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The Vermont Parkinson's *Advocate*

Newsletter of the Vermont Chapter,
American Parkinson Disease Association

Rock-A-Thon 2008 Moves To Burlington!

Rock-A-Thon 2008 is getting a face lift! We're jazzing things up a bit this year, with a new location and a new sound. The event will still be on the first Saturday in June – the 7th this year – and there will be rocking chairs, music, children's activities and dancing as usual. But we're moving to Burlington, at the top of top of the Church Street Marketplace on the lawn of the Unitarian Universalist Church, and we'll be celebrating that a cure for PD is closer than ever to the strains of some great jazz music!

As well as the usual opportunity to catch up with old friends, compete for fun awards and raise money for a great cause, you'll also be able to spend some time on Church St and enjoy the Burlington Jazz Festival. The Festival coincides with Rock-a-Thon so we will have a great opportunity to raise Parkinson's awareness.

We will be raffling a beautiful hand made quilt again, generously donated by Doris Desroches and there will be a silent auction with a huge variety of items to bid for. Our goal this year is to raise \$25,000. We've set ourselves a big challenge, but with your help we can do it! Although you will still be able to collect sponsor money the way we always have by bringing it on the day, this year we are launching the Rock-A-Thon on-line registration and donor page.



The page can be accessed from the website www.parkinsonsvt.org and will be an easy way to register, create and join a team and to collect pledges. The APDA Vermont webpage links directly to Chittenden Bank's secure site so donations made with a credit card are guaranteed to be safe. All you need to do is send one e-mail to your friends and family, tell them what an important fundraiser this is for people with Parkinson's in Vermont, and ask them to log onto the site and support you. Even if you cannot make it to Burlington to the Rock-A-Thon this year, you can still be a Pace Setter and

contribute \$25 to the event, either on-line, or by sending a check.

We are also aiming to get as many corporate sponsors as we can this year. If you know of an organization or company that we should approach, let us know! Why not ask your employer if they will match your fundraising efforts, and sponsor your team? Or perhaps you or your employer would like to contribute an item to the silent auction. Just give us a call and we will organize pick up.

There are plenty of ways to support Rock-A-Thon 2008, so please do what you can to help. We look forward to seeing you in Burlington in June!

**Vermont Chapter,
American Parkinson
Disease Association**

Contact Information

**For information about
Parkinson's disease, and
referrals to support groups
and medical professionals:**

Jean Baker, RN, Coordinator,
APDA Information and Referral Center
(802) 847-3366
or toll free (888) 763-3366
Jeanette.baker@vtmednet.org

**For information regarding
the state chapter and its
fund-raising and education/
outreach activities:**

Nicky Cribb,
Chapter Coordinator
(802) 827-9950
info@parkinsonsvt.org

**The Vermont Chapter
Board of Directors:**

Michael O'Connor, President
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Web site:

www.parkinsonsvt.org

Newsletter Helper:

Bill Brawley

National Web site:

www.apdaparkinson.org/



New Neuroscience Center Endowed at Fletcher Allen Health Care

A generous gift of \$2 million from Burlington neurosurgeon Nancy Binter and her husband, Dr. Bela Ratkovits (a radiologist at FAHC), has been given in honor of Dr. Binter's father, who lived for many years with PD. The goal of the gift is to enable the establishment of multidisciplinary centers of excellence for

stroke, movement disorders (including PD), and other neurological disorders. Creation of these centers is still very much in the planning stages and steering committees are in place to help guide their development. This is great news for the Parkinson's community in Vermont. Stay tuned for updates as they develop.

Link Established Between Drugs, Impulse Control Problems

Reducing dopamine agonist use reliably improves impulse control disorders, according to this study.

E-Move, an on-line newsletter and a partner with APDA, published this study on January 29, 2008.

Eighteen PD patients with impulse control disorder (ICD), either active or in remission, were identified from a study database. At the beginning of the study all patients were taking a dopamine agonist. Patients reported compulsive gambling (8), sexuality (7), and buying (3). When they were re-interviewed around 29 months later, 7 patients had stopped using an agonist, 5 had decreased their DA dose, and 3 had no change. Patients reducing their

DA dose increased their use of levodopa by a corresponding amount.

All patients who stopped using DAs experienced complete remission of ICD symptoms. Patients who decreased their DA dose had either full or partial remission. Of the 3 patients who did not change their DA dose, 1 remained fully symptomatic, 1 had partial remission, and 1 had full remission.

The authors have concluded, "For patients who develop an ICD in the context of DA treatment, discontinuing or significantly decreasing DA exposure, even when offset by an increase in levodopa treatment, is associated with remission of or significant reduction in ICD behaviors without worsening of motor symptoms."

Research Proves Value of Exercise For People with Parkinson's

Many types of exercise are beneficial to PD patients, according to a recent PD study reported in E-move.

The trials encompassed results from a total of 495 PD patients (67 percent male). Most interventions were delivered by a physical therapist in an outpatient setting, and included seated karate, aerobic exercise, strength and balance training, treadmill walking, qigong, and others. Most studies examined short-term effects, with follow-up of less than 6 months.

