**Potsdam Fibromyalgia Support Group**

**Newsletter**

# July, 2014

# History of the Potsdam Support Group

It is difficult to believe, but the Potsdam Fibromyalgia Support group first met on May 27, 1999 – making this our 15th year in operation. The group has aimed for a mix of lectures on special topics, guided discussions on special topics, and open discussions where people could just share what was on their minds.

We have had people come teach us about nutrition, Reiki, acupuncture, yoga, tai chi, qigung, self-hypnosis, massage, trigger point management. Several physicians have come to speak to the group, including a physiatrist, rheumatologist, pain specialist and a general practitioner.

The first newsletter was put out in October, 2001 – one side of a page on effective communication. Since then, the Newsletter has addressed a wide range of topics of interest to people with FM: talking to your doctor, fibrofog, FM medications, sleep, headaches, self-care strategies, social support, stress, relaxation, yoga, fatigue, meditation, coping strategies, and caregiver burnout. In 2007, we started the frequent column called “Trigger Pointers” with advice on identifying and managing trigger points. The goal was to provide self-care strategies to help people manage and minimize pain. Old newsletters and additional resources can be found on the web site: <http://people.clarkson.edu/~lrussek/FMSG.html>.

On May 12th, 2000, the mayor of Potsdam officially declared that date Fibromyalgia Awareness Day. That started a trend of Awareness Day events with special lectures and workshops. Massena officially declared May 12th Fibromyalgia Awareness Day a few years later.

Clarkson has had several student teams provide a number of 3-6 week long fibromyalgia wellness courses, Alexander Technique, chronic pain management, and headache management. These courses have been a great way for people with FM to learn more about managing their condition, while students learn more about the challenges of managing chronic conditions.

In turn, many people from the Support Group have given their time to work with physical therapy students learning about FM. Students have always valued that experience tremendously – the opportunity to get to know one person with FM well enough to really understand the issues related to having FM. Thanks to all who contributed their time and energy to educating the next generation of health care providers.

**Join us on Facebook – we now have a Facebook site just for our group.**

Although there are now many on-line support groups available on the internet, face-to-face meetings are still really important. There is nothing like laughing together and crying together to develop friendships and feel less alone.

The Potsdam group helped the Massena support group get started in 2002, and fostered a pain management group that was active for about a year in 2009.

While the Potsdam group is on sabbatical, people are encouraged to join other local fibromyalgia support groups:

* **The Massena Fibromyalgia Support Group** is on summer vacation, but will start up again in September. Contact group leader Maxine Dodge at 315-769-5778 or MMH Public Relations Office at 315-769-4262 for times and days.
* **The Northern New York Fibromyalgia Support Group** has recently formed in the Carthage area. You can find them on Facebook at nnyfibrosupportgroup or by email at [nnyfibrogroup@yahoo.com](mailto:nnyfibrogroup@yahoo.com). You can also call the Carthage Area Hospital for additional information or call 315-778-2027.
* **Join the Potsdam Fibromyalgia Support Group on Facebook!** We now have a private Facebook group just for our support group members. Contact Kris at [kris.a.lisdesigns37@gmail.com](mailto:kris.a.lisdesigns37@gmail.com) to join.

# July Fibromyalgia Support Group:

Monday July 28th, 6:30 pm. **Open discussion, information exchange, giveaways. Farewell to the group for a year.** Come join the gang for one last session!

# http://www.lonelyplanet.com/maps/pacific/australia/map_of_australia.jpgWhat is Leslie Doing Next Year?

C:\Users\Leslie Russek\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.IE5\DRRGYRCA\MC900133483[1].wmfI will be on sabbatical from Clarkson University from September, 2014 to April, 2015. My husband and I will be in Adelaide, Australia. We will both be doing research there. I will be working with at the BodyInMind Institute (<http://www.bodyinmind.org/>) with Dr. Lorimer Moseley, who studies how chronic pain remaps the brain and how specific types of exercises might be able to restore the normal mapping. The BodyInMind Institute is part of the University of Southern Australia, in Adelaide.

The idea is that once we ‘practice’ pain often enough, it becomes something of a habit and we react by habit, even if the original tissue damage is no longer present. One strategy to treat this pain is to use motor imagery – where we visualize performing a movement successfully without pain, either before performing it or instead of performing physically. Visualization helps the neurons to ‘practice’ healthier habits rather than the painful habits.

They have also looked at whether mirror therapy might be helpful for chronic pain. Mirror therapy is when you put a healthy arm or leg in front of a mirror that blocks the painful limb. When you move the healthy limb, you see what appears to be the painful limb moving in the mirror. This type of treatment has been used for years to treat phantom limb pain that sometimes occurs after amputations.

Some of the other research conducted by this group has been to look at how metaphors can alter our pain experience. Research has shown that how we think about our pain affects the pain experience. Pain is increased if we are greatly distressed by the pain and are worried that the pain means something is terribly wrong with our bodies. Research also shows that the more we learn about and understand our pain, the less pain and distress we typically feel. The research on metaphors looked at whether people could learn about their pain through metaphors, which are emotionally engaging and intuitively meaningful. Using metaphors and stories can help us ‘practice’ different ways of thinking about pain. The stories and metaphors used in this research are available as the book ***Painful Yarns***, by Lorimer Moseley.

So… I am looking forward to a productive time doing research in Australia. There will, of course, be time for some fun and relaxation. I will miss the group, but will enjoy this chance to recharge my batteries. Adelaide is known as a very livable city with many arts festivals, fine food and wine (it is in the Australian wine district). There are nearby beaches along the southern Australian shore. And, of course, our winter is their summer – so December will be balmy 80° days and 60° nights. Who could ask for more? Wish me well!

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 [lnrussek@clarkson.edu](mailto:lnrussek@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).