



# 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.*

Fall 2003

Volume 10

## The First Aid Myth that Refuses to Go Away: 1 in 3 Would Still Use a Spoon

By Christine Toes

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2003 research commissioned by the National Society for Epilepsy illustrates widespread misunderstanding about epilepsy in the United Kingdom (U.K.). Although similar market research has not been conducted recently in the United States, it is highly likely that figures are just as unsettling to families affected by epilepsy in the U.S.

According to the N.S.E. survey:

\* Percentage of those who would put something in the mouth, such as a spoon or a wallet to keep the person from “swallowing their tongue” (which is impossible): 30%

\* Percentage of those surveyed who would restrain someone having a seizure: 26%

Even more shocking is that one in twenty people in London, a city similar in many ways to New York City, think that epilepsy is caused by “evil spirits,” and a similar percentage think that epilepsy is contagious!



### More Public Awareness Needed

Clients often ask why the epilepsy organizations in N.Y.C. haven’t put more emphasis on public awareness, via TV and radio Public Service Announcements (P.S.A), and by advertising on subways and buses.

Although we recognize the importance of epilepsy education, (as evidenced by our free consumer conferences, school trainings, and police seminars), media costs in N.Y.C. are extravagant.

For example, \$110,000 would pay for:

- Two thirty-second TV spots on the national CBS evening news;
- Three months of 1,000 small ads on one line of the subway (at the non-profit rate).

**OR**, our board can choose to dedicate these funds to research. You can see that it is hard to justify spending money on a public awareness campaign instead of dedicating it to finding new treatments. We are brainstorming ways to promote awareness without spending a lot of money with a Chicago P.R. firm that offered to do pro-bono work for f.a.c.e.s.

*continued on page 13*

f.a.c.e.s.  
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## From the Coordinator

by Christine Toes



We've had a very exciting summer at f.a.c.e.s.! We'd like to thank Office Depot for their generous support of all our summer events: the **Mets** game, the **New York Liberty** basketball game, **rock climbing**, the **New York Aquarium** and picnic lunch, the **mural** project, **fishing**, and the **BBQ** at the New Jersey Shore. We also launched the f.a.c.e.s. Volunteer **Respite Care** program to provide parents with children undergoing epilepsy treatment with a few hours to take a break from the hospital. More than 20 families benefited from the two f.a.c.e.s. **apartments** over the summer. At our request, **Radio Disney** generously ran a National Epilepsy Foundation public service announcement more than fifty times over the course of two months.

As the fall approaches, we hope to expand some of our current programs, including the parent support group, events for teens, and partnering with organizations such as Exceptional Parent, Resources for Children with Special Needs, and the Brain Injury Association of New York on our educational conferences. We hope to be able to web cast our conferences, so that families across the United States can watch them live from their home or work computer. In continuing our quest for a cure, f.a.c.e.s. contributed \$75,000 to the National Epilepsy Foundation's Pediatric Epilepsy **Research** Fund, and supported research at the NYU Epilepsy Center and beyond.

Another program in the works is a two-hour training program on seizure **first-aid for babysitters**. We will be incorporating this training program into our fall conference. Please note that this program will only be offered if a minimum of ten people register. An additional program has been developed because epilepsy is increasing in the elderly population faster than it is in children. F.a.c.e.s. will be bringing an educational program called "**Senior Epilepsy Education**" or "S.E.E." to senior centers in Manhattan. If you know a senior affected by epilepsy who would like us to conduct the 45-minute presentation at their center, please let us know. F.a.c.e.s. will have lunch catered for seniors attending the presentation.

In order to continue to provide top quality services for our patients and families, we would really appreciate your help in filling out and returning the enclosed anonymous **survey**. What programs interest you? How can we better serve your needs?

Additionally, we need volunteer support for the **2004 f.a.c.e.s. Gala**, which you can read more about on page 9. Every contribution counts, \$10 or \$10,000, putting stamps on the invitations, or helping us make phone calls to prior supporters. If you are interested in volunteering for this event, please call me at 212.779.2041 or email [facescoordinator@yahoo.com](mailto:facescoordinator@yahoo.com).

Warm Regards,

*Christine*

*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](mailto:facescoordinator@yahoo.com).*

*The f.a.c.e.s. newsletter is edited by Christine Toes and Melissa Murphy with support from Daniel Miles, MD and Josiane LaJoie, MD*

# The New York Liberty Game and Parents Support Group

## Parent Support Group

A Parent Support Group held at NYU on May 18<sup>th</sup> prior to the WNBA game allowed parents to talk about their child's epilepsy and express what they would like to hear about at future support groups. One major topic of concern was which public and private schools in our area are most beneficial to children with epilepsy. Another topic was behavioral issues and whether they are caused by specific medications, the seizures themselves, or a combination of both. At the support group meetings, which will be held monthly

