

Support Group Newsletter

May/June 2006



“Alone we can do so little; Together we can do so much.”

--Helen Keller

As spring moves into summer, the RSDSA community is buzzing with awareness raising activities. Some of you are involved in fundraisers, and others are interested in getting the word out about CRPS/RSD! The efforts are impressive and important.

For example, **Bonnie Scherer** of Minneapolis recently worked with her local Fox News affiliate on a segment on CRPS that ran on May 2. Reporter Jeff Baillon focused on the plight of Skylar Fuller, a 12-year old with CRPS and also went to Boston to interview **Anne Louise Oaklander, MD, PhD**. Dr. Oaklander recently published research that proved CRPS/RSD was a nerve disorder and not a psychologic illness.

Above (left to right): The Refusing Self Disintegration support group in Big Spring, Texas; Olivia Pepling, Steve Kerestz and Casper at the 2005 Achilles Walk; Jannie White, an RSDSA member from Detroit, Michigan and her state representative Virgil Smith are working to get an RSD awareness bill passed.

Bonnie is also spearheading a team for RSDSA in the first-ever Achilles Walk for Hope and Possibility that will be held in Minneapolis (Hyland Park), June 17 at 7 am. If you would like to participate or pledge, please contact her at (952) 447 4930 or email RSDSMN@aol.com.

Lisa Delia is again leading the effort for the New York Achilles Walk, which will be held on August 6 in Central Park. Last year we raised a little more than \$25,000 with sponsorships and a matching fund grant-this year we want to raise more than \$100,000. For those of you who don't know about the Achilles Walk, it is sponsored by the Achilles Track Team, which was established by Dick Traum in 1983 to encourage disabled people to participate in long-dis-



tance running with the general public. Dick, its current President, is an above the knee amputee marathoner. RSDSA's participation in the walks gives us an opportunity to create awareness of how disabling the syndrome can be. But, as the name suggests, the feeling at the event is definitely one of hope and possibility for a cure.

Jannie White's Fight for Awareness

Speaking of hope and possibility, **Jannie White**, a member from Detroit is working with her State Representative **Virgil Smith**, to get an awareness bill passed in the Michigan legislature. They made terrific progress initially, but the bill, HB 5603, which passed in the house committee the end of February and went to the Senate's Committee on Health Policy for approval, was "tie-barred," or connected to another bill. The result was the elimination of the points regarding CRPS that mattered. Jannie held a rally in Detroit May 16. She will not give up until the bill is passed. We encourage you, particularly those in Michigan, to support Jannie's fight.

CRPS/RSD in the Media

Interview with Dr. Anne Louise Oaklander: Jordan Rich's interview with Anne Louise Oaklander, MD, Ph.D., director of the Nerve Injury Unit at Massachusetts General Hospital, April 2006 is on our website at <http://rds.org/3/research/index.html>. Member **David DeHart** contacted Rich and suggested the interview.

The New York Times, May 30 issue, "Doctors Struggle to Treat Mysterious and Unbearable Pain," focused on Cynthia Toussaint, founder of For Grace and her RSD story. Cynthia has suffered from CRPS/RSD for more than 20 years and is currently running for the California State Assembly.

House on Ketamine, May 23

Fox TV's popular series, *House*, portrayed the doctor after he was given ketamine while in surgery for a gunshot wound. The story told of his high-level hallucinations and memory loss. RSDSA, and several of the physicians who currently treat people with ketamine, are contacting the producers about the misrepresentation of the drug when used therapeutically. Our website, www.rds.org, has some current journal articles on using ketamine to treat CRPS/RSD.

