

The Carousel Network

Chronic Neuroimmune Diseases

Information & Support For Sonoma County

Chronic Fatigue Syndrome (CFS/CFIDS) • Fibromyalgia (FM)

Multiple Chemical Sensitivities (MCS) • Lyme Disease

122 Calistoga Road #216 • Santa Rosa, CA 95409-3702 • www.cndsinfo.net

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A letter from the editor...

Hello everyone! It's Pat O'Hara, your guest editor for this issue of the newsletter. There's a lot going on with *The Carousel Network* to tell you about in this issue, and also some important health news.

First of all, there are some changes in the works for TCN. As most of you know, Melissa Kaplan will be leaving us at the end of this year. Melissa has been with the group since near its inception, and has been president for the past 7 years. Her leadership has resulted in growing our group to the 73-member size it is today, and making available a significant body of multi-media information and support materials for people with a CFIDS, FM, MCS and Lyme. We all thank her for her years of service and friendship, and wish her well in her future journeys.

With Melissa's departure, we are holding elections for a new Board of Directors (the last page of this issue is your ballot). In addition to a new Board, we are still looking for a few volunteers to help with organizational tasks (see pg. 4). Please do your part—vote (here and in the national elections on November 2!) and volunteer if you can.

The health issues covered in this issue include the recent Vioxx recall, including some information on currently available and not-yet-approved alternatives for inflammation control and pain relief; and some important information the flu vaccine, FluMist.

A fond farewell from Melissa Kaplan

TCN President 1998-2004

December will be my last meeting and mark the end of my involvement with *The Carousel Network* (TCN). Thus, the potluck will be a good time for those who are thinking about helping TCN continue into the coming year (one year at a time!) to ask me questions and meet the other members who have volunteered to help keep things

going. I have set up a private email list for those who will be keeping things going to make it easier for them to coordinate their activities and share information. If you are going to be helping out, just go to <http://groups.yahoo.com/group/tcn-coordinators> and subscribe.

I've met a lot of very nice, often very sick, people since I started with the group back in 1993. I've learned a lot from people I've met (and the reading I've done!). I am also glad to have been able to help TCN out through the years. I've also been privileged to meet people who, despite their illness, regularly put themselves out to help others. I particularly want to thank Dolores Rhoads, Loretta Beach, Betsy Waters, Katherine Kirk, Carol Hansen and Pat O'Hara for their help over the past two years; and of course Jerry Sundahl for continuing as our videographer.

My health, like many of you, has (and will) fluctuate from feeling pretty okay to death looking like a good alternative. I learned several years ago that having some things to focus on outside myself usually makes me feel better, even when the effort takes a physical toll. Having at least one major interest (such as school, and later my writing) helped balance the work I did for TCN. Putting all of one's focus into one's own health isn't healthy (and there's research to support that)! The best way I can think of to put it is that we are people who are sick, not sick people.

As for me, 2005 will be my 12th year in Sonoma County, and my 16th year of being sick—time to try something new. I'm looking forward to working on some different types of writing and taking some classes. Maybe I'll see you around!

Take good care, everyone...

Melissa

Volunteer opportunities at TCN

With Melissa's departure from *The Carousel Network*, we are in need of a few volunteers to take on various organizational tasks (see next page for details). We have a strong slate of candidates ready to take over leadership, subject to your approval (see your ballot on page 13, and make sure to cast your vote!), but need some additional help. None of these tasks require the stamina of someone who is able to work; as a matter of fact, most of these tasks would require one hour or less of your time each month.

Please evaluate your situation and see if you can take on one of the tasks, or even part of one. Volunteering is a great way to meet and get to know others in the TCN community, as well as giving back a little bit to the community that you so often look to for support. Thanks to all who have already stepped up to the plate and volunteered!

CALL FOR VOLUNTEERS

We need your help to keep *The Carousel Network* going strong. Historically, our volunteers have been people with chronic neuroimmune diseases (CNDS), but we love assistance from friends and family members, too. What do we need assistance with? Just look for the **BOLDED UNDERLINED** tasks below. Please contact us at (707) 324-8881, or by email at volunteer-now@cndsinfo.net if you would like to volunteer.