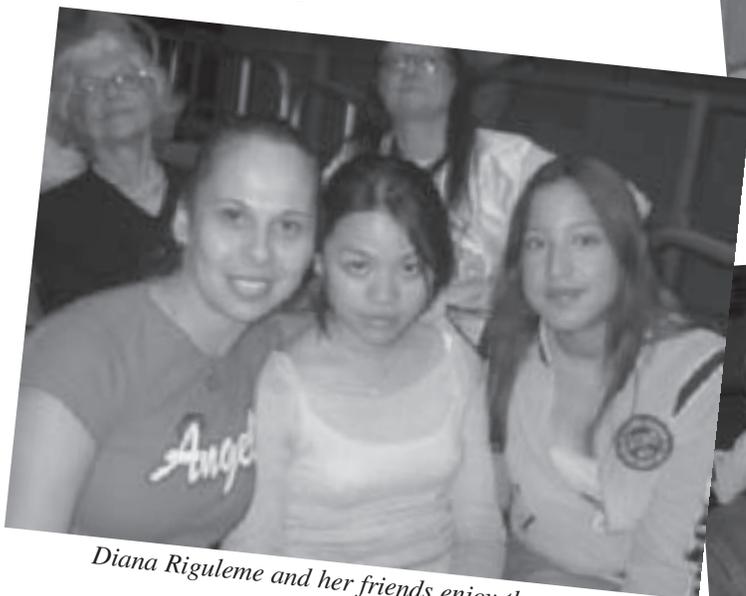
on Sundays from 11am to 1pm, beginning in October 2003, parents can bring their children to work on art projects, and lunch will be provided. The group will feature a short presentation on a specific topic, presented either by an invited lecturer or through an educational video. Parents can stay afterwards to discuss that topic, or to network with other parents. To be added to the Parents Support Group list, please call Christine Toes at 212.779.2041 or email [facescoordinator@yahoo.com](mailto:facescoordinator@yahoo.com).

## New York Liberty Game

Kids, teens, and adults with epilepsy attended the New York Liberty Game on May 18<sup>th</sup>, 2003. The New York Liberty donated the tickets to the event, and Office Depot donated gift certificates for snacks. Although it was a close game, the Liberty won in an exciting fourth quarter victory over the Houston Comets. Georgia Hoo and her family even made it onto the Jumbo-Tron screen at Madison Square Garden for their team spirit!



*Latuan and Kashaun Barnes*



*Diana Riguleme and her friends enjoy the game!*



*Courtney Carter with her friends, Makia and Beatrice*

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# Computers and Compassion in Epilepsy Surgery

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*By Werner Doyle, MD*

I was asked to write an article on “Computers and Compassion in Epilepsy Surgery.” At first I wasn’t sure what this topic meant.

Epilepsy surgery is the only surgery that I do. I have performed almost 2,000 epilepsy related operations in less than a decade at the NYU Comprehensive Epilepsy Center. What I do is extremely technical, involves an assemblage of high tech gear, and is very unique, since very few neurosurgeons in the world only perform epilepsy surgery. Being the primary surgeon for one of the busiest epilepsy centers in the world has given me vast experience. Having an interest in the application of computers and technology in neurosurgery has allowed me to develop techniques and devices that have changed the way surgery is done at our center. My surgery has evolved so that it is safer, less invasive, and the results better than the way I was taught during my training.

I have used computers and technology from the outset of my clinical career. I have developed databases, stereotactic and image processing software, surgical navigation devices and computer interfaces to improve epilepsy surgery. The thousands of pieces of data unique to each person having surgery is fused along with the MRI of the person to create a detailed road map that is used to make the surgery specific to each person’s needs. This results in smaller surgical openings, allows quicker recovery from surgery, produces little or no cosmetic effects, and most importantly produces more accurate and safer surgery with the best outcomes for seizure control. Our results are greatly improved from what was customarily considered typical for epilepsy surgery just 10 years ago.

In the most severe settings of epilepsy, medications do not control seizures, and the medication side effects can be as severe as any chronic disease. People with medically refractory seizures often experience deteriora-

tion in their neurological and cognitive function, which can make even daily activities difficult for them. It is in these cases that epilepsy surgery becomes most imperative as a management option. This is also the time when computers and high tech gear are most essential. Most often, epilepsy surgery can completely control the seizures in surgical candidates and return that person to normalcy. The frontiers of clinical neuroscience and the computer/techno-gear are just as important in all epilepsy surgery cases, regardless of severity. Yet in the most severe cases, the technology stands out. So does compassion.

*“Compassion without technology may reduce suffering, but compassion with technology may completely alleviate suffering caused by seizures.”*

Empathy and compassion are essential to epilepsy surgery. When surgical treatment is successful in the very worst cases, the associated compassion of the physicians and healthcare workers appears most visible. Technology also stands out as clearly having played an important roll. Computer/techno-gear and compassion are directly related in success and in failure. Compassion without technology may reduce suffering, but compassion with technology may completely alleviate suffering caused by seizures. Compassion drives the evolution of

neurosurgery by promoting the application of high technology to the understanding of neuroscience and to the treatment of neurological problems. It is compassion for the sick that drives the physician. And it is compassion in those whose seizures are controlled by surgery, towards others, whose seizures still remain uncontrolled, which continues to improve the life of people with seizures well after any encounter with neurosurgery and technology.

