A
larmed by the results of a national survey about epilepsy awareness among teenagers, the Epilepsy Foundation Western/Central Pennsylvania (EFWCP) in conjunction with the national Epilepsy Foundation unveiled an awareness campaign targeted at teens. The campaign, Entitled to Respect began in November and is supported by one of America’s hottest musical groups... *NSYNC. “People with epilepsy can do everything we can, except deal with people who make a huge hassle out of it. You know—the stares, the comments—outta line. It all starts with understanding...we’re entitled to respect,” said band members prior to the launch of public service announcements, distribution of educational material to teenagers, and the unveiling of an Entitled to Respect website, www.entitledtor espect.org.

A survey of 20,000 teenagers across America, including hundreds of Western Pennsylvania youths, reveals that those with epilepsy are likely to be isolated, rejected, or even bullied by their peers due to a lack of awareness of this common neurological condition. The results of the survey conducted in 2001 presents a startling but insightful picture. Compared to knowledge of conditions like asthma, HIV/AIDS, arthritis and Parkinson’s, epilepsy has the lowest level of familiarity among Western Pennsylvania teens. More then 80% of them did not know that epilepsy is not a mental illness and half of them did not know that epilepsy is not contagious. The data also indicates that the less teenagers are aware about epilepsy, the more likely they are to engage in behaviors that result in stigma and discrimination.

The Entitled to Respect campaign is based on the results of the teen survey that demonstrated a clear link between the level of awareness about epilepsy and behaviors that result in stigma. “Epilepsy is really tough on teens, especially socially,” said Dr. Jacqueline French, neurologist and epilepsy specialist at the University of Pennsylvania. “This campaign goes a long way towards helping teens understand what epilepsy is, and why you shouldn’t treat a person with epilepsy any differently than you would want to be treated.”

EFWCP kicks off the new year with Teen Getaway 2002, a weekend-long fun event for teenagers with epilepsy. EFWCP is also looking at organizing other teen-related events in different parts of the state, and identifying teen ambassadors to increase awareness of epilepsy throughout the year.

A quarterly newsletter written by, for and about parents of children with epilepsy.

Mark Your 2002 Calendar

March 15-17
Teen Getaway 2002; Mars, PA

March 18-22
Kids Speak Out!; Washington, DC

April
Live Internet Event; for children of parents with Epilepsy; TBA

Educational Event; Developing a checklist for your child’s IEP meeting; TBA

May 5
Family Picnic; North Park

June 1
Annual Conference; Erie

Please contact Ashima Sarin for further details at (412) 261-5880, (800) 361-5885 or email her at asarin@efwp.org
**[SPOTLIGHT]**

**Gillian Withey**

We are delighted that Gillian Withey has been selected to represent EFWCP at the Epilepsy Foundation’s Kids Speak Up! program. Congratulations Gillian! Kids Speak Up! is an advocacy program developed by the Epilepsy Foundation National Office as part of the Annual Public Policy Institute. The program allows young people to come to Washington DC to meet their elected officials and to help the Foundation present the need for a better public understanding of epilepsy and research towards a cure. Thirty young people between the ages of 7-16 are selected from all over the country. The children get to present their story and participate in fun events organized by the Foundation. The institute will take place from March 17-19, 2002.

For many years, Gillian has been an active and integral part of the EFWCP’s Teen program. Recently, Gillian became active in learning about the legislative rights of people with special needs, even attending the “Power Through Knowledge” conference held by the Pennsylvania Independent Living Council. Even though Gillian has had a long battle with epilepsy, she has been successful in many academic and extra-curricular activities, from playing the trumpet to beginning a business selling her own cross-stitch handiworks!

Gillian is looking forward to her upcoming trip. “I am excited about this chance to talk about epilepsy and increase awareness. This trip will give me a chance to hear what other kids with epilepsy have to say,” said Gillian. We wish Gillian good luck and can’t wait to hear her DC stories once she gets back!

**“MY WORLD”**

**Art and Poetry Corner**

We would like to see your child’s creative expressions of his/her experiences with epilepsy. Send in a drawing, poem, essay, sketch or a craft project. Selected entries may be featured in EFWCP’s publications and website. And remember, the entry does not have to be from a child with epilepsy. If you are a sibling, a friend, or a child of someone with epilepsy, we’d love to see your work. Each entry should be accompanied by the entrant’s name, age, and a brief background.

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**From the Desk of Greg: Support Services Coordinator**

As the Central PA Support Services Coordinator, I am very eager to serve anyone in my area dealing with epilepsy who needs help. Through our Support Services, children with epilepsy and their families can learn more about seizure disorders, and how to cope with the condition and its effects.

I was once told by a very wise man that to have passion in one’s life is one of the keys to happiness. I can certainly say that I have a great passion for the work I do here at the Epilepsy Foundation, and I look forward to helping you in any way I can.

Greg joined the central office of the EFWCP in June of 2001, and can be contacted at greg@epf.org.

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**School Alert Making a Difference**

Elizabeth Stansbury, Community Education Coordinator

As a new addition to the EFWCP, I have been busy traveling around Western Pennsylvania meeting with parents, kids, teachers, and school nurses. My phone is ringing off the hook to schedule presentations and training sessions. Do you feel your school could benefit from either an entertaining and interactive classroom presentation, or a professional training session for teachers? Call me! I would be happy to get in touch with the school nurse or principal and send information on services that EFWCP provides.

