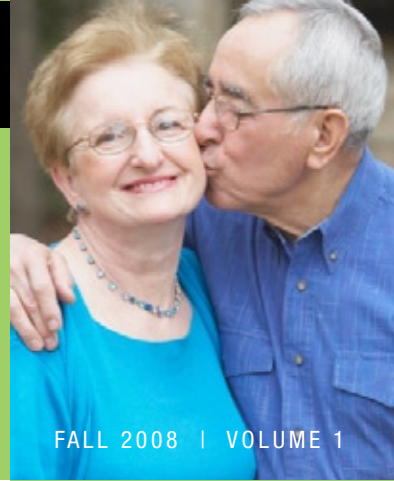




# Movement Disorders Clinic



FALL 2008 | VOLUME 1

## How botulinum toxin injection treatments helped one patient with Dystonia

Parkinson's disease is only one of many movement disorders we see in our clinic, Dystonia is the second most common condition we treat. Only 24, Lisa suffers from Cervical Dystonia, also known as 'torticollis'. Her head rotates involuntarily, forcing her to look over her right shoulder and she is unable to move her neck



muscles to look straight ahead. As a biology graduate student, she has to sit sidewise to look into a microscope, see her computer monitor or write notes on paper. Lisa found relief from her Dystonia in the last place she wanted to look, at the tip of a needle. After consulting with a Movement Disorder Specialist, Dr. Melanie Brandabur, she was told her best course of treatment would be injections of botulinum toxin. Botulinum toxin, commonly known as Botox, a chemical that selectively weakens overactive muscles, is an extremely effective therapy for dystonia that has been in common use for over twenty years. Lisa's extreme fear of needles made her very reluctant to have injections, but, after a trial of

## Rising Gas Prices and the Economy Affect Patient Care



As the current trend of fluctuating economic conditions, gas prices, and travels costs continues, we have seen a steady rise in cancellations of Parkinson's disease (PD) patients who had scheduled appointments in our clinic. When patients call to cancel they are specifically listing travel and gas costs as their reason, as many travel considerable distance for care. As a debilitating disease, it is vital for patients who suffer from PD and other disorders to see their doctors on a routine basis in order to access their status, regulate/change medications, provide speech and physical therapeutic services and assist with essential caregiver challenges.

We suggest that patients reach out and help each other. Carpooling to appointments, and calling us to schedule appointments on the same days. Or reach out to your local support group and find fellow patients in your area to ride share with. **For more information on local support groups visit [www.ppsg.org](http://www.ppsg.org).**

several oral medications failed to relieve her symptoms, she got up the courage to try the injections. After several treatments, her neck and head are almost fully facing forward. Lisa is now able to look into a microscope with-

**Dystonia** is a neurological movement disorder with involuntary sustained muscle contractions resulting in involuntary movements, twisting and/or abnormal postures. Currently there is a limited understanding of the underlying cause of dystonia; however, this condition can appear in a variety of forms. Dystonia may occur as a primary condition (idiopathic dystonia) in which dystonia is the sole manifestation or it can be associated with a wide variety of neurological conditions (e.g. parkinsonism, Wilson's disease, Huntington's disease etc.).



*continued on page 3*

**WWW.THEPI.ORG**



## TULIP PINS AND WRISTBANDS ARE IN

STOP BY OUR FRONT DESK AND PICK UP YOURS TODAY AND HELP RAISE AWARENESS AND SHOW YOUR SUPPORT FOR PARKINSON'S DISEASE. THE RED TULIP IS THE WORLD SYMBOL OF HOPE IN FINDING A CURE FOR PARKINSON'S DISEASE AND, THE LEAVES FORM PD.