Of the 9 studies examining physical functioning as an outcome measure, 4 reported a benefit from exercise, which according to the authors supports the conclusion that exercise improves physical

functioning.

Of 4 studies examining health-related quality of life, only 1 reported a benefit from exercise. However in this case, analysis of the actual results showed that that exercise did improve health-related quality of life.

Other effects examined were strength (improved in 3 of 4 studies), balance (improved in 4 of 5), gait (improved in 3 of 4), falls (improved in 0 of 2), and depression (improved in 0 of 4).

"Exercise is of benefit to people with PD in respect of physical functioning, health-related quality of life strength, balance, and gait speed," the authors conclude.

Awareness Day Scheduled for April 12

At Lake Morey Inn, Fairlee

The 10th Annual Parkinson's Awareness Day is slated to take place at the Lake Morey Resort in Fairlee on April 12. This is a new and exciting location for the event. Last year the Vermont Chapter held a meeting at Lake Morey that was very well received. Its location and proximity to the interstates will make travel a bit easier for folks who may not have attended in the past. The day promises to be informative, enlightening, and fun.

This year's theme is "Parkinson's Perspectives". We will hear from folks who may interact with PWP's and their families on many levels.

First will be a slate of rehabilitation specialists (speech, occupational and physical) who will speak about the various ways in which a therapist can be helpful. Many folks with PD may not be aware of what they can do to make their lives more manageable with simple interventions and equipment.

Next will be author and artist Steve Roberts who will speak as well as listen to the stories of PWP's and their family members. His book, *Cool Mind, Warm Heart*, is a collection of his essays about looking at challenges as a gift, and responding to them positively.

John Campbell of the Vermont Ethics Network will address

ethical issues in PD, particularly Advance Directives, decision making and planning. Finally, we will be able to split into two groups (caregivers/families and PWP's) allowing the caregivers time to network together and share stories and support.

The PWP's will be treated to a demonstration of an exercise technique called Neuromuscular integrative action (Nia). We are fortunate to have a practitioner locally who can share this with us. According to the website Nianow.com, "Nia is a body-mind-spirit fitness and lifestyle practice. Through expressive movement—The Body's Way—Nia empowers people to achieve physical, mental, emotional and spiritual well-being." This practice has been particularly helpful for PWP's in improving mobility and balance through raising awareness of the body's position in space, and how it is moving. This is a session that will be as participatory as you like, jump right in, or sit back and observe.

As in years past, a continental breakfast and luncheon will be served at Awareness Day. For dessert, we'll have a large cake celebrating our 10th anniversary. Watch your mailboxes for the flyer, coming out in early March!

Connecticut Parkinson's Working Group

Sponsors Research Symposium

On Saturday May 3, 2008, the Connecticut Parkinson's Working Group (CPWG) is sponsoring its second scientific symposium, and all members of the Parkinson community, (diagnosed people with PD, family, caregivers, medical professionals, and researchers) are invited to attend. The theme for the event is "Will we find the cure?" The symposium will be held on May 3, 2008 in Welte Auditorium, located on the Central Connecticut State University campus in New Britain, Conn. There is no entrance fee for the symposium, which will begin at 10 am and run until approximately 1 pm. However, it is necessary to register with CPWG by calling (860) 343-8278 or (860) 347-0134 or (203) 453-2655.

There will be three expert panelists attending the symposium. Ira Shoulson, M.D., is considered THE expert to whom all other clinical researchers turn for guidance when attempting to design or decipher a reasonable neuroprotective study. He has been conducting clinical research in PD since the 1970s. Dr. Shoulson is Professor of Neurology, Pharmacology and Medicine at the University of Rochester Medical Center, Director of Experimental Therapeutics (ETH), Louis C. Lasagna Professor of ETH, and long

time Chair of the Parkinson Study Group (PSG). He will discuss clinical research today in neuroprotective or disease modifying trials.

Xiangzhong "Jerry" Yang, M.D., Ph.D., from the University of Connecticut, is widely known and internationally respected for his research in stem cells, and is Professor of Animal Science and founding director of UConn's Center for Regenerative Biology. Dr. Yang produced the first clone of an adult cow in the United States in 1999. At the forum, he will discuss the potential of stem cell research in PD.

Andrew Feigin, M.D. is Associate Professor of Neurology and Associate Director of the Movement Disorders Center of North Shore LIJ. He heads the Neuroscience Experimental Therapeutics Division of the Feinstein Institute for Medical Research, with specific interest in using state-of-the-art imaging methods to develop new therapies for PD, Huntington disease, and other Movement Disorders. Dr. Feigin will discuss the exciting news about gene therapy that was published in this article.

Member Profile: Debbie Johnson-Surwilo

Debbie Johnson Surwilo leads a busy life. A working mom and an active volunteer with APDA Vermont, she served on the board for three years, and organizes many of the Young Onset Support Group activities. Debbie has also recently re-discovered her talent for photography and is turning her new hobby into a card making venture.

