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*Happy Spring!*

 **Epilepsy Society of Southern New York, Inc.**

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Spring 2006

Volume 12, No. 1

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*A Special Holiday Celebration*



On Tuesday, December 27<sup>th</sup>, the *Chris McCarthy Scholarship Fund* sponsored a trip to the Big Apple, where 50 of our guests joined together for an exceptional holiday gathering and enjoyed the famous **New York City Rockettes** in the “*Christmas Spectacular*” show at **Radio City Music Hall**.

The day continued on a journey to **Times Square**! No matter what team you're cheering for, you'll always have the best seats in the house at the **ESPN Zone's** private **Sky Box**. The sports arena and a fabulous buffet lunch was enjoyed by all.



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**From Our Leadership**

**Joseph J. DeLosa**  
President, Board of Directors

**Dear Friends,**

It's hard to believe that the Epilepsy Society is entering our 29th year providing services to people with epilepsy and their families. We will be planning our 30 year celebration for next year, and we hope you will all join us! More to come on that occasion.

Through referrals and requests from various agencies, we have broadened our service base to serve other disabilities besides epilepsy. Our caseload for Traumatic Brain Injury (TBI), Autism, Cerebral Palsy and others have greatly increased, and as a result we have started another corporation, **Capabilities Partnership, Inc. (CPI)**. You will hear more about that from the Chair of CPI, **Brian A. Witkin**, in our next newsletter. The Epilepsy Society will serve only those with epilepsy, and CPI will function to serve other disabilities. We have some exciting plans for both corporations.

We welcome a new member to our Board of Directors; **John M. Clemente**, Vice President, Business Development Officer at **USB Holding Co.**

On behalf of our Board and Janice Gay, I'm very pleased that we have a new Associate Director, **Leslie Slender**. Leslie has functioned as Janice's valued Director of Administration, and now she will assist us moving forward with our plans for the future.

**Joseph J. DeLosa,**  
President, ESSNY Board of Directors

**Appointed Associate Director**

We are pleased to announce that **Leslie Slender** has been appointed our new Associate Director.

Leslie has worked in various capacities at ESSNY, and brings over 15 years experience to us in various leadership roles and a diverse range of managerial achievements.

Implementing this imperative position is an important step toward our future plans and overall direction, and Leslie is well qualified to help us move forward.

## McCarthy Scholarship Fund gives... “Hope”



**Sean** is a 9-year-old non-verbal autistic boy, who suffers from an intractable seizure disorder. Sean has always taken an interest in dogs, and as his birthday approached we decided to get a yellow Labrador retriever, knowing that they are used to help people with various disabilities. Our hope was that the presence of a dog would help Sean in many ways, and assist in the challenges faced with both autism and epilepsy.

Our new puppy, “**Blue**” was named after Sean’s favorite TV show, **Blues Clues**. Sean and Blue became friends, and for an unknown reason, Sean’s teachers advised that he was doing better in school, and a decrease was noticed in his seizure activity. We were overjoyed.

Unfortunately our family suffered an unexpected loss 3 months later when “Blue” became ill. We were devastated and didn’t know how to explain to an autistic boy that the dog he looks for is never coming back. Feeling sad, we decided to wait to replace the dog.

The Holidays came and went and we were settling into the New Year when I heard from the Epilepsy Society inquiring about our loss, and offering to help research breeders when we were ready. The following day I was contacted again saying that a dog has been located. I was speechless and financially unprepared, but at the same time excited. Needless to say we went to see the dog and fell in love with her. While holding the puppy, a big surprise came our way when we were told that the **Chris McCarthy Scholarship Fund** would like to give Sean a gift...the gift of “**Hope**”. I could not express what I felt in my heart without crying. “**Hope**” was named by the staff of the **Epilepsy Society**, because they are all a great part of our lives.

*A special thanks to the McCarthy family and friends for giving us “Hope.”*

*By Lisa Rolff Fitzgerald*

## Bringing home the Bronze!

**Chanda Gunn** had a goal. She wanted to be in the **U. S. Olympic women’s hockey team**. And she was not going to let her epilepsy shut her out. So, she didn’t! Chanda, at age 25, was the starting goaltender for the team who achieved a **Bronze medal** in the **Winter Olympics in Torino, Italy**.

Diagnosed with juvenile absence epilepsy at age 9, and not understanding why everyone was so upset, her swimming career was abruptly called to a halt, as well as her interest in surfing.

After extensive testing, the good news was that the medication prescribed for her did control her seizures and she now looked for new activities. First came soccer, then street hockey. Goalie was her position.

**The University of Wisconsin** awarded her an athletic scholarship to play hockey. Early in her freshman year she suffered a series of tonic clonic



seizures and had to drop out of school and return home. Almost a year of tests followed and new treatment returned her seizure control.

