax | **714-916-0456**

Mailing Address | 9114 Adams Ave, #288, Huntington Beach, CA 92646

Website | [www.EpilepsySupportNet.org](http://www.EpilepsySupportNet.org)

- American Epilepsy Society - Report
- Understand the Importance of an EEG
- The Effects of Epilepsy in Women
- Epilepsy and Sleep
- Epilepsy and Diet
- Neuropsych Evaluations
- Taking Care of the Care Taker
- Surgical Options for Epilepsy



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info@EpilepsySupportNet.org

### Wear purple in support of November's Epilepsy Awareness Month

Educational Support Group Meetings are seeing high attendance as members seek expert information from epilepsy professionals.

Thanks to our 2012 Distinguished Speakers:

- Danniell Augustine, Esq.
- Dr. Valeh Karimkhani
- Dr. Lilit Mnatsakanya
- Kelly McKinnon, MS
- Dr. Wayne Nguyen
- Dr. Tracy Salazar
- Dr. Diane Stein
- Dr. Lily Tran
- Michael Uram
- Dr. Mary Zupanc



Thanks to the professionals who joined us for Epilepsy Awareness Month, Talk with the Doc. HOAG Drs. Andrew Ly and Jason Muir; Stephannie Moore, PsyD ABPN, Minh Thu Le, PhD, and Marilyn Fitzgerald.  
UCI Drs. Mona Sazgar and Jack Lin; and Virginia Monsanto  
CHOC Drs. Mary Zupanc, Grace Mucci and Jonathan Romain; Alexandra Rudd-Barnard, PsyD, Courtney Malave, Lexi Rudd Barnard, and Debbie Merced

## CONNECT

*Sign up for our monthly email reminders about our support groups:*

- Parents
- Adults
- Teens
- Children
- Community
- Epilepsy Walk

[www.EpilepsySupportNet.org](http://www.EpilepsySupportNet.org)

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Find us on Facebook

Connect with Linked In

Parents of Children with Epilepsy, we can sign you up to our online

[yahogroups.com](http://yahogroups.com), search **OCepilepsy**

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Become a Volunteer

We are currently seeking adult volunteers to assist in clerical work and at our support group meetings. Youth volunteer positions in our Teen Club and Friday Friends Club.



Special thanks to Lundbeck for sponsoring the event's food.