Description of Duties

Membership: Updates and maintains membership roster. Provides updates to newsletter volunteers. Creates and maintains membership-related forms and signs. Processes hardship waiver applications. (*D. Stone/P. O'Hara*)

Librarian: Keeps books and other resources and brings them to the meetings for members to review and check-out. (*B. Waters*)

Newsletter Creates, produces, and mails our bimonthly informational newsletter. Maintains mailing list, and works closely with person doing membership. (*P. O'Hara*)

Meeting Room: Opens and closes the meeting room, oversees set-up and post-meeting cleanup. (*L. Beach*)

Videography: Videotapes speaker meetings when appropriate. Maintains masters, boosts audio, and makes copies for the TCN Library. (*J. Sundahl*)

Webmaster: Creates and maintains this web site. (*K. Kirk*)

NEED VOLUNTEERS FOR:

MEETING ROOM RESEARCH: Free meeting rooms that fit the needs of our membership are hard to find. Occasionally, as happened this fall, we may lose a room we have been meeting in, due to the needs of the entity who owns the room. The room search can be done by one person, but it goes easier if two or more pitch in.

MEETING FACILITATOR: Runs the monthly meeting, facilitates discussion, and presents the speaker or video.

SPEAKER/PROGRAM COORDINATOR: Lines up speakers and videos, coordinates the calendar, sends out speaker confirmation and the thank-you letters.

RESOURCE DIRECTORY COORDINATOR: Maintains the Resource Directory, updating the MS Word version, converts to PDF format. Sends the updated PDF file, as well as the specific adds, updates and deletes, to the Webmaster for the online version and uploading the revised PDF file.

PRIMARY CONTACT PERSON: The primary contact person for TCN handles the bulk of the incoming phone calls from people who are sick and seeking information, and health professionals looking for support groups for their patients. Contacts are made by phone, email, and regular mail. The primary contact person should be well enough versed in the various diseases affecting members to help callers looking for referrals to other information and health resources, and to provide basic support. We have a virtual voicemail system, so this person would not have to divulge his or her home phone number or receive calls at home.

MERCK ANNOUNCES VOLUNTARY WORLDWIDE RECALL OF VIOXX®

*Excerpted from Merck press release <http://www.vioxx.com/rofecoxib/vioxx/>
September 30, 2004*

Merck & Co., Inc. today announced a voluntary worldwide withdrawal of Vioxx (rofecoxib), its arthritis and acute pain medication. The company's decision, which is effective immediately, is based on new, three-year data from a prospective, randomized, placebo-controlled clinical trial, the APPROVe (Adenomatous Polyp Prevention on Vioxx) trial.

The trial, which is being stopped, was designed to evaluate the efficacy of Vioxx 25 mg in preventing recurrence of colorectal polyps in patients with a history of colorectal adenomas. In this study, there was an increased relative risk for confirmed cardiovascular events, such as heart attack and stroke, beginning after 18 months of treatment in the patients taking Vioxx

compared to those taking placebo. The results for the first 18 months of the APPROVe study did not show any increased risk of confirmed cardiovascular events on Vioxx, and in this respect, are similar to the results of two placebo-controlled studies described in the current U.S. labeling for Vioxx.

“We are taking this action because we believe it best serves the interests of patients,” said Raymond V. Gilmartin, chairman, president and chief executive officer of Merck. “Although we believe it would have been possible to continue to market Vioxx with labeling that would incorporate these new data, given the availability of alternative therapies, and the questions raised by the data, we concluded that a voluntary withdrawal is the responsible course to take.” APPROVe was a multi-center, randomized, placebo-controlled, double-blind study to determine the effect of 156 weeks (three years) of treatment with Vioxx on the recurrence of neoplastic polyps of the large bowel in patients with a history of colorectal adenoma. The trial enrolled 2,600 patients and compared Vioxx 25 mg to placebo. The trial began enrollment in 2000.

