

fight against childhood epilepsy & seizures

f.a.c.e.s is a not-for-profit organization that supports pediatric epilepsy research and programs for children with epilepsy.

Spring 2003

Volume 8



Dylan's Journey

by his mom, Cherie Mignon

Dylan was a healthy, happy toddler until one Saturday evening in September 1986 when he had his first partial complex seizure. For the first few years, the seizures were few and far between. As time progressed, so did his seizures. Last year, Dylan had 3-4 brief seizures every morning. Dylan's father, Ted, and I decided that we would explore different options in order to try and stop Dylan's seizures. I educated myself by researching everything about frontal lobe epilepsy and institutions that had expertise in treating frontal lobe seizures.

In the summer of 2000, Dylan and I attended the Epilepsy Foundation's summer camp in Southern California. There, we met a volunteer who recommended that we speak to Dr. Devinsky. We were willing to try anything and by October 2002, we were on our way to NY for an evaluation and possible surgery.

Before our departure we spoke to many friends about our journey. We received overwhelming love and support from each and every one of them. We dreamed of a positive outcome for Dylan. We had ongoing contact with friends and family at home and kept them updated on Dylan's progress through e-mail. The support and comfort that we received was immeasurable and allowed us to stay positive during those long days and nights over the course of Dylan's three-stage surgery.

While Dylan was in the hospital, our family stayed at the f.a.c.e.s. apartment in Skirball Residential Towers. Because the apartment is right next to the hospital, it was easy for us to spend time with Dylan. We are extremely grateful for the support and comfort the apartment gave us, helping us to create a home away from home.

The Epilepsy Unit itself is remarkable, a model

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From the Coordinator

by Christine Toes

This summer, f.a.c.e.s. will provide financial-need scholarships for children and teens to attend epilepsy summer camps in the Tri-State area. We are also working with epilepsy organizations in NJ and CT to expand local epilepsy camps. See page 7 for more information on scholarships.

In late November, the f.a.c.e.s. apartment moved to the Skirball Residential Towers, a much more convenient location for our families. The one bedroom and studio apartments have beds, dressers, TV/VCR with basic cable, kitchenware, dishware, sheets, and towels. Most items were donated by generous individuals through our first annual appeal. We still need a few items for the apartments, which can be purchased at www.potterybarn.com under Christine Toes, f.a.c.e.s. housewarming registry event date December 2002.

F.a.c.e.s. hosted a small jazz fund-raiser on March 10, 2003 at Jazz Standard, serving mouth-watering barbecue donated by Blue Smoke. Special thanks to jazz great and trombonist Wycliffe Gordon, Totem Productions, Jazz Standard, Blue Smoke, David Swinghamer, Danny Meyer, and Richard Coraine.

The Brittany Bowl-A-Thon will be held at Plainview Lanes on Saturday, March 29th, 2003 and will benefit f.a.c.e.s. For more information, contact Lisa Krebs-Borgen at 516.681.0148.

Orrin Devinsky, MD has published a new edition to his book entitled Epilepsy: Patient and Family Guide. The previous edition was the best-selling book on epilepsy for laypersons and it can be purchased on www.Amazon.com.

Special thanks to Mark Strausman and Kim Rosner of Campagna for donating Christmas Eve dinner for the families staying in the f.a.c.e.s. apartments! We truly appreciate their generosity!

Please check out the new f.a.c.e.s. web site at www.nyufaces.org for updates on events and programs.

Do you recommend or highly recommend a physical therapist, occupational therapist, or speech therapist that has helped your child cope with their epilepsy? Do you have a great resource that would help other parents? Share it with others by adding it to our Resource Guide for Parents of Children with Epilepsy, by e-mailing facescoordinator@yahoo.com or faxing to 212.779.2331.

Donations to f.a.c.e.s. support epilepsy research and programs for children and teenagers affected by epilepsy. All donations are tax-deductible. Please e-mail your questions about f.a.c.e.s. to facescoordinator@yahoo.com.