When the Wisconsin program moved on, Chanda went to **Northeastern University in Boston**.

By her sophomore year she started every single game. By the end of that 1998 season she made the women’s national team.

Chanda is grateful for the support she receives from her teammates who all know about her epilepsy. They understand the various situations that can trigger her seizures, and they all try to keep her out of harms way.

**Our biggest Congratulations to Chanda and the United States Olympic women’s hockey team!**

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## Sudden Unexpected Death in Epilepsy

**W. Allen Hauser, MD**  
**Professor of Neurology and Epidemiology**  
**Columbia University**  
**Chair, Professional Advisory Board**  
**Board of Directors**  
**Epilepsy Society of Southern New York, Inc.**

A question frequently asked of professionals by people with epilepsy (or by their loved ones) is “will I die from a seizure”? While the answer to that question is in general no, there is a condition associated with epilepsy and may be seizure related that has caused increasing concern among families of people with epilepsy. There is a condition in which a person with seizures is found dead, frequently in bed, and without any obvious cause of death being identified despite full medical evaluation. There is at times some evidence of a recent seizure (bitten tongue for example) but this is not always the case. This condition is termed Sudden Unexpected Death in Epilepsy.

Sudden unexpected death in epilepsy (SUDEP) is one of the most frequently identified epilepsy-related causes of death. SUDEP occurs in about 4 of 10,000 people each year with new onset epilepsy or in those with well controlled seizures. This is similar to that seen in the general population. The frequency is considerably higher in people with chronic and uncontrolled epilepsy. In those with occasional seizures, 1 or two people per 1000 will die each year, and in those with severe, refractory seizures, up to 5 or 6 per thousand will die. SUDEP may occur at any age, but occurs most frequently in those between age 20 and 40 years of age, and may be more frequent in women.

Most SUDEP appears to be related to seizures. When witnessed, the fatal event generally occurred in association with a generalized tonic-clonic seizure. Two recent studies suggest that the frequencies of seizures, particularly generalized tonic clonic seizures are the strongest risk factor for SUDEP. People with one or more seizures a year are at a 20 fold increase in risk for SUDEP when compared with those who are free of seizures and this risk seems to increase with increasing numbers of yearly seizures. Onset of epilepsy at an early age and long duration of the disorder are other risk factors. Although SUDEP has not been associated with the use of any particular antiepileptic drug, some studies have reported an increased risk in those taking multiple AEDs. This is independent from seizure frequency. Frequent dose changes are also associated with an increased risk.

Although recent studies have been helpful in identifying people at risk for SUDEP, providing clues to mechanisms behind SUDEP, no single risk factor is common to all SUDEP, and it is likely that there are multiple causes of SUDEP. The underlying mechanism may be primarily cardiac with seizures (or a brain abnormality) triggering a cardiac arrhythmia but there is also strong evidence that the initial mechanism may be related to a primary respiratory failure. Further studies are needed to develop better understanding of basic mechanisms of SUDEP and to improve treatment strategies to prevent SUDEP.

Since the risk for SUDEP varies depending on individual profiles, people with epilepsy and concerned family members should discuss the risk for SUDEP with their physician. None the less, good seizure control seems of paramount importance to prevent SUDEP, and the person with epilepsy and their physician should strive to optimize seizure control.

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Chris is sending kids to camp!

## Camp Scholarships!

*The memory of **Christopher McCarthy** touches the lives of individuals who live with epilepsy. As we remember Chris' smile and laughter, his courage and strength, his love for baseball and good times, we are honored to offer summer camp scholarships sponsored by the McCarthy family and friends to children affected with epilepsy. Chris was one of the **Epilepsy Society's** first members, and we are privileged to help continue his legacy.*

Summer camps provide fun, healthy and educational experiences for all children. [The Chris McCarthy Scholarship Program](#), along with the [Epilepsy Society of Southern New York](#) is providing funding to help children with epilepsy participate in summer camps.

Each \$250 scholarship may be used to pay all or part of the cost for attending any summer camp selected by the child and parents.

Children ages 5 to 18 who have been diagnosed with seizure disorders and need financial assistance to attend camp are eligible to apply for this scholarship.

A stipend for transportation is also available, if needed.

To apply visit [www.essny.com](http://www.essny.com)

or call 845-627-0627 ext. 123

for an application



## Want to Chat?



ESSNY has a very active **Partner-to-Partner Telephone Network**. Volunteers from our Consumer Advisory Council who either have a diagnosis of epilepsy or have young or grown children with epilepsy are eager to share their experiences and answer your questions: What is surgery like? How do I prepare myself for surgery? How do I manage my time and energy with my child experiencing uncontrolled seizures? How do I help siblings? How do I answer personal questions about my epilepsy? Who do I tell and how?

Their experiences are invaluable to those who are moving along on a similar journey.