So, in epilepsy surgery, computers and compassion compliment, rather than contradict, each other. The editors of the **f.a.c.e.s.** newsletter knew more about me and what I do than I initially thought. What is it that I do as a neurosurgeon (techno-surgeon)? I reduce suffering with compassion and with computers.

# Rock Climbing at Chelsea Piers

The Young Professionals Group headed for the indoor climbing wall at the Chelsea Piers Fieldhouse in May. Two instructors helped everyone safely harness up and climb several different routes on the 30-foot wall. Jen, one of our wonderful instructors, is also a patient at NYU. She gave our group the special treatment by letting us jump on the trampolines and rope swing into a huge pit of soft padding! It was a great event and we'll definitely do it again soon. Due to feedback from teens and parents, the Young Professionals Group has extended its age range to ages 15 through 30. The next event will be a pizza and "Movie Night" held in late September. To join, please call Christine Toes at 212.779.2041 or email [facescoordinator@yahoo.com](mailto:facescoordinator@yahoo.com).



*Our instructor, Jen, with Janice, attired to take on the wall by storm!*



*The group finishes a challenging climb!  
(Left to Right: Vince, Jodi, Janice, Christine, and Alyssa).*



*Vince takes a break from a really tough route up the wall.*



*Even the parents had fun on the trampoline!*

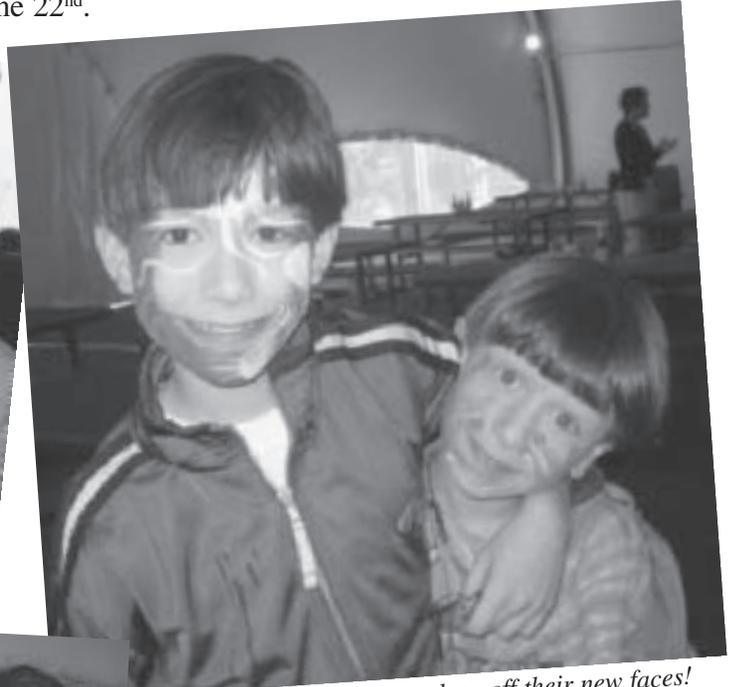


# *Under the Sea!*

On June 8, 2003, 100 people affected by epilepsy attended the f.a.c.e.s. event at the New York Aquarium. During a picnic lunch in the outdoor Seaside Pavilion, kids and teens sketched ocean-themed art in anticipation of the f.a.c.e.s Mural Project on June 22<sup>nd</sup>.



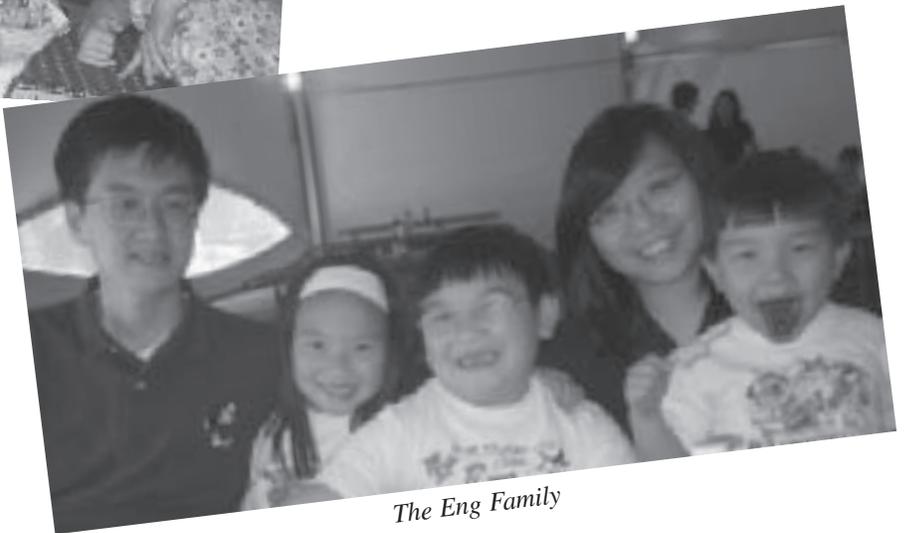
*The Rosenthal Family*



*Justin and Aubrey Canna show off their new faces!*



*The Ferreira Family enjoys their lunch after a great day at the aquarium!*

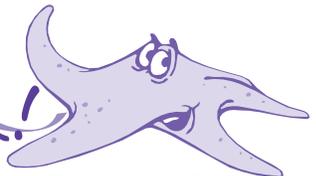


*The Eng Family*



*Rosalita Cora and her sister Elsa Hernandez use tissue paper to create the ocean floor.*