Yoga Program

Preliminary studies indicate that an alternative therapy such as yoga may be used effectively in reducing stress and seizures in patients with epilepsy. The NYU Yoga Program is aimed at reducing seizure frequency, maximizing rehabilitation, and improving overall quality of life. The program, initiated by Dr. Steven Pacia, was developed to focus on those patients who are clinically stable and have maximized the therapeutic benefits of their medication. Stress has often been cited as the most important seizure precipitant. Through an alternative therapy such as yoga, not only do we hope to reduce seizure frequency, but also to alleviate the anxiety, stress and depression often associated with epilepsy.



Yoga For Kids!!

JOIN OUR SPRING 2003
PEDIATRIC YOGA PROGRAM!

For more information contact: Trisha Spoto at 212.263.8322
or tricia.spoto@med.nyu.edu

A Psycho-Educational Support Group

If you're interested in discussing your concerns about epilepsy, sharing information, and learning about programs that are available to you, please call John Figueroa, A.C.S.W. at 212.263.8782

Young Professionals Social Group

(ages 20-32) will meet for coffee on Tuesday, March 25th at Starbucks on 29th St. and Park Ave. If you would like to attend, please call 212.779.2041

Not All Fun and Games

Flashing lights in video games can cause seizures

By Melissa Murphy

The popularity and complexity of electronic screen games (ESG) has escalated dramatically over the last decade. Children of all ages are so mesmerized by the latest video games' graphics and special effects, they find themselves engulfed in the games' allure for hours. Although video games bring excitement and entertainment to homes around the world, recent studies have found that there is a direct correlation between video games and seizures, called photosensitive epilepsy.

Photosensitive epilepsy occurs when natural or artificial light sources cause a child to have a seizure. These light sources are encountered in every day life, for example, alternating sun and shade and being exposed to strobe lights can cause seizures in people susceptible to photosensitive epilepsy.

The flashing lights, geometric patterns, and rapid scene changes in video games can also contribute to this type of seizure activity. Neurologists who specialize in photosensitive epilepsy say children are the most susceptible to this phenomenon but cases of photosensitive epilepsy diminish as children get older.

A study about photosensitive epilepsy was presented at the American Epilepsy Society's Annual Meeting in December 2002. The researchers reviewed medical data on 324 patients with epilepsy. From this group, they identified 13 patients between the ages of 9-18, who had suffered from seizures relating to electronic screen games. According to the research, the affects of photosensitive epilepsy can be reduced, even in children who have had a single tonic-clonic seizure associated with and possibly induced by video games. It is advised that children avoid the triggers of photosensitive epilepsy and follow treatment recommendations.

There are precautions parents can take in order to

lessen the probability that this form of epilepsy will occur in their children. Always monitor the amount of time that children spend playing video games. Children should play video games on a television with a small screen, in a well-lit room, and seated several feet away from the television to minimize their exposure to the strength of the flashing lights.

Photosensitive epilepsy is not common, although it does exist. Parents should remain conscious of the possible side effects that spending too much time playing video games can have on their children. Even though playing video games is for enjoyment purposes, maintaining children's safety and well-being is important.

J. Kiffin Penry Patient Travel Assistance Fund

When people with seizures need specialized care, it may not be available in their area. Travel expenses for individuals and families may sometimes be a barrier to such care, especially when other medical expenses add up. The Epilepsy Foundation offers a limited number of travel assistance grants, up to \$1,500 each, for people who must travel for specialized epilepsy care or testing. For an application and eligibility guidelines, contact the Epilepsy Foundation at (800) 470.1655, ext. 3726. This program is sponsored through a grant from Cyberonics, Inc.

-excerpt taken from Epilepsy USA magazine

The Make-A-Wish Foundation

Wishes Really Do Come True

by Laurie Adamkiewicz

To have a child with any sort of illness is a painful and frightening feeling for the entire family. Our son Kyle had a two and a half hour seizure when he was six years old. His seizures continued for the next few years despite the extraordinary care of his doctors.