Creating a well-matched partnership between individuals facing common concerns about living well with epilepsy is key to the success of this program. If you would like to speak with other individuals who are now or have been touched by epilepsy in some common way, please contact us.

### ESSNY Adult Epilepsy Support Group



Come join us on the third Wednesday of every month for the ESSNY Adult Epilepsy Support Group. We are located at **Good Samaritan Hospital**, 255 Lafayette Ave., Suffern, NY, 10901 on the 4th floor in the Patient/Family Education Resource Center.

The Adult Epilepsy Support Group is a friendly, open, unbiased environment where adults with epilepsy and parents of children with epilepsy can talk freely about their problems. Refreshments are provided by the hospital.

For further information on the **Telephone Network** and the **Support Group**, please contact **Ann Marie Bezuyen** at **845.627.0627 ext. 142**, or by email at [education1@essny.com](mailto:education1@essny.com).

### Patient and Caretaker Education Program on Epilepsy and Seizures

The doctors from the Epilepsy Program at Orange Regional Medical Center will present a free seminar about the following topics. Doctors will be available to answer questions.

- Epilepsy medications
- Other treatments: surgery, diets, vagal nerve stimulator
- What is neuropsychological testing and what is it for?
- Cognitive Rehabilitation
- What community resources are available for persons with epilepsy?

**Where:** Orange Regional Medical Center - Horton Campus Auditorium, 60 Prospect Avenue, Middletown

**When:** Saturday - April 8, 2006

**Time:** 8-9AM Registration and Breakfast  
9-12 noon: Educational Program

*Sponsored by Orange Regional Medical Center  
and the Epilepsy Society of Southern New York, Inc.*

Please register by calling at 1-888-321-ORMC (6762) or 845-344-2984



The time is approaching for my "1<sup>st</sup> Annual Walk For Epilepsy"  
on Sunday, April 30<sup>th</sup> at The State University of New York (SUNY),  
New Paltz campus from 1:00-4:00pm!

My name is Sara-Elizabeth and I was diagnosed with Idiopathic Benign Childhood Epilepsy and had my first seizure at 16 months old, but I am now off all medications and seizure free. My wish is to help others who are affected with epilepsy and live with this disorder on a daily basis.

Money is needed to raise awareness for epilepsy, and to support this outreach, I have organized a 2-mile walk together with the Epilepsy Society of Southern New York and SUNY. I hope that you and many others will participate as a walker or supporter and help make this a successful event.

For your convenience, we have attached a sponsor sheet on the back of this page so you can get started today collecting pledges!

Please help me follow my dream in my "1<sup>st</sup> Annual Walk for Epilepsy", and contact Leslie Slender at 845.627.0627 ext 123, or by email at [lslender@essny.com](mailto:lslender@essny.com) for further information on how you can help the many people who are affected with epilepsy on a daily basis. Please visit [www.essny.com](http://www.essny.com)

Thank you,

Sara-Elizabeth

“Sara’s 1<sup>st</sup> Annual 2006 Walk for Epilepsy”



Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip Code \_\_\_\_\_

Phone \_\_\_\_\_

Walkers pledges must ‘total’ a minimum of \$25.00.

Cash or checks made out to ESSNY

	Sponsor	Address	Amount Pledged
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Please bring form and pledges the day of Walk, OR mail to  
ESSNY, One Blue Hill Plaza, Box 1745 Pearl River, NY 10965  
Attn: Leslie Slender

## MEET OUR "KIDS"



*"If you would like to learn the fine art of Bunraku puppetry and volunteer your time to visit schools and perform with the puppets, or if you would like to "adopt a puppet" to help support this program and enjoy the acknowledgement of your support in all media coverage that our troupe receives, please call me."*

**Ann Marie Bezuyen**



Brian and Joe are having lunch in the cafeteria. While talking about a new movie, Brian suddenly has a seizure. Joe gets excited and upset and starts to run for Brian's teacher. Brian looks up from the floor and asks him where he's going. The two friends begin to talk about seizures...

Thus begins ESSNY's new **Kids On The Block Puppet Program**. The KIDS are a special troupe of disabled and non-disabled puppets. They dress and act like real children. They are nearly life-size. Like real children, each one has definite likes and dislikes, hopes and fears, talents and limitations.

Audiences interact directly with the puppet characters during a question and answer session at the end of each program. This unique form of communication provides young people with a safe environment to learn and develop an attitude of sensitivity and understanding that will serve them well for the rest of their lives.

The Epilepsy Society of Southern New York is providing free puppet programs to young school-aged children. Please call **Ann Marie Bezuyen** at **845.627.0627 ext. 142** for further information or to schedule a program for your school or organization.

