

Wavelength

A Publication of the Epilepsy Association of Utah

July 2008

The Epilepsy Association of Utah provides awareness, education, support services, and advocacy for and on behalf of all those dealing with the many challenges of epilepsy/seizure disorders.

The Executive Director's Corner



In April of 2007, I was introduced to Kris Hansen and the Board of Directors for the Epilepsy Association of Utah (EAU) when I applied for the position of Executive Director. I was immediately impressed with their commitment to the agency and more specifically, those that we serve and wish to serve. During my interview with the board, I envisioned the potential for this agency in outreaching to the over 20,000 citizens (1%) in Utah with epilepsy. Fortunately, I was hired and since then, I share nothing short of appreciation and respect for all those that have assisted as we move forward. The dedication to help people and families dealing with epilepsy is heartwarming and impressive. I look forward to my long-term relationship with EAU as we augment and expand our efforts throughout the state.

Current agency services efforts include the augmentation of our support group program in the Salt Lake, Utah, Davis and Logan counties. To better provide support services to individuals in these targeted counties, we are looking for volunteer support. Please join us!

In Salt Lake County, we are fortunate to have an individual that is helping develop a pilot program for support group services specifically for adolescent youth with epilepsy. Assisting us, and the main driving force behind it, is Michael Cox. He is a student intern from Salt Lake Community College and is extremely motivated for the support group's success. If you are interested in participating or helping with this program, please call our office.

Additionally, we are expanding our Education Program

H.O.P.E. (Helping Other People with Epilepsy) with the inclusion of two board members, Ms. Margo Thurman and Ms. Sarah Hansen, who have already presented epilepsy information to many schools and businesses in Salt Lake, Davis and Utah counties this year. If you are aware of a business, school, medical or protective services personnel that would benefit from this service, please contact our office.

Through it all, we have endeavored to seek the involvement of others to increase awareness and support for people dealing with epilepsy. In this legislative process, we were able to successfully do this and look forward to long and prosperous relationships as a result. Continued success, as you are aware, will require involvement. Please join us, it's important!

Lastly, Camp Spike and Wave is coming. The camp is scheduled for July 28 through August 1, 2008 and we will be providing registration information soon. As with last year, the camps 5-day / 4-night program will be held at the National Ability Center in Park City, Utah. If you are interested in registering your child, please call our office. We will again be looking for volunteer nurses and others for day and night assistance to help and have fun. If you are aware of someone interested in sponsoring / underwriting the cost of the camp for one or more children who might otherwise not be able to attend, please call our office. Your support for this camp program will be extremely helpful and appreciated.

In closing, I look forward to the growth and success of the Epilepsy Association of Utah and all of your active participatory assistance and advocacy for people with epilepsy to this end. Please volunteer!

Richard Montano
Executive Director
Epilepsy Association of Utah

Caregiving 101

By: Kris Hansen

Being a caregiver of a husband and daughter with seizures, I find myself feeling burnout sometimes. I found this resource on the internet at www.caregiving101.org with some ideas on how to prevent "Caregiving Burnout".

1. Choose to **take charge** of your life, and don't let your loved one's illness or disability always take center stage.
2. Remember to **be good to yourself**. Love, honor and value yourself. You're doing a very hard job, and you deserve some quality time, just for you.
3. **Watch out** for signs of depression, and don't delay in getting professional help when you need it.
4. When people offer to help, **accept the offer** and suggest specific things that they can do.
5. **Educate yourself** about your loved one's condition. Information is empowering.
6. There's a difference between caring and doing. **Be open to technologies and ideas** that promote your loved one's independence.
7. **Trust your instincts**. Most of the time they'll lead you in the right direction.
8. Grieve for your losses, and then allow yourself to **dream new dreams**.
9. **Stand up for your rights** as a caregiver and a citizen.
10. **Seek support** from other caregivers. There is great strength in knowing you are not alone.



H.O.P.E. Program

This year has been a busy time. The H.O.P.E. presenters have shared excellent information with approximately 350 people. We have spoken to parents, teachers, students, nurses, occupational and physical therapists, and para-educators. We are currently discussing a possible in-service for the Utah Peace Officers Standards and Training Academy and we have a new trained presenter in Vernal, Utah.

Remember if you, your teachers, your staff, your employees or your boss need help in truly understanding what a seizure disorder is and how it affects a person, that the Epilepsy Association of Utah (EAU) offers the Epilepsy Foundation's *Helping Other People with Epilepsy (H.O.P.E.) Mentoring Program*. If one is interested in receiving a *H.O.P.E.* presentation contact the Epilepsy Association of Utah at (801)566-5949 or email margo@epilepsyut.org or margothurman@comcast.net.