Vioxx was launched in the United States in 1999 and has been marketed in more than 80 countries. In some countries, the product is marketed under the trademark Ceox. Worldwide sales of Vioxx in 2003 were \$2.5 billion.

Results of the VIGOR (Vioxx Gastrointestinal Outcomes Research) study, released in March 2000, demonstrated that the risk of gastrointestinal toxicity with Vioxx was less than with naproxen, but indicated an increased risk of cardiovascular events versus naproxen. However, in other studies, including Merck’s Phase III studies that were the basis of regulatory approval of the product, there was not an increased risk of cardiovascular events with Vioxx compared with placebo, or Vioxx compared with other non-naproxen non-steroidal anti-inflammatory drugs (NSAIDs). Merck began long-term randomized clinical trials to provide an even more comprehensive picture of the cardiovascular safety profile of Vioxx.

“Merck has always believed that prospective, randomized, controlled clinical trials are the best way to evaluate the safety of medicines. APPROVe is precisely this type of study—and it has provided us with new data on the cardiovascular profile of Vioxx,” said Peter S. Kim, Ph.D., president of Merck Research Laboratories. “While the cause of these results is uncertain at this time, they suggest an increased risk of confirmed cardiovascular events beginning after 18 months of continuous therapy. While we recognize that Vioxx benefited many patients, we believe this action is appropriate.”

Merck has informed the U.S. Food and Drug Administration and regulatory authorities in other countries of its decision. The company also is in the process of notifying health care practitioners in the United States and other countries where Vioxx is marketed. Patients who are currently taking Vioxx should contact their health care providers to discuss discontinuing use of Vioxx and possible alternative treatments. In addition, patients and health care professionals may obtain information from www.merck.com and www.vioxx.com, or may call (888) 36-VIOXX (1-888-368-4699).

The results of clinical studies with one molecule in a given class are not necessarily applicable to others in the class. Therefore, the clinical significance of the APPROVe trial, if any, for the long-term use of other drugs in this class, consisting of COX-2 specific inhibitors and NSAIDs, is unknown. The company will work with regulatory authorities in the 47 countries where Arcoxia is approved to assess whether changes to the prescribing information for this class of drugs, including Arcoxia, are warranted. Merck is continuing to seek approval for Arcoxia in other countries, including the United States. *[Ed. Note: See article on pg. 8 for information on Arcoxia.]*

Merck will continue its extensive clinical program to collect additional longer-term data for ARCOXIA, its medication for arthritis and acute pain.

INSTRUCTIONS FOR PATIENTS ON HOW TO RECEIVE REFUND FOR UNUSED VIOXX

Merck will reimburse patients for unused Vioxx® (rofecoxib). Patients who return all or any portion of their prescription in its original container in accordance with the instructions of the National Notification Center (NNC) will receive a full refund of the price paid as reflected on their pharmacy receipt.

Patients seeking a refund should contact the NNC at 1-800-805-9542. NNC will ask for the patient's name, address and phone number. A postage-paid return kit will be sent which will instruct the patient as to how to return the product for reimbursement.

NON-PRESCRIPTION INFLAMMATION CONTROL

Compiled by Pat O'Hara

Now that Vioxx has been recalled, patients who have been taking it for long-term relief from inflammation must find an alternative. Alternative COX-2 inhibitors are still available in the U.S. (Celebrex and Bextra), but their future is in doubt (see pg. 9). Non-prescription choices include NSAIDs (non-steroidal anti-inflammatory drugs such as aspirin, ibuprofen, or naproxen), but these are not tolerated well by some people for long-term use due to gastric distress.

If you are one of these people, or you would rather just not take any of these drugs, there are many other types of non-prescription products that exhibit anti-inflammatory effects that may work for you. Some examples of these are listed below. As always, you should check with your doctor before trying any new treatment, including non-prescription medications.