**SMALL PINS \$5**

**LARGE PINS \$7**

**WRISTBANDS \$10.**



## LETTER FROM OUR CLINIC DIRECTOR

*Dear Friends:*

*Welcome to the first newsletter specifically about our Movement Disorders Clinic. The clinic's mission is to provide world-class, comprehensive services for patients with Parkinson's disease as well as other movement disorders such as parkinsonism, Parkinson's dementia, Dementia with Lewy Body disease, tremor, dystonia, tics, Huntington's disease, tardive dyskinesia, etc. The service we provide includes expert neurological evaluation and treatment, physical and speech therapy, patient education, and community information seminars. We continue to expand our services and offer patients the best care. Read more in this issue about the Wii Fit program, upcoming and ongoing Clinical Trials, and how to stay connected with us online.*

*As always we look forward to seeing you in the clinic.*

*Best Regards,*

Melanie Brandabur, M.D.



## Upcoming/Ongoing Clinical Trials

PI continues to conduct a record number of clinical trials. We are preparing to begin a new study involving Co-enzyme Q<sub>10</sub> named QE3. We are also working on developing a protocol for using the Wii™ system by Nintendo® and utilizing it for purposes of Parkinson's Disease that would help rate tremor and some cognitive aspects of the disease process. We are still recruiting for the Net-PD trial involving Creatine. If you would like to know more about our Clinical Trials please contact: Katharine Smith, RN Clinical Research Coordinator (408) 734-2800 x635, [ksmith@thepi.org](mailto:ksmith@thepi.org).



## COMING SOON AT PI

## Wii Fit in Our Clinic

The struggle has long been how to find an intervention for movement disorders like Parkinson's disease that is good for balance, that promotes regular movement, and is also fun. The Nintendo® Wii Fit™ appears to do all three. Exercise can improve your balance and it can prevent joint stiffening. Some studies have even pointed to exercise as being especially beneficial for those with movement disorders like Parkinson's disease. The Wii Fit with balance board gives the user feedback which can help you correct your balance and posture. Look for more information about this upcoming innovative new program as we develop ways to integrate it into our clinic.



## Hot Weather and Parkinson's Disease

With on and off hot weather, we remind Parkinson's patients to increase their water intake. Drinking enough fluids keeps your blood pressure up. Parkinson's medications will tend to dry you out. Water aids kidney function that can flush out drug byproducts and keeps things moving by increasing bowel activity. This helps constipation a frequent problem for PD patients.



# PI Online

Get the latest newsletters, event notices and more. Find us now on:

**Myspace:**  
**user-theparkinsonsinstitute**

**Facebook:**  
**The Parkinson's Institute and Clinical Center**

Connect to us to stay up to date on the latest events and news. Sign-up for the electronic News from PI on our website or by emailing [dev@theipi.org](mailto:dev@theipi.org)



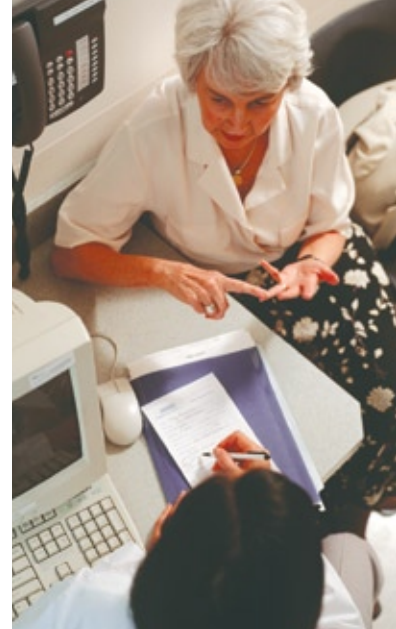
## COMING THIS FALL Monthly Ask The Doctor Seminars

Ever wish you had an hour to ask a doctor questions? We are excited to announce new monthly **Ask the Doctor Seminars** featuring the doctors from our clinic.