We tried every combination of medication and Kyle took test after test to try to figure out what was causing his seizures. We had a breakthrough when extensive tests showed that surgery could greatly reduce his seizures, and might completely eliminate them. We had no other choice but to take the risk. The surgery was successful and Kyle hasn't had any more seizures, even though he remains on medication.

Along the way, we decided to apply for a wish from the Make-A-Wish Foundation. Kyle met with representatives from Make-A-Wish and talked with them about his "wishes." He loves the outdoors, so he asked for a camper so we could travel around the US. Make-A-Wish and General Motors (GM) in Linden, NJ, worked on Kyle's wish together. We were welcomed with open arms in Linden, where Kyle and his brother, Keith, were thrilled to get a tour of the GM plant.

As we returned to the front of the plant after the tour, almost all of the employees had gathered there. Kyle's camper was parked outside! We gave

a thank you speech to the employees, many of whom had tears in their eyes. A stretch limo took us to two GM dealerships who had helped sponsor Kyle's gift, and we were taken to lunch. We went back to the GM plant to give our final thanks and words of appreciation to everyone.

When we arrived home after our wonderful day, Kyle's camper was parked in our driveway!

Kyle wanted to tell you a little about the experience from his perspective: "I had a hard time believing I was really going to have a wish granted. My first wish was to ride on Air Force One or to go to Australia to meet the Crocodile Hunter.

I picked a camper because I thought it would be fun to go camping and see different places around the country. The camper has bunk beds for my brother and I, a little kitchen and a shower. Our first trip was to Cape May, NJ. Then we went to Florida and we stopped at Cape Kennedy and met an astronaut who went on the space shuttle.

We've also gone to Cooperstown to the Baseball Hall of Fame. When we are at the campgrounds I like going fishing, swimming, I catch lizards and ride my bike. I just want to say thank you to Make-A-Wish for my camper. I love it."

Wishes can and do come true, and the Make-A-Wish Foundation is the magic behind it all.

The Make-A-Wish Foundation is the largest wish-granting charity in the world. Their mission is to, "Grant the wishes of children with life-threatening illnesses and to enrich the human experience with hope, strength and joy". Make-A-Wish accepts referrals, which are kept strictly confidential. If you would like to refer a child, contact your local Make-A-Wish chapter. In New York, call 516.944.6212, in New Jersey, call 908.964.5055 and in Connecticut, call 203.261.9044. You can also visit their website at www.wish.org.

(Dylan's story, continued from p.1)

for epilepsy units everywhere. The staff is knowledgeable, capable and caring. Barbara Clayton, RN and Diana Blackman from Dr. Devinsky's office were a tremendous amount of help throughout the entire process.

Our journey was a successful one. Over the course of ten days, Dylan received three surgeries and countless tests. It has been one month to date since the surgery and Dylan has remained SEIZURE FREE! Dylan is recovering and getting stronger every day. We are so grateful for this most amazing experience.

Want to Go to the Circus?

Morgan Stanley donated their box at Madison Square Garden for the Ringling Brothers Barnum and Bailey Circus! Performance is on Sunday, March 30th. Space for 15 children with epilepsy and one parent or guardian is available.

To register, call
212.779.2080



Don't Forget!

American Airlines has a program called "Miles For Kids In Need"

This special program provides air transportation for children needing medical treatment or a wish fulfilled.

For more information contact:

Marie Ising
Program Administrator
817.963.8158

f.a.c.e.s. volunteer program

Parents of children having epilepsy surgery often spend two weeks to two months in the hospital. Sometimes these parents need an hour to take a break, or they may just want someone to talk to who understands what they are going through. NYU allows

volunteers to fulfill this role after going through an approval process consisting of:

- ◇ Filling out an application
- ◇ Meeting with the volunteer services department
- ◇ Meeting the following medical requirements:
 - a physical (less than one year old)
 - a tuberculosis test (less than six months old)

If you are interested in volunteering, please call 212.779.2080 or e-mail nyufaces@yahoo.com. For specific information about the approval process itself, please call Volunteer Services at 212.263.6100.