Turmeric Root Extract (curcuminoids): Inhibits proinflammatory enzymes in arachidonic acid cascade; general antioxidant and nitric oxide scavenger; supports platelet function. Curcumin is the yellow pigment in the spice, turmeric. It has long been used as an herbal medicine, a seasoning and a dye in India and Southeast Asia. It is used in Ayurvedic Medicine. Findings have demonstrated curcumin:

- Exhibits anti-inflammatory effects by inhibiting leukotriene formation (an inflammation causing chemical in the body), inhibiting platelet clumping, and prompting the dissolution of clots.
- Has exhibited potent antioxidant activities.
- May protect against environmental carcinogens, especially cigarette smoke.
- Has anti-inflammatory effects which may be partially related to making more cortisol available from the adrenal gland, or improving responsiveness to cortisol.
- Combined with soy, may help prevent hormone-related cancers.
- In animal studies, exhibits antimutagenic and anticarcinogenic properties.
- Affects bile output from the gallbladder.

Rosemary Leaf Extract (carnosic acid and ursolic acid): Inhibits synthesis of leukotrienes and prostaglandins; neutralizes free radicals; stimulates Phase II liver detoxification.

Holy Basil Leaf Extract (ursolic acid): Helps modulate activity of proinflammatory enzymes and eicosanoids; protects gastric tissues; supports capillary integrity following inflammatory stimuli; protects against radiation-induced damage.

Green Tea Leaf Extract (catechins): Helps regulates proinflammatory enzymes and arachidonic acid metabolites; slows leukocyte migration into cells; potent antioxidant.

Ginger Root Extract (gingerols): Modulates inflammatory cascade reactions; supports platelet function; protects gastric lining.

Chinese Goldenthread Root (berberine): Supports rebalancing of COX enzymes; inhibits lipid peroxidation; supports platelet function.

Barberry Root Extract (berberine): Supports rebalancing of COX enzymes; inhibits lipid peroxidation; supports platelet function.

Baikal Skullcap Root Extract: Inhibits both COX-2 and 5-lipoxygenase pathways; potent flavonoid antioxidant protection.

Protykin® Polygonum cuspidatum Extract (resveratrol): Reduces prostaglandin synthesis; strong antioxidant protection against reactive oxygen molecules.

Flaxseed Oil (alpha- and gamma-linolenic acids): Supports the production of anti-inflammatory prostaglandins, strengthens immune cells, and minimizes autoimmune reactions (in which immune cells attack healthy tissues).

Quercetin: A member of the bioflavonoid family, a group of coloring pigments that provide plants with antioxidant protection against environmental stress; potent antioxidant and inflammation supporting properties work to inhibit inflammatory responses by helping reduce the amount of histamine to be released (histamine is the chemical that initiates the itching, sneezing, and swelling of a sudden reaction).

Bromelain: Pineapple-derived anti-inflammatory enzyme; supports inflammation response by breaking down fibrin which forms around inflammation, blocking blood and lymphatic vessels which leads to swelling; enhances the absorption of quercetin into the body when used in combination; also a proteolytic (protein-digesting) enzyme, supporting digestion.

Zinc: Reduces inflammation and promotes healing of wounds; is a constituent of the antioxidant enzyme superoxide dismutase (SOD). [The injectable form of SOD (available in Europe) is effective in the treatment of inflammation. Oral SOD products are available in the U.S., but it is not clear that orally-administered SOD can escape digestion in the intestinal tract and exert a therapeutic effect.]

Manganese: Recommended for strains, sprains and inflammation presumably because it increases the level of manganese-containing SOD.

Sources:

1. Timothy J. Smith, MD; *Renewal*, St. Martin's Press, NY, 1998. Also <http://www.renewalresearch.com>.
2. <http://www.immunesupport.com>
3. James F. Balch, MD and Phyllis A. Balch, CNC; *Prescription for Nutritional Healing*, Avery (Penguin Putnam, Inc.), 1997.
4. Michael T. Murray, ND; *Encyclopedia of Nutritional Supplements*, Prima Publishing, CA, 1996.

VIOXX'S MAKER SEES PROMISE IN NEW DRUG

by Rita Rubin, USA TODAY, www.usatoday.com/news/health, October 19, 2004 8:33 PM

The maker of Vioxx, the arthritis drug pulled from the market Sept. 30 because of safety concerns, reported favorable findings Tuesday from a study of a new, related drug not available in the USA.