Getting CRPS/RSD into your newspaper or on TV

Send a pitch letter or email, which is a proposed story idea, to your local newspaper editor or producer, keeping the following in mind:

1. Today, most editors prefer pitches via email, not letters. So your subject line should give an indication of why the editor should continue to read.
2. Understand that medium's audience. If it is a small local weekly newspaper you will have a greater chance of getting local person stories published. For a larger one, you will need to have a broader appeal.
2. The pitch should be short (200 words is good) and to the point. Write two or three paragraphs that "hook" them, and offer additional information if they contact you.
3. Determine your key messages and state them clearly. Messages should be educational and informative,
4. Give some facts, figures and sources so that it is easy to do. (see the RSDSA website for facts about CRPS)
5. Make sure you have the names and contact information of physicians or other experts who are willing to be interviewed. You can also refer the media to Jim Broatch, (877) 662-7737.
6. Provide contact information for yourself.

The Rachel Tobias Young Investigator Award



Last October, Rachel Tobias, a 21-year old medical student at Rice University who had CRPS, died tragically. In her memory, her family has helped us establish a young investigator award to encourage research into the cause and cure of CRPS.

Rachel Tobias Her mother writes, "Rachel was intelligent and was accepted to not one, but four BA/MD programs in her quest to become a doctor and help others, by, as she said, "giving back"; "Paying it Forward" was a concept in which Rachel truly believed. Her desire to become a doctor only came about as a result of her illness, RSD, from which she suffered with intense pain, 24/7, but was so brave, that few could really appreciate what she was enduring. Rachel did not want to burden others, and thus thoroughly hid her pain beneath her perpetual smile. "

RSDSA hopes that the young investigator award will inspire further research and help stop the pain of people who suffer from CRPS/RSD. Application information is housed on the website.

New Brochure on Hope and Transitions

RSDSA is compiling stories from our members for a brochure on Hope and Transitions. If you would like to share your story, please send it to us at RSDSA, 99 Cherry Street, Milford, CT., 06460.

We are looking for stories that will inspire others, particularly those who are newly diagnosed. We would like to limit the length to 600 words, so please do not focus on the details of how you developed CRPS/RSD, but what has happened to you since that has been inspiring or has changed you or your family in a positive way. In order to have the brochure available during National RSD Awareness Month in November, we must receive all contributions by September 5.

National Pain Awareness Bill Update

RSDSA, RSDHope, and For Grace have endorsed The National Pain Awareness Bill (HR 1020). We need your help to generate Congressional support for its passage. Please contact your local representatives and ask them to support this bill.

HR 1020

- Establishes a national center for pain and palliative research at the National Institutes of Health (NIH)
- Requires NIH to establish programs that develop and advance the quality, appropriateness, and effectiveness of pain and palliative care
- Authorizes the Department of Health and Human Services to award grants and contracts to further the education and training of healthcare professionals.

This bill is a huge step toward gaining federal recognition of the importance of pain as a critical and unanswered health care problem in America.

On June 13, 2006, there will be a Congressional Briefing on The Epidemic of Pain in America. The purpose of the briefing is to educate Congress on the serious need for federal policy reform affecting pain management. Contact your Congressional representatives and encourage them to attend this hearing. You can find information on the American Pain Foundation's website at www.painfoundation.org (click on Take Action Now!)

Publications Update

In Pain, Out of Work, Can't Pay the Bills is being reprinted with a new title: *In Pain and Panicked About the Bills*. We are finding that even people who have jobs and CPRS are having financial difficulties. This will be available on the website and in hard copy by the end of June.

Recognizing, Understanding, Treating CRPS has recently been updated and revised. It is available on the website and in hard copy from the home office. Just call 877-662-7737.

RSDSA Conference in Chicago September 8

On September 8, The RSDSA and the Rehabilitation Institute of Chicago will hold a one-day conference called *A Comprehensive Review of CRPS- Dispelling the Myths and Looking at Emergent Treatment*. It will take place at Northwestern Memorial Hospital Conference Center-3rd Floor, 201 East Huron, Chicago, IL 60611.