Need a volunteer opportunity?

It is important that we continue to augment our services for the over 20,000 people with epilepsy in Utah. Recently, our office has received several calls from people living in the Weber and Davis Counties who are seeking support for themselves and / or their family and friends. EAU is looking to identify someone that would be interested in being trained as a facilitator for a support group in this area. If you, or anyone you know, are interested in conducting monthly support group meetings, please call Richard Montano, Executive Director, at (801) 566-5949, or e-mail him at montanorb@yahoo.com.

Annual Epilepsy Conference

Please watch our web-site for the information for our annual epilepsy conference. This will be held in November! The University of Utah Neurology department has graciously offered their facilities for this conference. More details will be coming soon!!!

Seizure Tracking Website!

<http://www.seizuretracker.com> is a website designed to assist patients with epilepsy in managing medication schedules, doctor's appointments, and tracking seizures. You can print customized reports to take to doctor's visits. The report allows you to enter a description of the seizure, duration, type, your mood and possible triggers. This site looks really helpful and interactive. The best part – it's FREE!

Support Groups Are Here!

Recently, Epilepsy Association of Utah augmented its services by increasing the number of support groups in Utah. Our long standing support group in Sandy is doing an amazing job! We have added a second support group in Utah County, and the third in Vernal, with our fourth beginning in St. George. We are also in the process of training and developing a support group for youth and newly diagnosed patients in the Salt Lake area. All support groups are free of charge and welcome to anyone interested.

Youth Support Group

In the fall of 2007, Mr. Michael Cox began his Salt Lake Community College internship with the Epilepsy Association of Utah. The program he has designed will be open to all students in Utah dealing with epilepsy. The initial focus will be to identify participants in Salt Lake County. An adult support will be available during each session. Our current location is to schedule meetings at the Sandy City Library. In the future, we are looking to access local schools as host sites.

Support group discussion topics will include **Understanding Epilepsy, Relationships, Driving, Medication and Surgery, Study Habits and Education, Combating Non-Support Groups, Goal Setting and Relaxation Techniques.** It is also our desire to encourage participants to identify topics for discussion based on personal experiences in dealing with this disorder.

If you know of an individual or individuals, business or organizations that may be interested in sponsoring a session, or are interested in presenting to the group, please contact Richard Montano at (801) 566-5949. Sponsorship includes providing snacks and drinks for the participants.

Sandy Support Group

The Sandy Epilepsy/Seizure Disorder Support Group meeting is held on the second Wednesday or Thursday of each month from 7:00pm to 8:00pm at the Sandy Library located at 10100 South Petunia Way in Sandy. Wanda Akers, Epilepsy Association of Utah Board Member, has been facilitating the meeting for over eight years. The support group has been set in place to support individuals and family members who are living with Epilepsy and/or a seizure disorder. If you are interested in attending and would like an e-mail or phone call reminder of the session, you can call the EAU office at (801) 566-5949, Ms. Pat Rowe at (801) 485-0490, or Wanda Akers at (801) 943-5241.

NEW! Utah County Support Group

Ms. Julie Christensen, Epilepsy Association of Utah Board Member, has developed an epilepsy support group for Utah County. The sessions will be conducted the second Saturday of each month at the Provo City Library at Academy Square, from 3:00 to 4:00 in room 308. If you are interested in attending and would like an e-mail or phone call reminder of the session, you can call the EAU office at (801) 566-5949, or Ms. Julie Christensen at 801-375-2305

The next sessions are scheduled for July 12 and August 9.

New! Vernal Support Group

On June 10, 2008, the Epilepsy Association of Utah opened its newest support group for people dealing with this disorder, as well as their families and friends. The support group will be held every 2nd Tuesday of each month at the Uintah Public Library in Vernal, located at 155 East Main, (435) 789-0091.

The Epilepsy Association of Utah wishes to express our deepest appreciation to the Ashley Regional Medical Center and the Wal-Mart store for their interest in providing in-kind assistance for the support group and people dealing with epilepsy in the Uintah County and Vernal. Their generosity is much appreciated.

If you are interested in this support group or seeking more information about it, please contact Ms. Kari Hatch at (435) 790-8589.

Saint George Support Group

A Support Group in Saint George has also been started and meeting will be at the Saint George Library approximately every 5 to 6 weeks. For information related to time and date, please contact Wanda Akers at (801) 943-5241.