## UPCOMING EVENTS

- ***Sara's 1st Annual Walk for Epilepsy***  
*Sunday, April 30<sup>th</sup> at SUNY New Paltz campus.*



- ***Spring Outing Day Trip sponsored by the Chris McCarthy Scholarship Fund***  
*Saturday, June 10th to the Bronx Zoo*



- ***15th Annual Bowl-A-Thon***  
*Friday, June 23<sup>rd</sup> at New City Bowl in New City, NY*



- ***ESSNY Golf Outing***  
*Wednesday September 13<sup>th</sup> at New York Country Club, New Hempstead, NY.*



For further information on the above events please contact  
**Leslie Slender** at **845.627.0627 ext. 123**, or by email at [lslender@essny.com](mailto:lslender@essny.com)

## 2005 Donations:

Without the support of donors and volunteers, many of our efforts would not be achieved. We would like to thank the following individuals and corporations for their generous contributions. We sincerely regret any omissions or errors.

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## **CLINICAL CORNER**

### **Drug Name Confusion: Toprol-XL, Topamax, Tegretol and Tegretol-XR.**

The FDA recognizes that medication errors can sometimes occur when drug names look alike or sound alike. They have received reports of mix-ups between several drugs that all begin with the letter "T."

**Topamax** is used with other medications to control seizures and to prevent migraine headaches. **Tegretol or Tegretol-XR** is used to treat seizures and nerve pain. It is also used to treat bipolar disorder. **Toprol-XL** is a beta-blocker and is used to reduce hypertension (high blood pressure), to treat chest pain (angina), to treat heart failure, and to reduce the risk that a heart attack will recur.

According to the FDA, medication errors have occurred when prescriptions were poorly written, misinterpreted, or incorrectly labeled or dispensed. Computer selection errors have also played a role in this type of prescription error. In a number of cases, patients have suffered adverse events and in some cases they had to be hospitalized.

The key factor in these errors is the similarity between the product names. Adding to the problem is the fact that these drugs are often stored close to each other on pharmacy shelves. There is also some overlap between the available dosage strengths of these products. Consumers of prescription medications should follow some simple guidelines when picking up a new

medication or a renewal:

#### ► **Check the label on each prescription:**

Is this the name of the drug that my doctor prescribed for me?

Is my name on the label?

Is my contact information correct?

Does my doctor's name appear on the label?

#### ► **Check the contents:**

Does this look like my old medication?

Are these pills the same color, size and shape as the ones I've taken before?

Does the pill bottle contain the correct amount of pills?

#### ► **And remember to:**

Take your medication as prescribed.

Store your medication in a cool dry place.

**FDA MedWatch Safety Alert - Toprol-XL (metoprolol succinate) extended release tablets / Topamax (topiramate) tablets / Tegretol (carbamazepine) / Tegretol-XR (carbamazepine extended release)**

<http://www.fda.gov/medwatch/safety/2005/safety05.htm#Toprol>

**FDA Patient Safety News: Show #46, December 2005**

## Our New Location:

### In **Orange County...**

615 Rt. 32

Highland Mills, NY 10930

Phone: (845) 928-1126

Fax: (845) 928-1198

### In **Westchester County...**

200 White Plains Road

Tarrytown, NY 10591

Phone: (914) 332-5059

Fax: (914) 332-5086

## News from the Vocational Services Department:

- We are pleased to announce 2 promotions within the department; **Lora Lavelle** and **Tara Zucconi** have both been promoted to Senior Employment Specialists. Congratulations Lora and Tara!
- A warm welcome to 3 new Employment Specialists at ESSNY : **Adrienne Diemer**, **Beth Trout**, and **James Allen**.
- Due to an increase in our placement contract in Orange County, we are providing additional employment opportunities within the county.
- One of our strongest supportive employers, **Bergen Supply of Pearl River**, has hired their 6<sup>th</sup> consumer for a stock position.
- **Blue Hill Management** has hired their 5<sup>th</sup> person through ESSNY as a security guard for the facility at Blue Hill Plaza.
- **Saturn of West Nyack** is right behind with their 2<sup>nd</sup> ESSNY consumer working as a lot attendant.

On behalf of our clients and staff, we thank all of the companies that continue to support our work in the Vocational Service Department.

## Update from the Service Coordination Department:

We are happy to announce the expansion within our department, as we assume 2 new essential programs. Our staff has begun a **Structured Day Program** for our consumers, which will provide an opportunity for individuals with a traumatic brain injury to engage in meaningful recreational life activities.

We are also starting the **Intensive Behavioral Planning Program**, which will provide clinical interventions to assist individuals in their daily lives.

Pictured below is our staff happily delivering holiday food, and making holiday visits to our consumers!



## We're Online, Check Us Out

For up to date information regarding any of our programs, services, upcoming events and pertinent information please check the Society's website at [www.essny.com](http://www.essny.com)