"I'm doing something for me," she acknowledged recently. "It's a way of getting back some enthusiasm for what life has," she added. Debbie says it was the Living Well Celebration held by APDA Vermont at the end of last year that really got her started. When she saw the request for people living with Parkinson's to bring their crafts to display at the event, Debbie said she decided "on a whim" to make some cards.

Although she has taken photography classes in the past, and has enjoyed crafting, more recently she said she has not found time for her hobby. Now much to her surprise, Debbie's whim is turning into a money making venture. Initially it was friends, family and co-workers who asked her to make cards for them. The photos of pretty flowers and striking trees and landscapes mounted on card turned



Debbie Johnson-Surwilo, right, with Jean Baker, Nicky Cribb, and Cassie Blanchard

out to be very popular, and it wasn't too long before her chiropractor offered to let Debbie show cards at his office and her cousin suggested she start selling them on-line.

Because she credits APDA Vermont and the Living Well Celebration for prompting her to take some time for herself, Debbie has decided to donate a percentage of her profits to the chapter.

"I just make cards when I have a few minutes," she said. "It's fun right now and this is definitely a work in progress, but for as long as I keep selling them I want the chapter to benefit because that's where it started," she added.

You can purchase Debbie's cards at <http://voilet.etsy.com>.

Become A Supporting Member

Celebrate 10 years of APDA Vermont by becoming a member! It's hard to believe, but APDA Vermont was formed 10 years ago! Last year was the first time we invited people living with Parkinson's to officially join APDA Vermont. About seventy five people took us up, and we're hoping to double that number for 2008. By becoming a formal member of APDA Vermont you are helping us to continue serving the Vermont Parkinson Community.

With the support of members and grants from Wal-Mart and National Life Insurance Co. last year, the chapter was able to host membership meetings at Lake

Morey, and the Living Well Celebration in November. Similar gatherings are planned this year, welcoming everybody in the Vermont Parkinson community and offering opportunities to socialize and celebrate our 10th birthday!

Please consider becoming a member today! Individual memberships start at \$15, and all funds raised benefit Chapter activities on behalf of the Parkinson's community throughout Vermont. Mail your check to: APDA VT, PO Box 104, Bakersfield, VT 05441, or call Nicky Cribb, Chapter Coordinator at (802) 827-9950. E-mail: info@parkinsonsvt.org

Web Site Tip of the Month

Kathrynne Holden, MS, RD, a dietician and author of numerous books on Parkinson's disease and nutrition, answers reader's questions at a web site sponsored by the National Parkinson Foundation. Responses are sometimes posted the same day. Holden also posts recipes and news regarding research and related topics. Other forums at the site include "Ask the Doctor" and "Ask the Surgical Team." Check it out at: <http://forum.parkinson.org/forum/>

Welcome To ... Holland?

Editor's Note: While the following essay was written about a child with disabilities, a reader suggested that it's very relevant to those recently diagnosed with Parkinson's disease.

By Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this. ...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the

day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced

than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around ... and you begin to notice that Holland has windmills ... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy ... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away ... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

Support Group Meetings and Contacts

Bennington, VT Parkinson's SG
3rd Thursday, 10:30 a.m.
2nd Congregational Church,
Hillside St. Bennington
Contacts: Dorothy Roy 802 442-8374 &
Nancy Bower (802) 447-0119

Wilmington, VT Parkinson's SG
Contact: Jean Baker (802) 847-3366

Burlington, VT Parkinson's SG
Contact: Jean Baker (802) 847-3366

Green Mountain Parkinson's SG
Contact: Jean Baker (802) 847-3366

Newport Vt. Parkinson's SG
3rd Tuesday, 10:30 a.m.
Contact: Sid & Estelle Burton (802) 626-3707

St. Johnsbury Parkinson's SG
Contact: Jean Baker (802) 847-3366

Morrisville, VT Parkinson's SG
Last Wednesday, 1:00-2:30 p.m.
Lamoille Home Health & Hospice
Contact: Amanda Shiverick (802) 888-4651

Upper Valley Parkinson's SG
3rd Tuesday, 2:00 p.m., DHMC
Contact: Bill Brawley (603) 643-7494

Rutland, VT Parkinson's SG
1st Thursday, 2:00 p.m.
Contact: Alan Connoly (802) 747-5363

Springfield, VT Parkinson's SG
Contact: Jean Baker (802) 847-3366

St. Albans, VT Parkinson's SG
Contact: Jean Baker, (802) 847-3366

Ticonderoga, NY Parkinson's SG
Contact: Joan Miller (518) 585-2533
Plattsburg, NY
4th Thursday, 5:30 p.m.

CVPH
Contact Barbara Lichtig, (518) 561-6549
or Joy and John Mazur (518) 561-3875

Canton Potsdam, NY
Monthly May - September
Canton Potsdam Hospital, 2nd floor
Darlene Snell, (315) 265-4696
Contact: Bonnie Rupert, (315) 764-7818

Central Vermont Parkinson's SG
Contact: Bruce Talbot (802) 496-6768



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