# f.a.c.e.s. *Mural of the Sea!*



The School of Visual Arts (S.V.A.) selected f.a.c.e.s. as one of their “Special Projects” for the “Mural of the Sea.” They donated their space for the kids and teens to decorate a mural for the NYU Comprehensive Epilepsy Center’s waiting room with colored tissue paper, fish, coral, and more. Parents had fun working on two panels of their own. As soon as the mural is installed, a small reception will be held at the NYU CEC for the families who helped put it together. A plaque listing all the participants will go next to the mural.

Mark Strausman of Campagna and Fred’s at Barneys New York, donated the kids’ food for the two-part project, held on June 22<sup>nd</sup> and June 29<sup>th</sup>. On June 22<sup>nd</sup>, an art therapist from SVA led a workshop for the parents on “Creative Parenting

Skills,” and on June 29<sup>th</sup>, parents played a game developed by the Epilepsy Coalition of New York State, called “Seizure Sense™.”



*Jen Mauro, the S.V.A.’s Special Program Coordinator and Kashaun Barnes*



*Jennifer Prevete and her mom, Theresa hard at work!*



*Melissa Cohen and Adrian Cora paste their fish to the mural!*

*Special thanks to the SVA’s Art Therapy Graduate Students:*

**Lesley Aчитoff**

**Amy Duquette**

**Julie Walton**

**Melissa Cohen**

**Mariya Gershman**

**Stacy Yamano**

**And to Jennifer Mauro, MPS, ATR-BC**

**Coordinator of Special Programs and Projects at the School of Visual Arts**

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# Research Announcements

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## Treatment of Attention-Deficit Disorder, Cerebral Palsy, and Mental Retardation in Epilepsy

Josiane LaJoie, M.D. & Daniel K. Miles, M.D.

Abstract:

Epilepsy in childhood is often associated with other neurologic disorders, including attention-deficit/hyperactivity disorder, cerebral palsy and mental retardation. A single pathologic process may explain both epilepsy and these associated disorders. However, in some cases, distinct etiologies may be present. Recognition of these problems is essential, as is individualized treatment. Proper classroom placement; behavior modification, speech, occupational, and physical therapies; pharmacological agents; and even surgical procedures have a role in the management of these co-morbid disorders. Diagnostic criteria and therapeutic modalities used in these syndromes will be discussed.

Epilepsy & Behavior 3 (2202) S42-48.

If you would like a copy of this article please call 212.263.8325.

### Infantile Spasms Study

The NYU Comprehensive Epilepsy Center seeks to enroll individuals who have been treated for infantile spasms as voluntary participants in a retrospective study on the therapeutic outcome of treating infantile spasms.

Interested participants should contact Daniel Miles, M.D. at 212.263.8318.

### Yoga Program

Preliminary studies indicate that an alternative therapy such as yoga may be used to effectively reduce stress and seizures in patients with epilepsy.

For more information, please contact

Tricia Spoto at 212.263.8322 or at [tricia.spoto@med.nyu.edu](mailto:tricia.spoto@med.nyu.edu).

### The Epilepsy Cure Project

The Epilepsy Cure Project is a non-profit organization whose mission is to improve the lives of people with epilepsy by serving as a catalyst for more effective therapies for epilepsy. The Epilepsy Cure Project supports innovative research in both academic and industry settings. In addition, The Epilepsy Cure Project provides small proof grants, assistance to physicians and scientists on starting a company, assistance in ensuring protection of intellectual property, annual advisory meetings for new startups, annual funding meetings to facilitate promising companies and various funding sources, and outreach programs to increase the visibility of the need for new epileptic treatments and drugs. You can contact The Epilepsy Cure Project at 703.437.9720 or at [EpilepsyCure@aol.com](mailto:EpilepsyCure@aol.com).

### NEUROFEEDBACK

COMING SOON . . .

A pilot study that will examine the effects of biofeedback techniques for reducing seizure frequency.

On April 14<sup>th</sup>, 2003 the Health Insurance Portability and Accountability Act (HIPAA) went into effect. It is designed to protect patients' and research participants' right to privacy and to maintain the confidentiality of all patient research and medical records.

If you would like to read more about HIPAA, information is available on the web at <http://www.hhs.gov/oct/hipaa/>.



