



**TRIGEMINAL NEURALGIA ASSOCIATION  
TEXAS SUPPORT GROUPS NEWSLETTER  
October 2005**

**HURRICANE RITA**

Our hearts go out to all of those affected by Hurricane Rita. If you have moved because of the storm, please provide Shelly Wilson with your new address so we can continue to get the newsletter and meeting schedule to you. Shelly can be reached either via e-mail at [swilson@tna-support.org](mailto:swilson@tna-support.org) or by calling 817-416-7202.

**TNA DONATIONS**

Because of hurricanes Katrina and Rita, contributions to non-profit organizations are down with the exception of disaster relief agencies. TNA is one of those organizations who contributions are lower than expected for this time of year.

If you plan on making a tax-deductible donation to TNA this year and can afford to do it now rather than at the end of the year, TNA could put your contribution to good use immediately. TNA will still need contributions at the end of the year but for those of you who can send in your donation today, TNA would appreciate it.

Please send your tax-deductible contribution to TNA, 2801 S.W. Archer Rd., Gainesville, FL 32608 or you can contribute on TNA's website at [www.endthepain.org](http://www.endthepain.org). Thanks!

**LYRICA IS NOW AVAILABLE!**

There is a new anti-seizure medication available to facial pain patients. The prescription drug is called Lyrica and is manufactured by Pfizer.

This is a newer formulation of Neurontin that has been available in Europe since 2004 and in Mexico since the fall of 2004. Patients in those countries are reporting fewer side effects when taking Lyrica versus when they took Neurontin.

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A big difference between Lyrica and Neurontin is that Lyrica stays in your system longer so you don't have to take it as frequently.

If you try Lyrica, send your experience (good or bad) to Shelly Wilson via e-mail at [swilson@tna-support.org](mailto:swilson@tna-support.org) or mail it to Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092. Let us know how the switch from Neurontin to Lyrica went. Do you have fewer side effects? If this is your first Pfizer anti-seizure medicine, how did it work for you? We'll share the results in future newsletters.

## **PFIZER'S LYRICA NOW AVAILABLE FOR PATIENTS**

*Press Release – September 21, 2005*

Pfizer Inc announced today that Lyrica (pregabalin) capsules c-v, a new prescription medication for the management of neuropathic pain associated with diabetic peripheral neuropathy (DPN), postherpetic neuralgia (PHN) and adjunctive treatment of partial onset seizures in adults with epilepsy, is now available in U.S. pharmacies.

“I am pleased to be able to prescribe Lyrica for my patients,” said Dr. Edgar Ross, director of the Pain Management Center at Brigham and Women's Hospital in Boston. “Until now, we've had limited options to treat patients with these types of neuropathic pain. I have seen the benefits of Lyrica in providing rapid and sustained pain relief among my patients in the clinical trials.”

Developed by Pfizer, Lyrica has a newly defined mechanism of action and represents an important treatment advance. It is the first treatment approved by the U.S. Food and Drug Administration to treat two distinct forms of neuropathic pain, and is the first new antiepileptic drug introduced in five years.

Neuropathic pain, one of the most debilitating forms of pain, is caused by nerve damage that can result from underlying conditions, such as diabetes or shingles. Nearly half of the 18 million Americans with diabetes will develop some form of diabetic neuropathy over the course of their disease.

PHN is a complication of shingles, a painful outbreak of rash or blisters on the skin caused by a reactivation of the same virus that causes chicken pox (the herpes zoster virus). Each year, about 150,000 Americans develop PHN, which is often characterized as constant, stabbing, burning or electric shock-like sensation.

The most common side effects of Lyrica are dizziness, sleepiness, dry mouth, swelling of hands and feet, blurred vision, weight gain and trouble concentrating. The discontinuation rate due to side effects was low. Patients with a history of drug or alcohol abuse may have a higher chance of misuse or abuse of Lyrica.

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For more information: [www.lyrica.com](http://www.lyrica.com)

## **TNA REGIONAL CONFERENCE – DALLAS, TX**

Save the date! TNA will hold a one-day regional conference at UT Southwestern Medical Center in Dallas on Saturday, February 18, 2006 for patients, supporters, and health care providers to attend. Registration brochures with all of the details will be mailed out in November.

The last regional conference we had in Dallas, November 2003, featured primarily speakers from the DFW area. We sold out of seats 5 weeks before the conference.

This conference will feature some of the best health care providers throughout the state of Texas. We've booked an auditorium for this meeting but our membership has tripled in size since November 2003. So, if you plan on attending, make sure to save your seat by registering as soon as you get your registration brochure in November.

## **MEDICARE PART D TIMELINE**

**Now:** Seniors can apply for “Extra Help”

**Beginning in October 2005:** Plans will begin releasing details on plan design and pricing

**November 15, 2005 – May 15, 2005:** Initial enrollment period

**January 1, 2006:** Medicare Part D benefits begin; Prescription Processing phase begins

**June 1, 2006:** 1% permanent premium increase per month for eligible individuals who did not enroll during initial enrollment phase

## **WEBSITE OF INTEREST**

[www.cvsmed.com](http://www.cvsmed.com) – get a free informational booklet detailing an introduction to Part D: Medicare's New Prescription Drug Coverage and \$10 in coupons (or call 1-800-508-1635 to request it)

## **YOU'RE THE BOSS AT THE HOSPITAL**

The following article ran in USA TODAY on September 19, 2005.

*When a loved one needs care, don't be afraid to speak up*

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Hospitals are places of healing and recovery. Most people who work in them are caring and dedicated.