## Ask the Doctor Online

**Now you can ask questions online or read our FAQ to see if it is already answered. Read new articles on "PD and Anxiety" and "PD & Depression."**

*Disclaimer: We can answer general questions about Parkinson's disease and medication, but we cannot give a specific diagnosis or specific advice about your conditions and medication in this column.*



## Botox and Dystonia

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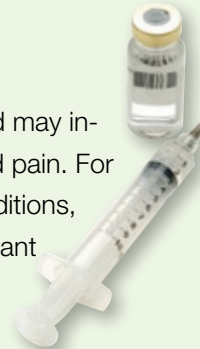
out sitting sideways in her chair and is busy choosing a topic for her Master's thesis. Pretty as well as smart, she has also found time to start dating and now has a much easier time looking at her date across the table during a romantic dinner. She still hates needles, but definitely rates the few minutes she spends getting the injections a reasonable price to pay for several months of relief.

Most people know of Botulinum Toxin (BTn) injections as a treatment for wrinkles; however, the true wealth in this chemical treatment is its overall effectiveness in the management of dystonia and other movement disorders. The Movement Disorders Treatment Center at the Parkinson's Institute specializes in the use of BTn for a variety of conditions that result in involuntary muscle contractions including primary dystonia, Parkinson's disease, essential tremor, hemifacial spasm and Tourette's syndrome. Currently, there are two forms (serotypes) of BTn approved by the Food and Drug Administration for use in selected medical conditions. These are BTn-A (Botox) and BTn-B (Myobloc). Both of these forms are now used in clinical practice to treat dystonia, hemifacial spasm and wrinkles. However, the

indications are expanding and may include treatment of tremor and pain. For most patients with these conditions, BTn injections provide significant but variable relief of symptoms that lasts for weeks to months (an average of 3 months). However, repeated injections are required to sustain benefit over long periods of time.

Botulinum toxin therapy is safe and effective in the treatment of strabismus and in the symptomatic treatment of various forms of Dystonia. Botulinum toxin therapy is not curative in chronic neurological disorders. For most indications, botulinum toxin should be used by committed interdisciplinary teams of physicians and related health care professionals with appropriate instrumentation. The safety of botulinum therapy during pregnancy, breast feeding, and chronic use in childhood is unknown.

If you would like to set up an appointment with a Movement Disorders Specialist at the Parkinson's Institute and/or if you have questions of how Botulinum Toxin may benefit you, please call 408-734-2800.



GET MORE  
INFORMATION AT  
[WWW.THEPI.ORG](http://WWW.THEPI.ORG)

Enjoy our newly decorated clinic. Thank you to Dorrit Egli who donated numerous pieces of art from her private collection and to artist, Cindy DeLuz who's donation of six wonderful photographs now decorate our exam rooms and hallways.





## Upcoming Patient Events Hosted at PI

OCTOBER 30

10 am

**Author and PD Patient, Dr. Thomas Grayboys share his journey through Parkinson's and Dementia**

*Call 408-734-2800 for more information and to RSVP for these events.*

NOVEMBER 18

1-3 pm

**Newly Diagnosed Seminar- Discussion and Q&A with the Doctor**

*Call 408-734-2800 to RSVP*

## At the Institute

- Weekly Science Seminar Series
- Weekly Gait & Balance Class
- Monthly Choir Group

CHECK WEBSITE  
FOR DAYS AND TIMES  
[WWW.THEPI.ORG](http://WWW.THEPI.ORG)

### CONTACT US:

The Parkinson's Institute  
and Clinical Center  
675 Almanor Avenue  
Sunnyvale, CA 94085  
408.734.2800  
800.655.2273  
info@thepi.org  
clinic@thepi.org

### ONLINE:

**Myspace:** user-  
theparkinsonsinstitute

### Facebook:

The Parkinson's Institute  
and Clinical Center

### OFFICE HOURS:

Monday – Friday  
8:30am -5:30pm  
[www.thepi.org](http://www.thepi.org)



**The  
Parkinson's Institute  
and Clinical Center**

675 Almanor Avenue  
Sunnyvale, CA 94085-2934

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