THE F.A.C.E.S. GALA SUPPORTS EPILEPSY RESEARCH, OUR EVENTS AND PROGRAMS THROUGHOUT THE YEAR, CLINICAL CARE, AND MUCH MORE!

**WHEN:** MONDAY, MARCH 1, 2004

**TIME:** 6:30 PM COCKTAILS & SILENT AUCTION  
8:00 PM DINNER & LIVE AUCTION

**WHERE:** NEW YORK HILTON

**WHAT:** SILENT AUCTION, DINNER & LIVE AUCTION TO BENEFIT FIGHT AGAINST CHILDHOOD EPILEPSY & SEIZURES AT THE NYU COMPREHENSIVE EPILEPSY CENTER

**PRIOR EMCEES  
HAVE INCLUDED:** STONE PHILLIPS

**PRIOR SPECIAL GUESTS  
HAVE INCLUDED:** ROBIN WILLIAMS, DAN RATHER

**PRIOR HONOREES  
HAVE INCLUDED:** OLIVER SACKS, PHD AND FORMER HOUSE OF REPRESENTATIVES WHIP TONY COELHO, FOUNDER OF THE AMERICANS WITH DISABILITIES ACT

**SPECIAL GUEST:** JULIANNE MOORE

**ATTIRE:** BUSINESS

**TICKET PRICES**

\$400 INCLUDES ONE TICKET  
\$750 INCLUDES ONE TICKET WITH PRIORITY SEATING  
\$1,000 INCLUDES ONE TICKET WITH PREMIER SEATING

**TABLE PRICES**

\$10,000 INCLUDES BLACK AND WHITE JOURNAL AD AND TEN TICKETS  
\$15,000 INCLUDES SILVER JOURNAL AD, TEN TICKETS, AND PRIORITY SEATING  
\$25,000 INCLUDES GOLD JOURNAL AD, TEN TICKETS, AND PREMIER SEATING

*We need your help!*

Volunteers are needed to:

1. Sell tickets, tables, and journal ads.
2. Solicit auction items (dinner gift certificates, sports memorabilia, theatre and sports tickets, wine, jewelry, etc.).
3. Make phone calls to prior donors and supporters.
4. Organize and catalogue items.
5. Help set up the auction on March 1<sup>st</sup>.
6. And much, much more!

For further information, contact Christine Toes at 212.779.2041 or email [facescoordinator@yahoo.com](mailto:facescoordinator@yahoo.com).

# The Future of f.a.c.e.s.

## *By the f.a.c.e.s. Steering Committee*

f.a.c.e.s. has grown by leaps and bounds since its formation in 1996 due to tremendous work by our volunteers and staff. As f.a.c.e.s. moves into a new stage and takes on even greater challenges, we are updating our mission statement and logo to better reflect our goals for the future.

**CURRENT MISSION:** The mission of f.a.c.e.s. is to improve the quality of life for children with epilepsy through clinical care, education and research.

**REVISED MISSION:** The mission of f.a.c.e.s. is to improve the quality of life for all people affected by epilepsy through progressive research, education and awareness, and community-building events.

**CURRENT LOGO:** Purple children's handprints

**REVISED LOGO:** Lisa Nelson and her colleagues at strategic branding company, Spring Design Partners, have generously volunteered their time and talents to develop the new f.a.c.e.s. logo. Stay tuned for the winter newsletter when the new logo will be unveiled!

**VISION STATEMENT:** F.a.c.e.s.' vision for the next 3 years is to focus our efforts on:

- Funding research into epilepsy and into new epilepsy treatments, including alternative and complementary approaches;
- Promoting epilepsy awareness through creative and inexpensive means;
- Expanding educational and social programs to serve more constituent groups, such as senior citizens;
- Measuring our success and developing new programs by analyzing customer satisfaction surveys and client feedback.

## *Congratulations*

**Lesley Achitoff, Ida Mack and Jean-Anne Madden were selected as the  
f.a.c.e.s. Volunteers of the Quarter!**

**Many thanks to you for all of your hard work!**



*Ida Mack volunteers for f.a.c.e.s. by doing projects from her home.*



*Lesley Achitoff, a student in the art therapy program at the School of Visual Arts, coordinated the f.a.c.e.s. Mural of the Sea project. She is pictured here in front of one of the mural panels now on display, with Melissa Cohen, one of the students who worked on the project.*



*Jean-Anne Madden has coordinated several events for f.a.c.e.s., including the NY Mets game and the NY Yankees trip.*

# D O N A T I O N S

Thank you to the following f.a.c.e.s. contributors  
(May 15, 2003-August 8, 2003)

## \$15,000 +

Elan Pharmaceuticals, Inc.  
GlaxoSmithKline

## \$10,000 +

Novartis Pharmaceuticals Corporation

## \$5,000 +

Steven Spiegel

## \$3,000 +

Parents Against Childhood Epilepsy, Inc.

## \$2,000 +

Brittany Bowl-A-Thon  
Xcel Pharmaceuticals

## \$1,000 +

Daniel & Alice Cunningham  
Lee & Lisa Einbinder  
Rising Stars Dance Studio, Inc.