Merck yanked Vioxx because a study comparing it with a placebo found a higher risk of heart attacks and strokes among patients on the drug. Researchers reported findings from that study at the American College of Rheumatology meeting Monday in San Antonio.

In Tuesday's presentation at the meeting, Merck researchers focused on Arcoxia, which, like Vioxx, is a type of drug called a COX-2 inhibitor. Celebrex and Bextra are the only COX-2 inhibitors still on the U.S. market, but Merck has applied to introduce Arcoxia, now sold in 48 other countries.

Merck's Arcoxia study differed from its Vioxx study in two key ways. For one, the average patient was treated for only nine months. In the Vioxx study, the increased risk of heart attack and stroke did not appear until after 18 months.

For another, the Arcoxia study compared it with another arthritis drug, diclofenac, not a placebo. The study found similar rates of heart attacks and strokes in both groups. (Arcoxia seemed gentler on the digestive tract — the main selling point for COX-2 inhibitors — than diclofenac, Merck said.)

But some scientists say that only studies comparing COX-2 inhibitors with a placebo can answer the cardiovascular safety question. They point to questions about the first study to suggest that Vioxx raised the risk of heart attack and stroke. That study compared Vioxx with naproxen, which, like diclofenac, is a traditional non-steroidal anti-inflammatory drug, or NSAID.

Merck has argued that naproxen protects against cardiovascular problems rather than that Vioxx triggers them. Though some subsequent animal and human studies suggest that might be true, it has not yet been proven.

It would be unethical to do a long-term study of Arcoxia vs. a placebo in arthritis patients because they need something to relieve their pain, says Sean Curtis, senior director of clinical research at Merck. The study that led to Vioxx's withdrawal was designed to see whether it could prevent the recurrence of colon polyps, not relieve pain, so a placebo could be used.

"We have ongoing studies with Arcoxia that will allow for a very appropriate assessment of long-term safety," he says. "These studies will include extensive safety data beyond 18 months of exposure."

Status of Celebrex and Bextra

On October 7, 2004 the Associated Press (AP) reported that prescriptions of Celebrex and Bextra initially surged following the Vioxx recall. However, they reported that many doctors are now concerned about these drugs as well after European regulators announced that they were launching a safety investigation into this entire class of drugs. Following that, the AP reported, an editorial in the New England Journal of Medicine also raised questions about the safety of these drugs.

If you are taking either Celebrex or Bextra, stay tuned to the news for continuing developments in these investigations. And, as always, consult your doctor if you have any questions.

ARTHRITIS DRUG LUMIRACOXIB HAS LOW ULCER RISK

by David Douglas, Yahoo! Health News, posted October 15, 2004 10:24 AM ET

SOURCE: Journal of Rheumatology, September 2004

NEW YORK (Reuters Health) - Compared with ibuprofen, the use of lumiracoxib by patients with osteoarthritis is associated with a lower risk of gastric ulcers. The risk is similar to that seen with celecoxib (Celebrex), another COX-2 inhibitor.

Lumiracoxib is "effective and it doesn't cause ulcers," lead investigator Dr. Christopher C. Hawkey told Reuters Health.

Lumiracoxib is made by Novartis and marketed under the name Prexige. It is approved for use in the UK and Mexico, but not yet in the US.

Other evidence, he said, suggests that the drug is safe in terms of cardiovascular and other potential adverse effects — of note, given the recent withdrawal of Vioxx because of the risk of heart trouble.

Hawkey, of the University of Nottingham, UK, and colleagues compared lumiracoxib with ibuprofen and celecoxib in 1,024 patients with osteoarthritis.

The subjects were randomly assigned to receive 200 or 400 milligrams of lumiracoxib once daily, 800 milligrams of ibuprofen three times a day, or 200 milligrams of celecoxib once daily for a total of 13 weeks.

The rate of stomach ulcers was 4.3 percent in the low-dose lumiracoxib group and 4.0 percent in the high-dose group, according to the report in the Journal of Rheumatology. The ulcer rate in the ibuprofen group was 15.7 percent and in the celecoxib group, 3.2 percent.

