

## -Update On New Anti-Epileptic Drugs-



Lawrence J. Hirsch, MD

Fortunately, there are several developments in this area this year. Two new antiepileptic drugs (AEDs) have been approved, Vimpat (lacosamide) and Banzel (rufinamide). In addition, there are new extended release formulations of existing AEDs, Keppra-XR and Lamictal-XR. Finally, there is another formulation of Lamictal available, which is a "melts-in-your-mouth" type called Lamictal-ODT. Below is a brief summary of these.

### Vimpat (generic name: lacosamide)

Vimpat is a new medication approved for add-on use in those older than 16 years with partial-onset seizures, meaning seizures that start in one part of the brain (also known as focal seizures, partial epilepsy, or localization-related epilepsy, and would include seizures from any lobe such as temporal lobe epilepsy or frontal lobe epilepsy). It is approved for use in combination with any other AED. It can be taken with or without food, and can be crushed if needed. It is usually taken twice per day, and can begin working within a week.

Overall, Vimpat is well tolerated, with no significant effects on alertness, thinking, mood or weight and only rare allergic reactions. The most common side effects are dizziness, headache, nausea and double vision, all of which occur more often at higher doses.

How well does it work? In the clinical trials leading to approval, just under half of patients (40-49%) had their seizure frequency cut in half. Overall, this is probably comparable to several other AEDs, though no studies have compared Vimpat directly to other AEDs.

### Banzel (generic name: rufinamide)

Banzel is a new medication approved for add-on use in children 4 years of age and older and in adults with a specific epilepsy syndrome known as Lennox-Gastaut Syndrome (LGS). LGS is a syndrome that includes multiple seizure types that are usually difficult to control, and patients are typically cognitively impaired. Seizure types include tonic (brief whole body stiffening), atonic (sudden loss of muscle tone), absence (staring) and generalized tonic-clonic ("grand mal", or convulsions). Some of these seizures can cause sudden falls, known as "drop attacks", particularly the tonic and atonic seizures. Banzel is best taken with food, can be crushed if needed (though it has a bitter taste), and is usually taken twice per day.

The most common side effects of Banzel are sleepiness and nausea/vomiting, but it can also cause dizziness, headache, blurred vision and tremor. These side effects are usually worse at higher doses. It seems to have little if any adverse effect on thinking or behavior.

How well does it work? Overall, seizures decreased by about 1/3 in the clinical trials. Drop attacks decreased by 40% (almost half). As there are not many effective options for these patients, this is a welcome addition to the fight against seizures in LGS.

Continued-

For more information on LGS, please see the LGS foundation website at <http://www.lgsfoundation.org/>.

### Keppra-XR (generic name: levetiracetam)

This is a new extended-release form of Keppra that allows once a day dosing. It provides the same medication, but releases it slowly over many hours in the gastro-intestinal tract.

### Lamictal-XR (generic name: lamotrigine)

This is a new extended-release form of Lamictal that allows once a day dosing. It provides the same medication, but releases it slowly over many hours in the gastro-intestinal tract.

For further information on antiepileptic drugs, please see: <http://www.essny.org/medicalinfo.html> or [http://www.epilepsy.com/EPILEPSY/seizure\\_medicines](http://www.epilepsy.com/EPILEPSY/seizure_medicines) or <http://www.epilepsyfoundation.org/about/treatment/medications>

## Structured Day Program

The CPI TBI Structured Day Program has been up and running since November 2008.

Our program focuses on enhancing each individual's independent living skills, socialization, and increased community inclusion. This program is person centered, focusing on what each individual wants to learn, improve, and participate in.

A typical day in the program may include a variety of activities such as cooking/baking a recipe of the group's choice— which the staff here has certainly enjoyed! The group may go shopping at the mall and other local stores, participate in various board games such as Monopoly or Uno, play a Nintendo Wii video game, use the pool table, or learn more about the computer and internet. Other activities that take place in the center are learning how to budget, literacy training, art and music classes, and horticulture.