## \$500 +

Harry & Jeann Braunstein, "In honor of Jeffrey Levine's 50<sup>th</sup> Birthday"  
Roberto Bucci  
Alvin & Joan Einbender  
Barry Fishleberg Company, Inc.  
Bernard & Susan Leifer  
Vincent & Sophie Riso, "In honor of Jeffrey Levine's 50<sup>th</sup> Birthday"

## \$300 +

Julie Blum  
Ted & Gail Fass  
Peter Sterling

## \$200 +

Dr. Blas Anaya Amalbert & Gladys Anaya  
Philip & Theresa Bilello  
Robert Domus & Nancy Bryce  
Doherty Enterprises, Inc.  
Andrew & Jill Ellner, "In honor of Jeffrey Levine's 50<sup>th</sup> Birthday"  
Junior League of Oranges & Short Hills  
Jeffrey & Randi Levine  
Howard & Delores Lichtenstein, "In honor of Jeffrey Levine's 50<sup>th</sup> Birthday"

## Gifts In Kind

Laurie & Chuck Adamkiewicz  
Jessica Levine  
Debbie Peel  
Tim McCarthy & Radio Disney  
Pete Rodriguez  
The School of Visual Arts  
Mark Strausman of Fred's at Barneys  
New York

## Special Thanks

to Renee Dugan, Cassie Cone and  
Susan Geraci for their hard work  
developing the Senior Epilepsy  
Education, "S.E.E." program, through  
the NYU Wagner School's Masters in  
Public Administration (M.P.A.)  
program.

## \$200 + (cont.)

Herbert & Teresa Migone, "In appreciation of the care to  
Dylan Long"  
Mutual of America Securities Corporation, "In honor of  
Jeffrey Levine's 50<sup>th</sup> Birthday"  
Bob & Jodie Ross, "In honor of Jeffrey Levine's 50<sup>th</sup>  
Birthday"  
Stewart & Donna Senter, "In honor of Jeffrey Levine's  
50<sup>th</sup> Birthday"

**Some corporations will match your donation!**

**Check with your company to see if your contribution to f.a.c.e.s. can be matched.**

**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 \$200 or more.**

*The NYU Comprehensive Epilepsy Center and f.a.c.e.s.  
would like to send our sincere condolences  
to the family of*

*Peter Anthony Carlesimo.*

*“His family was his  
religion and his work  
was his passion.”*

When asked by a reporter how Peter Anthony Carlesimo was so accomplished on so many levels while raising ten children, his son P.J. replied, “My father would not have understood this question. For him it was very simple. His family was his religion and his work was his passion. He never made it more complicated than that.”

Friend John O’Neil wrote, “In loving memory of Peter Anthony Carlesimo, a wonderful man who treated me like one of his children during my years at Fordham University. It was truly a privilege to have known “Big Pete.” Love, Johnny “O.”

*We would like to thank the following individuals and corporations  
for their donations in memory of Mr. Carlesimo:*

Carl & Christine Beck  
William & Valerie Brannan  
Hubert & Claire Brown  
Linda Bruno  
Alison Bush  
Katherine Byrne  
Jeffrey Campbell  
B. Vincent Carlesimo  
Vincent B. Carlesimo  
Rick & Donna Carlisle  
Jonah & Shannon Cave  
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Thomas & Diane Crowley  
James & Jean Ann Curley  
John Curley  
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David & Paula Diaz  
Marc Donnefeld & Catherine  
Shannon  
William & Carol Eyres  
William & Barbara Farlie  
Terrence Fay  
Velma Fedele  
Elizabeth Fortunato  
The Franson Family  
Friends of Brian Committee  
Stan Fuchs  
Andrew & Wendy Furman  
Charles Galliera  
Joseph & Patricia Gasparino  
Oliver & Eileen Gelston  
Harry & Joanne Glickman  
Dr. Howard & Barbara Gould  
The Haggerty Family  
Joseph Halsema

Richard & Mari Harter  
John Hefferman  
F. Perry Hodge  
W. James & Patricia Host  
Jennifer Jacobsen  
Arturas & Gina Karnishovas  
Teri Keiser  
John & Mary Kelly  
Kevin Kilgallen  
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Chris & Kim Koenig  
Frank & Terrienne Laino  
Kevin & Patricia Lamb  
Rick LaMoine  
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David Neal  
Walter & Mildred O’Brien  
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radical.media, inc.  
Rebman, Linhares & Beachem  
Leo A. Ressa  
Dr. Joseph Rizzo  
Patricia Rizzo  
C.W. Rogers  
Allison Romang  
Katherine Rosati  
Samuel & Joan Saccardo  
St. John’s University  
Dr. W. Norman Scott  
William & Brynne Shaner  
Stuart & Roxanne Sharoff  
Marlene Shiffman  
Simon & Deitz, LLC  
Mickey Strasser  
Charles & Kelly Sweeney  
Jeff & Niamh Thurman  
Annie Tonsienasom  
Michael Tranghese  
The University of Connecticut  
Foundation, Inc.  
Albert Vertino III  
Frank & Mimi Walsh  
Jim Walsh  
Scott & Jaqueline Wasserberger  
James & Christine Whitaker  
John & Mary Wood  
Dr. & Mrs. Francis Wyckoff

# GO FISH!

On Saturday, July 19<sup>th</sup> f.a.c.e.s. chartered a fishing boat off the south shore of Long Island. The sun was shining and the fish were biting! Congratulations to the Matos Family for catching the “Fish of the Day”!