The researchers conclude that lumiracoxib is "a well- tolerated alternative to standard non-steroidal anti-inflammatory drugs."

CHICKEN SOUP FOR THE FLU SHOT SOUL

Health Sciences Institute e-Alert, <http://www.hsibaltimore.com>, October 21, 2004

It's always something. Or when it comes to the flu vaccine it seems that way. Every year there's a new wrinkle; a feared pandemic, a run on doctors' offices that create shortages, or – as is the case this year – a vaccine manufacturer is shut down, creating scarce supplies, thefts of vaccine caches, black market sales, etc. Always something.

As Moshe ben Maimon might say: It's meshuggah.

Ben Maimon was a 12th century Jewish philosopher and physician who recommend this treatment for influenza and colds: chicken soup. As the story goes, Moshe drew on classical Greek medicine to support his recommendation, but I'll bet you a dollar he actually picked it from his mom.

I was reminded of Moshe's soup cure when I came across an Associated Press item about a flu vaccine clinic offered in Fergus Falls, Minnesota. Because of the nationwide vaccine shortage, the clinic received no supply of the vaccine at all. So when people came by to get a flu shot, they were given a can of chicken soup and a box of tissues instead.

When Kris Ehresmann, the head of Minnesota's immunization program, heard about the soup giveaway, with some amusement she told the AP that it was, "better than nothing."

Better than nothing, indeed. In fact, according to one study, chicken soup is full of good nutrition and even has natural anti-inflammatory properties. That's much more than I can say for the flu vaccine.

Grandma's penicillin

Stephen Rennard, M.D., is a researcher at the University of Nebraska where he studies the defense mechanisms of the lung. One day, while enjoying his wife's homemade chicken soup, he wondered if something in the soup might have an anti-inflammatory effect on the respiratory viral infections responsible for colds and the flu.

From a recipe called "Grandma's Soup," Dr. Rennard had his wife prepare several batches for laboratory tests to examine the soup's effect on neutrophils; white blood cells that stimulate mucous release. As reported in a 2000 issue of the medical journal *Chest*, Dr. Rennard and his team found that the ingredients of the soup clearly inhibited the movement of neutrophils.

In other words, chicken soup may actually trigger a cold and flu-fighting reaction in the body. But it doesn't end with neutrophils inhibition.

Many chicken soup recipes call for exactly what a sick person needs: ingredients that are nutrient-rich, such as onions, carrots, celery, parsley, sweet potatoes, parsnips and turnips (all of which were included in Grandma's Soup).

In an interview with Reuters, Dr. Rennard also acknowledged that the steam from the warm soup may help soothe inflamed sinuses. And when someone lovingly prepares the soup for you – a doting Grandma, for instance – the care itself may provide a therapeutic psychological boost that promotes healing.

Spice it up

Dr. Rennard's Grandma's Soup recipe calls for salting and peppering to taste, which is good advice.

Sodium is an essential electrolyte that promotes hydration. That's not to say that salt should be shoveled in, but adding some salt is a plus, unless your doctor has instructed you to avoid it.

And don't hold back on the pepper either. Natural medical physician Dr. Joseph Mercola suggests that plenty of pepper will help thin respiratory mucus when fluids in the mouth and throat are stimulated. He adds that the main ingredient of chicken soup – that is, of course, chicken – contains cysteine; an amino acid that also thins mucus.

So if you drop by a clinic to get a flu shot and receive soup instead, don't think you're getting the lesser of two treatments. With a large pot of chicken soup simmering on the stove, you just might have your healthiest flu season ever.

Sources:

1. "Chicken Soup Replaces Flu Vaccine," The Associated Press, 10/14/04, www.ap.org.
2. "Chicken Soup Inhibits Neutrophil Chemotaxis In Vitro" *Chest*, Vol. 118, No. 4, October 2000, www.chestjournal.org.
3. "Chicken Soup is Medicine, U.S. Scientists Confirm," Reuters, 10/17/00, archives.cnn.com.
4. "Chicken Soup Good For Colds and Your Heart," Dr. Joseph Mercola, 4/4/01, www.mercola.com.

