Looking Back, Looking Ahead, Looking to Serve You

I want to thank all of you for making this past year such a wonderful experience for me and for the team of the Capistrant Center for Parkinson’s Disease and Movement Disorders.

Everything that’s happened so far—meeting and partnering with amazing patients and families; offering new programming; working to increase community awareness and understanding of Parkinson’s and other movement disorders; lobbying for funding for medical research; and receiving financial support from various sources to grow our services—is all geared toward one goal: providing a caring, compassionate center of excellence for individuals managing Parkinson’s and other movement disorders so they can live high quality, productive lives.

In the coming year, we will continue to provide innovative clinical treatment options as well as emotional and educational support groups, information and referral services, and encouragement to patients and families. If we can be of assistance, please call us at 651-232-2098.

On behalf of everyone at the Center, best wishes for a happy and healthy holiday season and New Year!

Jawad A. Bajwa, MD
Medical Director

Research Review

The Center is excited to announce its research poster submission to the American Association of Neurologists conference scheduled for spring 2010. This submission represents our first research study focused on critical therapies which are used to improve patients’ quality of life. The poster explains the positive clinical outcomes of including BIG-like motion practice in a patient’s care plan (please see BIG and LOUD article in this issue).

We are also planning to participate in a clinical trial sometime next year that will investigate the combined use of therapies, exercise, and medication in conjunction with deep brain stimulation (DBS) for Parkinson’s disease. We will keep you informed as more details of the trial are finalized.
Has your spouse become hard of hearing? Have your friends grown taller or taken up speed walking?

Parkinson’s patients often express these or similar thoughts, unaware of the subtle, gradual changes that have occurred in their own lives since the onset of the disease. At the time of diagnosis, the loss of dopamine may have already caused quieter speech (which means a person might have trouble understanding their loved one), some changes in posture that prevent the ability to “stand tall”, and smaller and slower movements that can impact the quality of walking, dressing, and other daily activities.

A person with Parkinson’s disease is still capable of talking LOUD and moving BIG, but the brain is sending weaker signals, leading to quieter, smaller actions. Sensory problems make it difficult to perceive the mismatch between communications from the brain and the resulting behaviors. These smaller movements and quieter speech become the patient’s new sense of normal.

LSVT LOUD and LSVT BIG are therapies used specifically with Parkinson’s patients; they can also be applied to individuals with other neurological disorders. LSVT (Lee Silverman Voice Treatment) was originally developed between 1987 and 1989. It is now called LSVT LOUD, offering an intensive, larger-than-life exercise program for the speech motor system. LSVT LOUD is considered the “gold standard”, the best of the best when it comes to treating speech challenges in Parkinson’s patients. LSVT BIG (based upon the principles of LSVT LOUD) offers a rigorous, larger-than-life exercise program for the limb system. Our center is proud to provide speech, occupational, and physical therapists trained in these specialties.

Intensive, repetitive activities are seen in one-to-one sessions; there is a focus on big, overstated movements and sound, with feedback that retrains the perception of “what is normal” for a Parkinson’s patient. The therapy, which is upbeat and energetic, encourages daily practice and ongoing encouragement from caregivers. In addition to improving the quality of speech delivery and physical movement, BIG and LOUD helps to enhance balance, posture, strength, stamina, and the ability to perform different tasks more safely and efficiently. As patients experience an easier time with mobility and speech, they tend to increase their participation in social situations and enjoyable leisure pursuits, resulting in an overall improvement in quality of life. To learn more about how BIG and LOUD might be the right choice for you or someone you love, please call 651-326-2178.
We Could Have Danced All Night

A diagnosis of Parkinson’s does not necessarily mean someone has to sit around and watch life pass him—or her—by. In fact, some Parkinson’s patients have been putting on their dancing shoes and kicking up their heels, thanks to the new ballroom dancing class that the Center has begun to offer.

Every Wednesday at 5:00 p.m., a group of up to 14 people has been meeting to dance, laugh, and socialize, turning the 7th floor of Bethesda Hospital into a swinging hot spot.

Dick and Jeanne Kedrowski are avid dancers and ballroom dance instructors who are donating their time to teach the fox trot, tango, waltz, and many more dance styles to our group.

“This class is full of people with a zest for life,” says Dick. “They just want to continue doing some of the same things they enjoyed prior to their diagnosis.”

While Parkinson’s disease makes movement more difficult, the beat of the music and the up tempo attitude of our dancers makes ballroom dancing a great way for couples affected by Parkinson’s to exercise together.

In the course of an evening, the most common comment heard is “it feels good to move.” Mike Sandmann, director of physical medicine for Bethesda Hospital, reinforces the many benefits of dance. “It’s not about moving around perfectly like a professional dancer…it’s about giving patients a chance to work on balance and body control, and to stretch to prevent joint stiffening. And you sure can’t ignore all the smiles you see throughout the class.”

Due to its popularity, we will be starting another beginner’s class in February 2010. So, if you want to be part of the dance scene at Bethesda and start the New Year out on a good foot (or feet!), look for registration information in the near future.
Gwen Mensen Receives Award

Gwen Mensen, Physical Therapist, has been awarded the second annual Todd J. Enright award. The award is presented to a person in the East Metro area who has demonstrated an extraordinary commitment to serving the needs of people and families living with Parkinson’s disease.