New f.a.c.e.s. Studio Apartment Wish List:

The faces apartments have a two month waiting list. The new f.a.c.e.s. studio apartment helps us accommodate more lower-income families traveling far distances to receive epilepsy treatment at NYU, but we cannot provide this service without your help. Over 30 families have benefitted from the apartment since 2001.

f.a.c.e.s. is seeking Rent Sponsors to underwrite the rent for the apartment.

Donations to f.a.c.e.s. are tax-deductible.

Please contact 212.779.2041 for more information.

SUMMER CAMP

E.a.c.e.s. will sponsor fifteen children with special needs who would like to attend summer camp. Contact 212.779.2080 for information on how to apply for a financial need scholarship. Camps include (but are not limited to) :

EFNYC CYO Day Camp on Staten Island

Call Carol at 718.317.2255 for a brochure. This camp is designed for children ages 5-12. There are 4 sessions lasting 2 weeks long. The last session is one week. The sessions are M-F from 8:30 A.M. to 3:30 P.M. Counselors receive seizure first aid training and a registered nurse is on duty at all times. The camp features a wheelchair accessible pool, arts and crafts, music, sports, drama, nature, and outdoor play. **COST:** \$125 per week. Bus service is an additional \$70 per week. **DATES:** July 7- August 22.



The Epilepsy Institute Travel Day Camp in New York City

Call Andrea at 212.677.8550 for a brochure. A one-week day camp designed for ages 12-16 with a primary diagnosis of epilepsy. The camp runs 9:00 A.M.- 4:30 P.M. with different trips and events around the Metropolitan area. Transportation to and from the central meeting area at 257 Park Ave. S, lunch, snacks and all admission fees are included. Siblings may also attend, if space allows. Room for 10 teens. Staff to child ratio is 3:10. **COST:** \$0 **DATES:** August 18-22.

EF-New Jersey Camp Nova in Blairstown, New Jersey

Call Veronica at 609.392.4900 x210 for a brochure. A one-week overnight camp for ages 8-25 with epilepsy and/or developmental disabilities. Includes swimming, boating, campfires, outdoor sports, beach volleyball, fishing, nature walks, and more. A neurologist is on-call and there is also an on-site nurse. Camp counselors are trained in first aid. **COST:** \$525 per camper. **DATES:** August 17-23

EF-Western Central Pennsylvania's Camp Frog in North Springfield, PA

Call Beth at 800.361.5885 for a brochure. A one-week overnight camp for kids grades 4-12 with seizure disorders. The camp is only for West/Central PA. residents. It is located on the shores of Lake Erie. Kids can experience archery, horseback riding, a climbing tower, sand volleyball, indoor-outdoor hockey, soccer, miles of hiking trails, boating, fishing, swimming, sailing, water-skiing, and canoeing. Waterfronts are supervised by certified lifeguards, staff are trained in seizure first aid, and a pediatric neurologist and nurse are on-site. **COST:** T.B.A **DATES:** July 6-12

EF-Rochester-Syracuse-Binghamton's Camp EAGR in Warsaw, New York

Call Joan at 585.442.4430 for a brochure. One-week overnight camp for kids with epilepsy ages 8-15 who are ambulatory and capable of managing their own personal needs. Held at the YMCA of Greater Buffalo's Camp Weona. Activities include swimming, canoeing, fishing, horseback riding, arts & crafts, organized sports, hiking, epilepsy education, and campfire sing-a-longs. Camper to staff ratio is 3:1. There is an on-site neurologist, and 2 on-site nurses for distribution of medication and basic first aid. Camp counselors are certified in seizure first aid. **COST:** \$250 **DATES:** August 17-23

EF-Connecticut Easter Seals Camp in Hebron, CT

Call Deanna at 800.899.EPIL for a brochure. A one-week overnight camp for kids ages 6-18. The facility includes a health center, auditorium, indoor heated pool, greenhouse, Arts and Crafts Center, a Nature Center, and a Challenge & Group Initiative course. All counselors receive specialized training in seizure recognition and first aid. Camper to counselor ratio is 3 or 2:1 and a licensed nurse is in residence at all times. **COST:** \$1,300 for out-of-state campers and \$605 for in-state campers. Cost of a 1:1 aid is not included. **DATES:** July 13-18