Newly Diagnosed Support Group

EAU is currently in working on a newly diagnosed patient group. This will be held at the University of Utah. If you are interested in developing a support group or helping with newly diagnosed patients. We are in the process of scheduling a Support Group Training Session that will lend important assistance in addressing the needs of people with epilepsy dealing with a new diagnosis. Once the training is complete, we will provide additional information with respect to meeting schedules.

CBYC '08 A Great Success

Thank you for everyone that attended CBYC this year - we had 310 attendees! This is our largest crowd **ever**. Thank you! Our special guest speaker Stacy Julian was amazing. She was an inspiration and spoke of getting enjoyment from little things. We hope that Stacy will be willing to return next year.

Crop Because You Care 2009 will be held on **January 31st**. Please put it on your calendars. Registration will begin in late October or early November. You can view photos of this year's event at the EAU web site. We are sad to see two of our crop committee members leave us for next year. Thank you, Karen and Rachael for all of your support and love. We couldn't have done this without you. For updated information on our crop committee, to give suggestions, vote on crop items, and other fun things visit www.cropbecauseyoucare.blogspot.com.

If you are interested in being part of CBYC please fill out the following form and return it to the EAU office at 1995 West 9000 South Level B West Jordan, Utah 84088 or to Kris at kris@epilepsyut.org



CROP BECAUSE YOU CARE 2009 INTEREST FORM

My Name: _____

Organization Name: _____

Address: _____

City, State, Zip Code: _____

Telephone: _____

Email: _____

I would like to become an active member of the CBYC Committee

I am able to offer in-kind assistance in this effort (i.e. printing, marketing, advertising, raffle and silent auction donations, supplies, etc)

I am interested in becoming a vendor for CBYC

I am interested in advertising at CBYC

Introducing...Your 2008 EAU Board of Directors!

Richard Montano, Executive Director

Kris Hansen- President

Margo Thurman- Vice-President

Julie Christensen- Secretary

Michael Richards- Treasurer

Wanda Akers- Parent & Family Networking

Dr. Francis Filloux

Sarah Hansen

Michael Siler

Pat Rowe

Intern

Michael Cox

Crop Committee Head

Bethany Blackham

Web Master

Jarin Blackham

Mindy Brown

Newsletter Editor

Wendy Danielson

Past President

Alden Caldwell



Thank you to everyone
for your continued
support of the EAU !

Legislation Photos!!!

House Bill 361 became a Law "Anti-Seizure Drug Notification"

By: Richard Montano & Margo Thurman

On May 5, 2008, House Bill 361, "Anti-Seizure Drug Notification," an amendment to the Pharmacy Practice Act (section 58-17b-605), became effective as a Utah state law. The Epilepsy Association of Utah (EAU) is proud to have lobbied both the Utah House and Senate and enabled House Bill 361 to pass unanimously. The EAU received full support from the physicians. This bill was introduced and sponsored by Representative Eric Hutchings and Senator Curtis Bramble at this year's General Legislative Session.

Controlling break-through seizures is the optimum goal of this bill as it takes into consideration the possible bio-equivalency differences (80% to 125%) from one like drug to another, and the connection that any switching may result in seizure control loss.

Through the combined efforts for the Epilepsy Association of Utah's Board of Directors, Mr. Gary Thorup, Mr. Kurt Stenbridge and Mr. Spencer Guthrie from GlaxoSmithKline, Mr. Richard Knoespel, Abbot Industries, Mr. Reed Searle, Mr. John Renteria, Community Advocate / volunteer, Dr. Awaiz, Riaz, University of Utah Medical Center, Dr. Tom Houts, Ms. Sherry Wittwer, NAMI, and all others that expressed support proved extremely helpful in making this important bill.

Special acknowledgment of appreciation to Representative Eric Hutchings and Senator Curtis Bramble for sponsoring House Bill 361, and all other elected officials that supported it.

- House Bill 361 requires a prescribing physician to be involved in the process by writing prescriptions for anti-seizure drugs - **"Dispense as Written;"**
- In situations where a pharmacist is unable to fill a prescription as written, a pharmacist is required to **notify the prescribing physician prior to making a substitution.**

Unfortunately the bill does not apply to those on Medicaid. House Bill 361 was a beginning step and Utah was the first state to pass such a law. Many other states have failed. For complete information about H.B. 361, visit www.le.utah.gov.



Ceremonial Bill Signing- Governor's office



Thank you dinner at Madeline's Restaurant



Happy 4th and
Pioneer Day!