IMPORTANT INFO ON THE FLUMIST™ VACCINE

<http://healthservices.appstate.edu>

FluMist is the first nasal mist flu vaccine in the US. Most people catch the flu by breathing in the virus after someone nearby who is infected coughs or sneezes. Because FluMist is a fine nasal mist, it is administered where influenza virus usually enters the body—the nose. The vaccine is indicated for active immunization against influenza A and B viruses in healthy children and adults, 5-49 years of age. It is not indicated for individuals less than 5 years of age or 50 years of age or greater.

Persons with allergies to eggs or other parts of the vaccine, with a history of Guillain-Barré syndrome, with known or suspected immune system problems, with asthma or reactive airway disease, or who are pregnant should not get FluMist.

Also, because FluMist is a live-virus vaccine, influenza viral shedding may occur up to 21 days after a person has received the vaccine, making them potentially contagious to others with immune system problems.

SEVERE PAIN RELIEF MAY BE POSSIBLE WITH A COMMON ANESTHETIC DRUG

<http://www.medicalnewstoday.com>, October 13, 2004

A novel treatment using a common anesthetic drug has shown success in reducing the severe pain caused by Complex Regional Pain Syndrome (CRPS), according to a study published in the September 2004 issue of *Pain Medicine*. CRPS, a disorder that can be associated with chronic pain resistant to conventional therapies, affects between 1.5 and 7 million people in the United States. CRPS is sometimes also known as Reflex Sympathetic Dystrophy (RSD).

"This pain disorder can be very difficult to treat. Currently-available conventional therapies, at best, oftentimes only make the pain bearable for many CRPS sufferers," said Ronald E. Harbut, MD, PhD, of Penn State Milton S. Hershey Medical Center, corresponding author of the study. "In our retrospective study, some patients who underwent a low-dose infusion of ketamine experienced complete relief from their pain, suggesting that this therapy may be an option for some patients with intolerable CRPS."

Thirty-three patients with unrelenting CRPS were treated using this novel approach developed by Dr. Graeme E. Correll, BE, MBBS, in Mackay, Queensland, Australia. Pain relief and the duration of this relief appeared impressive. After only one treatment, there was complete relief in 76% (25) of the group. 54% of the patients remained free of pain for more

than three months, 31% for more than six months. Although the relief of pain did not last indefinitely, it was noted that following a second treatment given to 12 of the patients, the outcome was improved. In this retreated group 58% remained pain free for more than a year and almost 33% experienced relief for over three years. The most frequent side effect was a feeling of inebriation with less frequent effects including hallucinations, dizziness, light-headedness and nausea.

"Ultimately, we want to find a way to improve the quality of life for those who suffer with intolerable and endless CRPS — that is our hope," said Harbut. Although optimistic about these early findings, "Certainly more study is needed to further establish the safety and efficacy of this novel approach." (A large clinical study is currently planned and under development at Penn State Hershey Medical Center.)

Rollin M. Gallagher, MD, MPH, Editor-in-Chief of Pain Medicine, notes, "How medical breakthroughs occur is usually a story of human ingenuity and perseverance fueled by compassion and intellect. Dr. Correll's promising innovation, forged by necessity in tiny resource-poor clinics in the jungles of Papua-New Guinea and Northern Australia and carefully shepherded to publication by his co-authors, may herald an effective treatment for one of mankind's most enigmatic and agonizing diseases. Prospective, controlled studies must follow to establish its safety and efficacy."

FROM THE LIBRARY SHELVES

by Betsy Waters, TCN Librarian

One of the great benefits of being a member of The Carousel Network is having access to a wonderful variety of information about your illness. The library is an important part of our organization, and has been growing every month. We now have current books about fibromyalgia, CFIDS, Lyme, and MCS, as well as videotapes and copies of handouts from our previous meetings. The library is open for business immediately after the meetings, from 4:00 – 4:30 PM. You can check out library materials one month, and return them the next. Please stop by the library table soon and have a look!

"You 're only given a little spark of madness. You mustn't lose it." - Robin Williams