The day-long conference, co-chaired by **R. Norman Harden, MD**, and **Joshua P. Prager, MD, MS**, will focus on medical and clinical issues in the morning. The afternoon sessions will feature **Louise Plaster**, founder of the South Carolina RSD Association, who will explore the idea that "I have RSD, but it Doesn't Have Me." **Christin Englehardt**, an RSDSA insurance consultant, will help individuals with CRPS with insurance-related questions. **Jim Broatch** and **Debra Nelson-Hogan** will also talk about what RSDSA is doing to help members.

We invite you to participate in this event. Bring your questions, your success stories, your friends. **For RSDSA members, there is no charge to attend, but we do require a \$50 seat reservation deposit that will be refunded to you when you register on Friday (we will not refund the deposit for "no shows.")** In addition, you may listen to the medical presentation on Saturday morning.

Space is limited to 100 attendees. If you have any questions, please call 877-662-7737.

Housing

Rooms have been reserved at the Radisson Hotel & Suites Chicago, 160 East Huron Street, Chicago, IL. The Radisson hotel is located across the street from Northwestern Memorial Hospital. Please call the reservations department from 9:00 am until 5:00 pm at 312/787-2900 and indicate that you are attending this course in order to receive the corporate rate of \$194 for single or double occupancy or \$234 for a one-bedroom suite. Tax is 14.9%. The daily rate

for parking is \$37 day with unlimited in and out privileges. The cut-off date for room reservations is August 18, 2006. However, the room block could reach its maximum before this date. Rooms and rates revert to a space-available basis after the room block has reached its maximum or after the cut-off date.

To search for other hotel options, you may visit <http://www.chicagotraveler.com/chicago-hotels.htm> or call 1-800261-8159.

| A Comprehensive Review of CRPS— Dispelling the Myths and Looking at Emergent Treatment. Friday, September 8 | |
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| 8:15-8:30 AM | Welcome Jim Broatch, Executive Director, RSDSA |
| 8:30-9:00 AM | What We Know — and What We Think We Know—About CRPS R. Norman Harden, MD |
| 9:00-9:30 AM | Available Treatments RIC staff |
| 9:30-9:45 AM | Break |
| 9:45-10:15 AM | Emerging Therapies Joshua P. Prager, MD, MS |
| 10:15-10:45 AM | Managing Expectations and Patient Responsibility RIC staff |
| 11:00-11:30 AM | I Have RSD, but It Doesn't Have Me Louise Plaster |
| 11:30-12:15 PM | Q&A |
| 12:30-1:45 PM | Lunch: Report on Research with Small Fiber Injuries Anne Louise Oaklander, MD, PhD |
| 2:00-3:45 PM | Surviving and Thriving with CRPS/RSD Guided discussions that include family, financial, insurance, and work issues. |
| 3:45-4:00 PM | Break |
| 4:00-5:00 pm | RSDSA: Promoting Awareness and Change Jim Broatch and Debra Nelson-Hogan |

A Comprehensive Review of CRPS— Dispelling the Myths and Looking at Emergent Treatment

Friday, September 8
Registration

Enrollment in this course is limited to 100 attendees and early registration is advised.

Please TYPE or PRINT your name.

Name _____

Home Phone (____) _____

Home Address _____

City _____ State _____ Zip _____

E-mail _____

RSDSA membership is listed under the name of _____

Please note: registration will not be processed without a deposit of \$50 to be returned when you pick up your name badge on September 8. If you are not a member, please complete the form below or call 877-662-7737 to join today. Please mail this form with your check payable in US\$ to RSDSA, 99 Cherry Street, Milford, CT 06460.

Join RSDSA

Yes, I would like to be a member and support RSDSA

- Patient/non-medical (\$15)
- Patient non-medical outside the US (\$25)
- Can't afford the membership fee, but I would like to add my name to those who support RSDSA.

For credit card orders, please complete:

- Visa MasterCard Amex

Card number

Exp Date

Signature

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____

Email _____



Please make check or money order in \$US payable to RSDSA
Mail your check with this form to RSDSA, 99 Cherry Street, PO Box 502, Milford, CT 06460