Thank you to the following f.a.c.e.s. contributors (December 12, 2002- February 4, 2003)

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Alice Pollner
UCB Pharma, Inc.
Neil and Stacey Weiss

\$3,000+

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Although every donation to f.a.c.e.s. is important, we regret that in order to keep our newsletter costs to a minimum, we can only acknowledge donations of \$100 or more.

Parents Conference *

- 9:30am [Continental Breakfast and Sign-in](#). Booths with educational information made available by conference partners and sponsors
- 10:00am [New Medications and Treatments and Their Side Effects](#), by Orrin Devinsky, MD
- 10:40am [Epilepsy Surgery](#), by Pat Dean, RN, and Howard Weiner, MD
- 11:10am [The Vagal Nerve Stimulator and The Ketogenic Diet](#), by Josiane LaJoie, MD
- 11:40pm [Cognitive Issues in Children](#), by Charles Zaroff, MD
- 12:10pm [Questions I am Afraid to Ask About Epilepsy](#), by Pat Dean, RN and Aviva Bojko, MD
- 12:40pm Lunch provided in Alumni Hall
- 1:30pm [Yoga and Exercise](#), by Steven Pacia, MD
- 2:00pm [Hot Topics in Pediatric Epilepsy](#), by Daniel Miles, MD
- 2:30pm [Developmental and Social Issues](#), Speaker TBD
- 3:00pm [Resource Panel](#), by Joe Valenzano, President and CEO of Exceptional Parent Magazine; Karen Schlesinger, Executive Director of Resources for Children with Special Needs; and Christine Toes, Program Coordinator of Fight Against Childhood Epilepsy and Seizures
- 3:30pm [Refreshments and Mingling](#) in Alumni Hall
-

Adult Conference *

- 9:30am [Continental Breakfast and Sign-in](#). Booths with educational information made available by conference partners and sponsors.
- 10:00am [New Medications and Treatments and Their Side Effects](#), by Daniel Luciano, MD
- 10:40am [Epilepsy Surgery](#), by Edward Bromfield, MD and Werner Doyle, MD
- 11:10am [The Vagal Nerve Stimulator](#), by Eric Geller, MD
- 11:40pm [Behavioral Issues](#) by Kenneth Alper, MD
- 12:10pm [Melatonin](#), by Josiane LaJoie, MD
- 12:40pm Lunch provided in Alumni Hall
- 1:30pm [Questions I Am Afraid to Ask About Epilepsy](#), by Pat Dean, RN, and Edward Bromfield, MD
- 2:30pm [Adult Resources in New York City](#) by representatives of The Epilepsy Institute, The Epilepsy Foundation of New York City, and The New York Open Center
- 2:50pm [Adult Resources in the Tri-State Area](#), by representatives of The Epilepsy Foundation of Connecticut, The Epilepsy Foundation of Southern New York, The Epilepsy Foundation of Long Island, The Epilepsy Foundation of New Jersey, and The Epilepsy Foundation of Northeastern New York
- 3:30pm [Refreshments and Mingling](#) in Alumni Hall

* Schedule and speakers are subject to change.

Spanish Conference *

- 9:30am Continental Breakfast and Sign-in. Booths with educational information made available by conference partners and sponsors
- 10:00am New Medications and Treatments and Their Side Effects, by Blanca Vasquez, MD
- 10:40am Epilepsy Surgery, The Vagal Nerve Stimulator and The Ketogenic Diet, by Blanca Vasquez, MD
- 11:10pm Diet and Alternative Therapies, by Blanca Vasquez, MD
- 11:40pm Lunch provided in Alumni Hall
- 12:30pm Neuropsychological Assessment in Epilepsy and Memory Problems, by Lorna Myers, PhD
- 1:00pm Psychiatric and Cognitive Co-morbidities in Epilepsy, by Blanca Vasquez, MD
- 1:30pm Psychological Problems in Epilepsy and Their Treatment, by Lorna Myers, PhD
- 2:00pm Resource Panel, by John Figueroa, MSW and Ines Castro, CSW, from The Epilepsy Institute
- 2:30pm Epilepsy in Special Populations, Speaker TBD
- 3:00pm Refreshments and Mingling in Alumni Hall

*Schedule and speakers are subject to change.