*Special thanks to:*

**Matthew Freilich**

**Jim Kelly**

**Nancy Joly-Murphy**

**William Murphy**

**Pete O’Neil**



*The Royston Family*



*Brian from Captain Lou Fleet helps Hector Matos unhook the big catch of the day.*



*Connor Ellsweig and Just Lunning became instant friends.*



*Fabio Biguzzi proudly holds his first fluke.*



*Robert Toorres and Diana Riguleme enjoy the sun.*



*Gaye Pecker and her daughter, Tilly, wait patiently for the fish to bite.*

## **The First Aid Myth** *continued from page 1*

One inexpensive idea we can implement in time for National Epilepsy Awareness Month in November is a “Make Your Own T-Shirt” workshop. Anyone interested in this public awareness project can bring in his or her own t-shirt on one of three dates in October and use paint, stencils, and sequins to create your own public awareness message. I am definitely not an artist but I wear the t-shirt I made (featured on page 1) whenever I can. It may not be perfect, but it means a lot to me.

Although I came up with: “Epilepsy. What’s Your Cause?” you can use any short motto that speaks to you. Maybe yours will say, “Epilepsy is not contagious.” When you wear your t-shirt, you’ll be surprised at how many questions people will ask, and how many people you can educate every time you wear it!

A **t-shirt workshop** will be held for parents and teens at Art Day on Sunday, October 19<sup>th</sup>, and those attending the Conference on Epilepsy in November are encouraged to wear their t-shirts to the conference. Photos of the best t-shirts will be featured in the Winter f.a.c.e.s. Newsletter.

With a little bit of creativity, telling others not to put a spoon in someone’s mouth or not to restrain someone having a seizure doesn’t have to mean sacrificing research dollars.

# Epilepsy and Herbal Medicine

*Editor's Note: Although some patients with epilepsy are trying to treat their seizures with herbal therapy, these herbs have not been approved by the Federal Drug Administration (F.D.A.) and can increase the possibility of seizures, often by reducing the effectiveness of anti-epileptic medications. You must discuss all medications you are taking with your physician, including over the counter medicines and herbs, in order to maintain the most effective treatment regimen.*

## Herbal Medicine Chart

Developed by the Epilepsy Foundation of Southern New York, 2002

HERB	CLAIMED BENEFIT	SEIZURE POTENTIAL
Black Cohosh	Menopausal complaints; premenstrual syndrome (PMS).	1 seizure case reported.
Borage	Skin problems; inflammatory disorders; osteoporosis; diabetic neuropathy; acute respiratory distress; hypertension; elevated serum lipids.	Contains gamolenic acid, may lower seizure threshold.
Cranberry	Urinary tract infections; kidney disorders and infections.	Currently no known seizure potential.
Damiana	Aphrodisiac; prevention and treatment of sexual disorders.	Lowers seizure threshold.
Echinacea	Common cold, cough/bronchitis, fevers; urinary tract infections; inflammation of the mouth and pharynx; infection prevention; wounds and burns.	Currently no known seizure potential.
Evening Primrose Oil	Breast pain; neurodermatitis; PMS; hyperactivity; high cholesterol levels; hot flashes.	Contains gamolenic acid, may lower seizure threshold.
Garlic	Arteriosclerosis; hypertension; raised levels of cholesterol.	Currently no known seizure potential.
Ginkgo Biloba Seeds	Dried and fresh leaves extract produced MAO inhibition in rats; symptomatic relief of organic brain dysfunction; intermittent lameness; vertigo; ringing in the ears.	Tonic/clonic seizures reported. May lower seizure threshold.
Ginseng	Lack of stamina; fatigue and debility; loss of appetite; malnutrition and wasting; anxiety; impotence and sterility; neuralgia; insomnia.	May lower seizure threshold.
Goldenseal	Inhibits growth of parasites and used for intestinal infections; eye and other infections; direct tumor-killing effect and promotes production of white blood cells.	Contains hydrastine; may lower seizure threshold.
Green Tea	Stimulant and anti-depressant; treatment for the passage of large amounts of urine (diuresis); anti-inflammatory; antidiarrheal; cancer preventive; plaque inhibitor and dental caries preventive.	Contains 1 - 4% caffeine (10 - 50 mg/180 ml). May lower seizure threshold if more than 3 cups/day.
Guarana	Stimulates circulation, heart and diuresis due to caffeine content; increases gastric and biologically active amines (catecholamine) secretions.	Contains caffeine and theophylline; may lower seizure threshold.
Herbal Phen-Fen	Weight loss; increasing metabolism and thermogenesis.	Contains mahuang and ephedrine; lowers seizure threshold.
Kava Kava	Nervousness and insomnia, a sedative and sleeping agent; asthma; rheumatism; dyspepsia; cystitis; syphilis; gonorrhea; weight reduction.	Generalized tonic/clonic seizures reported both from toxicity and acute withdrawal.
MaHuang	See Phen-Fen.	Contains ephedrine and pseudoephedrine; seizures reported.
Melatonin	Sleep aid; jet lag; antioxidant; hypnotic; antiapoptotic.	May increase or decrease seizure activity.
Metabolife 356	See Phen-Fen.	Seizures reported.
St. John's Wart	Mild antidepressant; sedative; counters anxiety; anti-inflammatory, antiviral, antibacterial; first-degree burns, contused injuries; tonsillitis; asthma; calcifications in blood vessels of the brain.	Seizures reported.