But I wouldn't voluntarily leave a loved one alone in one. That's because hospitals also can be dangerous, confusing and impersonal. A report in 2000 from the Institute of Medicine found that up to 98,000 people die from preventable infections, drug mix-ups and other errors in U.S. hospitals each year; a recent update estimated similar death rates, despite some attempts at improvement. And safety isn't the only concern: Too often, studies show, patients and their families leave hospitals poorly informed about the treatment they've received or the follow-up care they need.

Hospitals say they are trying to do better. Any visit to one reveals their efforts: the signs that remind staffers to wash their hands, the double-checking of identity bracelets, the careful questioning of patients. You're having surgery on which leg today, Mr. Smith? There's also much going on behind the scenes, including an increase in computerized prescriptions and record-keeping.

That's all great. But when your own child, spouse or parent is hospitalized, you should walk through those doors with open eyes and the attitude that you are a crucial part of the care team.

"It's important to convey a sense of capability and confidence ... even if it's a sham," says Suzanne Geffen Mintz, president and co-founder of the National Family Caregivers Association ([www.nfcacares.org](http://www.nfcacares.org)).

Greg Barg, editor of *Today's Caregiver* and the website [caregiver.com](http://caregiver.com), says: "You are the expert on your loved one. Don't be afraid to speak up."

Rule One: Be there. "Stay in that room 24/7 if you can," says Susan Sheridan, president of Consumers Advancing Patient Safety ([www.patientsafety.org](http://www.patientsafety.org)). Line up friends and relatives to help stand vigil. Your presence is especially crucial during admitting and discharge, when important information is exchanged, and in the days after surgery, when the risk of infection and other complications is highest.

Though some hospitals still have restrictive visitation policies, many now encourage family members to stay overnight and provide them with beds or fold-out chairs.

Once bedside, there's much you can do. Mintz says to be prepared with:

- Documents that might affect medical decisions – for example, an advance medical directive outlining the wishes of a patient no longer able to express them.
- A typed list of any medications the patient takes.
- For patients with chronic conditions, a written medical history and a list of all the physicians and other professionals involved. Include phone numbers.

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After you offer some information, start gathering it. Find out how best to keep in touch with the physician in charge of your loved one's case. If the doctor makes rounds at the same time each day, try to be there with a short list of questions. Get to know the nurses and their routines. Ask when they change shifts. (That can be a hectic time, so save your questions until a new nurse settles in. It also can be a dangerous time, Barg says, because nurses are preoccupied with exchanging notes. So stay put and watch for trouble, anything from a fall from bed to a spike in temperature.)

If you see a problem, speak up, politely but firmly. Mintz says: "You want to go in with the assumption that everybody is trying to do the right thing, but mistakes happen, and we do need to watch out."

### **REQUEST FOR E-MAIL ADDRESSES**

If you have an e-mail address where we can send you this newsletter and our meeting schedule, please e-mail Shelly Wilson at [swilson@tna-support.org](mailto:swilson@tna-support.org). This helps us save on our mailing and copying costs.

Also, if you change your e-mail address, make sure to advise Shelly as well. Thanks!

### **UPDATES FROM OUR MEMBERS**

Botox is doing a good job for Floyd.

Angela has been on 90 mg of Cymbalta for about two months. It has reduced the frequency and level of her pain from TN. She still has bouts of pain but any help is a miracle. She had been on 2400 mg of Neurontin for months and it did not help her and the side effects were terrible. Angela wishes "Good luck to all".

This month, Bill is going to Pittsburgh to see Dr. Peter Jannetta at Allegheny General Hospital to see if he thinks he is a good candidate for a second MVD. If he is, Bill plans on having the MVD while in Pittsburgh. We wish him the best!

If you would like to share an update with our group, please let Shelly Wilson know. Send an e-mail to [swilson@tna-support.org](mailto:swilson@tna-support.org) or a written note to 604 Aberdeen Way, Southlake, TX 76092.

### **FUTURE TEXAS MEETING DATES**

Austin at St. David's Gamma Knife Center – 10/12  
Dallas at Zale Lipshy Hospital –10/26  
Fort Worth at Baylor All Saints – 11/1  
Hill Country – T.B.A.

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Houston – T.B.A.  
San Antonio – 10/11, 11/8, 12/13  
Tyler at East Texas Medical Center – T.B.A.  
Waco at Hillcrest Baptist Medical Center – 11/14

### **TREASURER’S REPORT – NORTH CENTRAL EAST TEXAS**

<b>Beginning Balance 8/31/05</b>		<b>\$3460.56</b>
<b>Donations Received</b>	<b>\$1019.40</b>	
Striking Back books	616.63	
Supplies	128.99	
Long Distance	27.05	
Postage	<u>9.50</u>	
<b>Total Expenses</b>	<b><u>\$782.17</u></b>	
<b>Ending Balance 9/29/05</b>		<b>\$3697.79</b>

### **FINANCIAL CONTRIBUTIONS**

Local TNA chapters *do not receive* funding from the national office. If you would like your tax-deductible contribution to go toward your local Texas chapter, please make your check payable to the order of Trigeminal Neuralgia Association and in the memo field put the name of your support group (i.e. North Central Texas chapter, Houston chapter) then mail it to Shelly Wilson, 604 Aberdeen Way, Southlake, TX 76092 for processing.

Please remember to also support the efforts of the Trigeminal Neuralgia Association’s national office. Typically, they are the first ones to make contact with new TN sufferers. They provide us with convention materials, run the national website, promote research, and a host of other activities.

Trigeminal Neuralgia Association  
2801 SW Archer Rd., Gainesville, FL 32608  
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[www.endthepain.org](http://www.endthepain.org)

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