**Potsdam Fibromyalgia Support Group**

**Newsletter**

##  September, 2013

# September is Pain Awareness Month

 Pain touches each one of us at one time or another. Pain can begin for many different reasons. Yet as common as pain is, the medical community is just beginning to understand and better address the many forms of pain. Partners for Understanding Pain developed this fact sheet to provide information and to distinguish among the three types of pain—chronic, acute, and cancer pain. Acute pain has a distinct beginning and end and is the result of illness or injury. This type of pain usually can be largely relieved with appropriate treatment, as can cancer pain. It is important that the pain be taken seriously and managed as part of sound patient care.

 Currently there is no cure for chronic pain and, as a condition that can affect individuals life- long, it also needs to be taken seriously. Chronic pain is now thought of like a chronic a disease, similar to diabetes or hypertension. Like diabetes and hypertension, once you have this chronic disease, it sometimes does not matter how it developed. Although some sources of pain, such as cancer, osteoarthritis or a herniated disc, can be identified, it is sometimes not even possible to determine what structures in the body cause a person to experience chronic pain. Nevertheless, a multidisciplinary treatment approach can help people with chronic pain regain control of their lives and reduce their sense of suffering.

 CHRONIC PAIN FACTS: Chronic pain lasts. Pain is considered chronic when it continues beyond the usual recovery period for an injury or an illness. It may be continuous or come and go. Persistent pain is when the body is unable to recover from an injury or illness. Chronic and persistent pain differ because chronic pain can be a malfunction of the nervous system, causing pain to be perceived even once tissue healing has occurred. Both chronic and persistent pain are real, can be very stressful for both the body and the soul and require careful, ongoing attention to be appropriately treated. Both chronic and persistent pain can be intractable, as the cause of pain cannot be removed or treated.

 Chronic pain is the number one cause of adult disability in the United States. Chronic pain can touch nearly every part of a person’s daily life. It also has an impact on the family and, because of its economic and social consequences, it affects us all. Chronic pain can be a source of frustration for the health care professionals who seek to provide care and assistance. Incidence: The American Chronic Pain Association (ACPA) estimates that one in three Americans (approximately 50 million people) suffers from some type of chronic pain Causes: Lower back problems, arthritis, cancer, complex regional pain syndrome, repetitive stress injuries, shingles, headaches, and fibromyalgia are the most common sources of chronic pain. Others include diabetic neuropathy, phantom limb sensation, and other neurological conditions.

 Although chronic and persistent pain often cannot be cured, they can be managed in collaboration with a health-care team. A physician can prescribe medications and determine whether interventions, such as injections or surgery, might be appropriate. A physical therapist can help you develop an appropriate exercise program and learn self-management strategies. Exercise is one of the best treatments for chronic pain, both to decrease the pain and to optimize your function. A psychologist or counselor can help you cope with the stress associated with chronic pain. Negative thought processes can amplify pain, so it is important to learn to deal with the negative thoughts that often accompany pain. In all cases, the individual with chronic pain must take an active role in the pain management process. For example, since stress amplifies pain, relaxation strategies such as yoga, meditation, or biofeedback can help decrease pain.

 There are a number of resources available to help people with chronic pain. The American Chronic Pain Association (<http://www.theacpa.org/>) and Pain Action (<http://www.painaction.com>) both have web sites with a lot of useful information for patients. The Potsdam Fibromyalgia Support Group website has extensive information in old newsletters (<http://people.clarkson.edu/~lrussek/FMSG.html>) . And, of course, a support group can provide companionship in the struggle with chronic pain.

Some of the information in this piece comes from The American Chronic Pain Association (<http://www.theacpa.org/>).

# In the News: Very Low Dose Cyclobenzaprene for FM

 Tonix Pharmaceuticals is a specialty pharmaceutical company developing new treatments for challenging disorders of the central nervous system, including fibromyalgia and post-traumatic stress disorder (PTSD). At the International Pain Society's Ninth World Congress on Myofascial Pain Syndrome and Fibromyalgia Syndrome in August, they announced that they were developing a special formulation of very low dose (VLD) cyclobenzaprine (CBP) specifically for FM and PTSD. They presented research showing the presumed mechanism by which the cyclobenzaprine works.

Previously reported research (note, the research was supported by Tonix), suggests that a very low dose of CBP at bedtime improved restorative sleep, decreased pain, tenderness and depression.

CBP is a muscle relaxant medication, often used for chronic muscle spasm. However, in the doses normally used (10-40 mg/day), side effects of drowsiness, dizziness and dry mouth are often troublesome. And, it is not clear if people with FM get a long term benefit from those high doses. The new research looked at taking a rapidly released CBP only at bed-time as a way to both avoid the side effects and to improve quality of sleep. Dosing for this VLD protocol was ≤ 4 mg/day – as much as 10x lower dose than normally prescribed.

The research also looked at quality of sleep. In particular, they looked at something called ‘cyclic alternating pattern’, which is a measure of sleep instability, or arousal during sleep. They also looked at time sleeping vs. awake at night. The specific changes in sleep pattern in response to the VLD CBP were complex, but the bottom line was that restorative sleep and symptoms improved in the VLD CBP group, but not in the placebo group.

It will be interesting to see if VLD CBP becomes part of the FM treatment arsenal.

* Press release from Tonix available at: <http://www.tonixpharma.com/media-center/press-releases?detail=494>
* Moldofsky H, Harris HW, et al. Effects of bedtime very low dose cylcobenzaprine on symptoms of sleep physiology in patients with fibromyalgia syndrome: A double-blind randomized placebo-controlled study. *J Rheum.* 2011;38(12):2653-2663.

# Women’s Wellness Day at CPH:

 On Saturday, September 28th, CPH is offering a day long program with presentations on diabetes, heart disease, stress reduction, celiac disease, migraines, fitness, nutrition and more. Dr. Russek will be giving the presentation on migraines an women. Reservations are required, so contact Lyndsay Macagg at 261-5413 to reserve a space.

# Acupuncturist to Speak at the October Meeting!

#  Shelby Connelly, acupuncturist, has agreed to talk about acupuncture at the October 28th Support Group meeting. It should be an excellent session, so put it on your calendar.

# September Support Group Meeting:

 The next meeting of the Potsdam Fibromyalgia Support Group will be **6:30 pm on Monday, September 23rd.** The meeting will be an open discussion and workshop: **Resources Available for Managing Pain.** Various resources will be available, such as pain diaries, tools for communicating with your physician, and web sites with educational materials.

This newsletter is a joint effort of Clarkson University and Canton-Potsdam Hospital. If you would prefer to receive these newsletters electronically, please send your email address to gilberta@clarkson.edu. You can access current and previous Potsdam Fibromyalgia Support Group Newsletters on our web site: [www.people.clarkson.edu/~lnrussek/FMSG](http://www.clarkson.edu/~lnrussek/FMSG).