The Epilepsy Foundation of Southern New York does not advocate the use of these agents. This chart was developed as a service to clients.

### References:

MINCEP (Minnesota Comprehensive Epilepsy Program) Epilepsy Report, January 2000; PDR for Herbal Medicines, Medical Economics, Montvale, NJ, 2000; PDR for Nutritional Supplements, Medical Economics, Montvale, NJ, 2001; "The Trouble with Fat-Burner Pills," Ian Smith, M.D., *Time*, August 27, 2001

Stay tuned to the Winter 2003-2004 edition for an article by Daniel Luciano, MD on herbal medicine for epilepsy.

## f.a.c.e.s. Customer Satisfaction Survey (Version 4)

Dear Friend,

At f.a.c.e.s., we try to continuously improve our events and programs. Please return this anonymous survey to us via mail at: 11 E. 32<sup>nd</sup> Street, Basement office, NY, NY 10016 or via fax at 212.779.2331. You can also return this survey in the envelope inserted into the newsletter.

What f.a.c.e.s. programs and services have you recently utilized?

On a scale of 1-3 (1=worst, 3=best), how well did these programs or services meet your needs?

<b>Please <u>CIRCLE</u>:</b>	<b><u>Did not meet needs</u></b>	<b><u>Met needs somewhat</u></b>	<b><u>Met needs well</u></b>	<b><u>Comments?</u></b>
Conferences	1	2	3	_____
Conference audio tapes	1	2	3	_____
f.a.c.e.s. Apartment	1	2	3	_____
Newsletter	1	2	3	_____
Website	1	2	3	_____
Broadway City Arcade	1	2	3	_____
Circus	1	2	3	_____
Mets Game	1	2	3	_____
Liberty Game	1	2	3	_____
Rock Climbing	1	2	3	_____
N.Y. Aquarium	1	2	3	_____
Mural Project	1	2	3	_____
Fishing Trip	1	2	3	_____
BBQ at the Shore	1	2	3	_____
Other (please list):	1	2	3	_____

\*Additional comments on any of these programs? \_\_\_\_\_

\*What other programs or services would you be interested in? \_\_\_\_\_

\*If you weren't able to benefit from our programs or services, why not? \_\_\_\_\_

\*Are you a parent of a child with epilepsy or an adult with epilepsy?

(Circle one) Parent    Adult    Other: \_\_\_\_\_

Thank you for your feedback! Christine Toes and Melissa Murphy

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

**Sunday, September 14**

Teens/Young Professionals Bowling Event  
at Bowlmor Lanes (2-5 pm)

**Wednesday, October 8**

Teens/Young Professionals Rock Climbing Event  
at Chelsea Pier (7-9 pm)

**Sunday, October 19**

Art Day at the Children's Museum

**Saturday, November 8**

Conference on Epilepsy at NYU

**Saturday, November 15**

New Jersey Bowl-A-Thon  
Contact:[amnesia904@aol.com](mailto:amnesia904@aol.com)

**Monday, March 1, 2004**

f.a.c.e.s. Gala

### **Other Local Epilepsy Events**

(NOT affiliated with f.a.c.e.s.)

#### **Epilepsy Foundation of Southern New York:**

Oct. 4<sup>th</sup>, **Walk for Epilepsy** at Rockland Lake in Congers, NY  
and Nov. 9<sup>th</sup>, **Guitars for Life Concert** at Helen Hayes  
Theatre in Nyack, NY.

Contact: Leslie Slender at [exec@efsny.com](mailto:exec@efsny.com).

#### **Tuberous Sclerosis:**

Thurs., Nov. 13, **Comedy Night** at the Copacabana in Manhattan.

Contact: Liz Buchsbaum at [Esob89@aol.com](mailto:Esob89@aol.com).

#### **Epilepsy Foundation of New Jersey:**

Autumn Gala honoring Orrin Devinsky, MD, at the Madison  
Hotel in Convent Station, NJ. Contact: Heather at 609.392.4900.

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