Special Pizza Session During Lunch for Students with Epilepsy ages 13 to 21!!!

Teens and young adults are invited to a pizza lunch from 12pm to 2pm where an epilepsy nurse and young people living with epilepsy will address topics including dating, alcohol, drugs, and how to talk about epilepsy with others. Kim Parker, RN, an epilepsy nurse from the NYU Comprehensive Epilepsy Center, will address medical questions. This is also a great opportunity to meet other young adults with seizure disorders and to help plan events for the Young Professionals Social Group for 2003-2004. All questions will remain confidential.

No parents, please.

VOTE!

If offered, would you or someone you know attend the following lectures (CIRCLE those that apply). Please note that attending some of these lectures might require you to miss other lectures during the day.

- 10:00am Epilepsy for Seniors and their Caretakers, by Edward Bromfield, MD
- 10:45am Epilepsy Basics (Diagnosis, Treatment and First Aid), by Barbara Clayton, RN
- 3:30pm Talking with your OB-GYN, by Josiane LaJoie, MD
- 3:45pm Pregnancy, by Souhel Najjar, MD
- 4:15pm Child Safety for Parents with Seizure Disorders and Helping Your Children Understand Epilepsy, Speaker TBD
- 4:45pm Menopause, Speaker TBD

OTHER lecture(s) you would like to see offered at this course: _____

CONFERENCE REGISTRATION

Please **circle** the one conference you will attend. If you plan on attending several lectures in different rooms, circle the conference where you will be attending the most lectures:

Adult Conference
Parents Conference
Spanish Conference
Pizza Session (ages 13-21 ONLY)

Please provide us with the following information:

Name: _____
Number of Guests Attending: ____
Address: _____
City, State: _____ Zip: _____
Phone Number: (____) _____
E-mail Address: _____

You will not receive a confirmation of enrollment,
but you may call 212.779.2080 if you wish to confirm.

If you do not wish to be added to the Fight Against Childhood Epilepsy and Seizures mailing list, check the box below. Individuals on our mailing list receive a free quarterly newsletter, two conference brochures per year, and an annual appeal letter. We do not rent or sell our mailing list. You may be removed from our mailing list at any time.

I **do not** wish to be added to the F.A.C.E.S. mailing list.

Please **fax** form to: 212.779.2331.

You may also **mail** form to:

NYU-f.a.c.e.s.

11 E. 32nd Street, Basement Office

New York, NY 10016

Registration may be **e-mailed** to nyufaces@yahoo.com



Upcoming f.a.c.e.s. Events

Saturday, March 22	Epilepsy Seminars for Parents, Adults, and Spanish-speakers
Saturday, March 29	Brittany Bowl-A-Thon on Long Island
Sunday, March 30	Circus Event (TBD)
Sunday, April 6	Party at Broadway City
July 2003	WNBA New York Liberty Game
Summer 2003 TBD	Kids Event: Baseball or Football Game
Summer 2003	Summer Camp Scholarships

The Epilepsy Foundation of Southern NY held its 25th Anniversary Awards Dinner on March 1st in Westchester. Congressman Sherwood L. Boehlert was honored at the event along with employees of the NYU Comprehensive Epilepsy Center. Please contact Leslie Slender, at 845.627.0627 or email at exec@efsny.com for more information.

Sign-up for the Brittany Bowl-A-Thon!

Saturday, March 29th at 8pm at
AMF Plainview Lanes on Long Island
For more information, contact Lisa Krebs Borgen at
516.681.0148

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