Need guidance on IEP meetings? Both Ashima and I can be a resource for those of you in Western Pennsylvania for these meetings. Call us with your questions, and we will work diligently to help make sure your child’s needs are met in the school setting.

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**Greetings from Gretchen: Community Education Coordinator**

I am very happy to be working for the EFWCP. I have lived with epilepsy for the past 14 years, and am more than willing to share my personal experiences with others to educate and help them through difficult times. I have overcome many obstacles, and welcome the opportunity to help others overcome theirs. As the Community Education Coordinator for the Central PA office, I am available to provide services for your child’s classmates, and teachers, as well as attend IEP meetings to support you and your child. Please feel free to contact me at the Foundation should you require any of our services!

Gretchen joined the central office of the EFWCP in June of 2001, and can be contacted at gret@epf.org.

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**Memos from Program Staff**

**Hello!**

Ashima Sarin, Children and Family Services Coordinator

I recently joined the EFWCP, and it is both exciting and challenging. I am enjoying every working minute of it! As the Children and Family Services Coordinator, Western PA, my job is to help you in any way possible, answering your questions, providing you information and support, and getting our programs and services across to you. Not the least of my responsibilities is organizing fun events for all of you. Upcoming events include Teen Getaway, Family Picnic, Pirates Fun Run, and Camp Frog and everyone who comes to those events is sure to have a terrific time.

I wish to thank all of you who have given me the opportunity to listen to their stories and offer help. I urge all of you to call me and talk about any and all issues you are facing with epilepsy, and give me the opportunity to assist you. Hope to see you all in the near future!

Ashima joined the EFWCP in November of 2001, and can be contacted at asar@epf.org.

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**Teen Getaway 2002!**

**March 15-17**

We invite all teenagers with epilepsy to join us for Teen Getaway 2002. This fun-filled weekend will take place at The Family Retreat Center in Mars, PA. Activities include indoor and outdoor games, plenty of good food! You’ll have a blast! Register today!

For questions or reservations, Call Ashima before February 28 at 412-261-5880.
Thank You

We would like to thank the following schools for inviting our community educators, Elizabeth Stansbury and Gretchen Knaub, to visit and talk about epilepsy and seizure disorders:

Western Pennsylvania Area
- Washington Elementary 1/01
- Kerr Elementary 12/01
- Hopewell Junior High 1/02
- Seneca Valley Intermediate High 1/02
- Port Vue Elementary 1/02
- Vana Elementary 1/02
- Center Elementary 1/02
- St. Therese 1/02

Central Pennsylvania Area
- Walnut Bottom Preschool – 9/01
- Kids on Camp – 9/01
- Gettysburg High School – 9/01
- Lower Paxton Elementary – 10/01
- Middle Paxton Elementary – 10/01
- Carlisle High School – 11/01
- Centre Hall Elementary – 11/01
- Carroll Elementary – 11/01
- Wilson College Childcare Center 12/01
- Juniata School District – 12/01
- Steelton-Highspire High School – 1/02

Remember, these presentations are free and anyone can request them.

Your child’s school could be next!

BOOK REVIEW

TREATING EPILEPSY NATURALLY: A GUIDE TO ALTERNATIVE AND ADJUNCT THERAPIES by Patricia A. Murphy

In this book, Patricia Murphy gives a fascinating account of her struggle with epilepsy, and her move towards using natural healing instead of conventional medicine. She focuses on a holistic approach that deals with epilepsy from all aspects of the disorder: diet, special supplements, exercise, sleep requirements, and stress reduction.

The first section provides a general overview of epilepsy with conventional diagnosis and treatments. Here, Murphy also talks about her personal struggle that started when she was diagnosed with epilepsy at the age of 21. When traditional medicines failed to control her seizures, she turned to holistic medicine and diet that became her turning point towards a seizure-free life.

The second section, which I consider the most enlightening, focuses on food power. Murphy highlights the benefits of the well-known Ketogenic diet: special herbs, food supplements, and organic vegetables. The third section is a move towards brain wave control through relaxation and body therapy techniques.

While the information in this book is interesting, I have two concerns: first, it is impossible to consider the entire gamut of alternative healers, and know which is best for your child. Second, starting a new plan can pose incredible risks. In her effort to present a comprehensive approach, Murphy talks about too many subjects throughout the book without presenting a significant theme. The last two sections dealing with epilepsy at the work place, and epilepsy affecting different age and gender groups, also doesn’t offer any new information on these subjects.

Murphy’s book is interspersed with interesting anecdotes about herself and other people she met during her treatment journey. For all those interested in the subject of holistic medicine, the book is worth reading, it does invoke important questions about our day-to-day diet and mental and physical health decisions.

NOTE: PLEASE CONSULT YOUR NEUROLOGIST OR TREATING PHYSICIAN BEFORE MAKING ANY CHANGES IN YOUR CHILD’S TREATMENTS OR THERAPIES PRESCRIBED BY YOUR DOCTOR. AND, SEEK MEDICAL ADVICE BEFORE TRYING ANY “ALTERNATIVE” OR “HOLISTIC” TREATMENT.