“I feel Gwen is most deserving of this remarkable recognition for her dedication to our Parkinson’s patients,” says Jawad A. Bajwa, MD, Medical Director, Capistrant Center for Parkinson’s Disease and Movement Disorders. “Her deep desire to make a positive difference in their lives is an inspiration to anyone who works in this field. Excellent work, Gwen!”

A $1,000 honorarium accompanies the award, which is named after Todd Enright. Todd died unexpectedly and his parents, Dennis and Kathy Enright, directed Todd’s memorial gifts to the Capistrant Center in recognition of the work of their close friend, Dr. Terry Capistrant.

Respite: A Loved One’s Partner in Care

It might be a new term to some, but respite care is a service that provides outside care professionals to take over for a primary caregiver so that he or she can have a break from everyday caregiving duties. Respite care is short-term or temporary care of anywhere from a few hours up to a couple of weeks. It can occur in the home or at a separate care facility, allowing a caregiver to get some much needed rest while assuring consistent, quality care for the patient.

Parkinson’s Association of Minnesota (PAM) is offering limited assistance (in the form of a grant) to families so they can purchase respite care services. Grants are awarded on a first-come, first-serve basis until the funds for the fiscal year are depleted; the current fiscal year will end May 31, 2010.

To access more information about the PAM grant or to download the application, please visit http://www.parkinsonmn.org. A social worker at Bethesda Hospital will be happy to help walk a family through the grant application process.

Save The Date

Tuesday, February 16
and Wednesday, February 17, 2010

Parkinson’s Action Network (PAN) Conference
University of Minnesota--Minneapolis Campus

Parkinson’s patients, families, and friends are invited to attend this free, two-day educational event. Receive updates from experts on research, treatment innovations, and advocacy.

For more info, contact jackiehc@gmail.com
Capistrant Center Receives $40,000 Gift

This past summer, the Parkinson Association of Minnesota (PAM) gave a $40,000 gift to the Capistrant Center for Parkinson’s Disease and Movement Disorders. The gift will support the Resource Center, speaker’s bureau and support groups, Living Well with Parkinson’s classes, and exercise classes. In making this gift, Paul Blom, President of PAM, said, “I am delighted to be part of answering Dr. Capistrant’s call to ‘spark an era of combined effort to attack Parkinson’s disease.’”

“This generous gift puts us in a landmark position to collaborate metro- and state-wide in providing world class care for patients with Parkinson’s disease,” says Jawad A. Bajwa, MD, Medical Director.

“Support of this kind is important to patients and families as they navigate their journey with Parkinson’s,” comments Cathy Barr, CEO, Bethesda Hospital. “This allows us to take a holistic approach to care.”

In The News

It’s been a good year for raising awareness on behalf of Parkinson’s disease and other movement disorders. WCCO TV visited during a community open house that offered free screenings and tours. Dr. Bajwa was interviewed about the importance of early diagnosis and the range of high quality, specialized programs and services offered at Bethesda Hospital.

Soon after that story, WCCO TV also interviewed one of our patients who had been initially misdiagnosed elsewhere because of several “difficult to connect the dots” Parkinson’s symptoms. Her path luckily crossed Dr. Bajwa’s path during a brief stay at St. Joseph’s Hospital. Based on Dr. Bajwa’s assessment and treatment, she is now enjoying a return to the daily life she loves. This patient’s story is an important reminder of what Dr. Bajwa shares during every educational opportunity: not everything that shakes is Parkinson’s, and Parkinson’s doesn’t always shake.

Dr. Bajwa then appeared as a guest on The Mary Hanson Show, the longest running cable program in the United States. He discussed the latest developments in Parkinson’s diagnosis and treatment, including deep brain stimulation (DBS) and Botox therapy. This episode was broadcast several times throughout the state.

If you are a patient or caregiver with a story you’d be willing to share to help educate our community about Parkinson’s or other movement disorders, please let us know.
Classes
(All programs are held at Bethesda Hospital, 559 Capitol Boulevard, St. Paul)

Support Groups

Monthly general focus groups:
First Monday 1-3:00 p.m.
Second Tuesday 10:00 a.m. - noon
Fourth Monday 6:30 p.m. - 8:30 p.m.

Monthly PSP and MSA focus group:
Second Monday 6:30 p.m. - 8:30 p.m.
Call 651-232-2258 for more information

Parkinson’s Disease/Movement Disorders
Fitness Exercise Classes
Monday-Friday, 11:30 a.m. – 1:00 p.m.
$4 per person/per session
Call 651-232-2258 (primary physician approval is required prior to first class)

Tai Chi for Parkinson’s and Wellness
Every Monday, 10:30 a.m. - 11:30 a.m.
$5 per session
Call 651-232-2258

Living Well with Parkinson’s
An introductory class to understand the disease and its treatment
Offered every other month
Free with RSVP
Call 651-232-2258 to register

Disclaimer: The content in this newsletter is intended to be informational. Please check with your own physician before making changes in your treatment.