Some recent community based activities have been playing sports or taking walks at the local parks, going to the lake, and even attending special trips at the Bronx Zoo, Rye Playland, and Ellis Island. Many more exciting and educational events are planned, so please contact us for more information!



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**Rockland Support Group Moving!**

When our Adult Epilepsy Support Group resumes in September after our summer break we will be located in the Community Rooms at the Palisades Center Mall in Nyack. This is a central location with easy access to public transportation. Contact education3@essny.com for more details!

**Our Westchester Office has moved!**

*The new address & phone # as of August 1st.*

**75 South Broadway-Suite 444  
 White Plains, NY 10601**

**Phone # (914) 304-4233**

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# Janice W. Gay Retires



On April 15th over 50 staff, board members, industry colleagues, and friends gathered to honor Janice W. Gay on her retirement after 33 years of dedicated service. The party was to thank Janice for all of her hard work and dedication in building our agency from a group of concerned parents who could not find the services they needed to help their children with epilepsy. Under Janice's leadership ESSNY flourished into a thriving agency with a broad range of services and support for those with a multitude of disabilities. Congratulations Janice and enjoy your well deserved retirement!



There are 23 Chris' Kids this summer!

The Chris McCarthy Summer Camp Scholarship Program provided almost \$20,000 for children to attend camps this summer. Chris' Kids went to day camps, overnight and town camps, and camps for horseback riding, technology, basketball, and many more.

Thank you to Tim and the McCarthy family for sponsoring this wonderful program, especially in this current difficult economy!

## Mark Your Calendar! Upcoming Events:

**Orange County Bowl-A-Thon!**

Date: Saturday, October 10th, 2009  
 Place: Colonial Lanes  
 78 Brookside Avenue,  
 Chester, NY 10998  
 Time: 6-9 p.m.  
 Contact us at (845) 627-0527 for sponsor sheets and more information!

**Epilepsy Gala!**

Date: Saturday, November 7th, 2009  
 For more details go to:  
[www.theimportanceofone-epilepsygala.com](http://www.theimportanceofone-epilepsygala.com)  
 Don't miss out on the first Annual 'Epilepsy Idol' Competition!



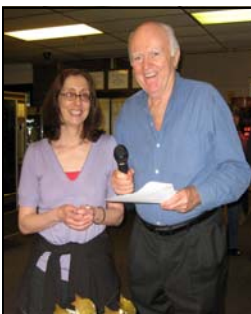
## Fundraising Events!



**Our Rockland Bowl-A-Thon**

celebrated its 18th Annual Event at the New City Bowl on June 19th, 2009. Many people came to bowl and have

fun with us. Over 7,000 dollars was raised through the sponsorships and raffles sold by our dedicated supporters.



Our second annual **Travis O'Keefe Memorial Epilepsy Fundraiser** was held on June 27, 2009 at the Hub Shopping Center in Nyack. The Thomas Clifford's Martial Arts again helped to raise funds for our programs. It was a beautiful afternoon and much fun, prizes, and music were enjoyed by all who attended this fantastic event.



**2008 Financials**

Rounded to Thousands with % difference from 2007

	<u>ESSNY</u>		<u>CPI</u>	
Revenue and Support				
Fees & Grants	\$1,147.9	7.8%	\$747.3	6.7%
Contributions	\$28.5		\$0.3	
Interest Income	\$4.5		\$0.1	
Other (incl McCarthy Fund)	\$158.0		\$0.0	
	\$1,338.9	10.9%	\$747.7	6.7%
Expenses				
Program Services	\$961.6	4.1%	\$614.6	11.3%
Support Services*	\$362.8	68.1%	\$93.2	5.3%
* Increase - move to new Agency office	\$1,324.4	16.3%	\$707.8	10.4%
Increase in Net Assets	\$14.5		\$39.9	

For more details on the financials for either the Epilepsy Society of Southern New York and/or for Capabilities Partnership, Inc. please contact us on 845-627-0627.