Parkinson’s Progress report

APRIL

Parkinson’s Awareness

Did you know…

Nebraska has the highest prevalence per capita for Parkinson’s disease in the world?

Did you know…

Nebraska along with South Dakota, North Dakota, Minnesota and Iowa are in the “Heartland Hub” of the top five states for the disease?

Did you know…

Nebraska was the first state to have a Parkinson’s registry?

Did you know…

WE CAN MAKE A DIFFERENCE BY GETTING INVOLVED!

Several mayors throughout Nebraska are declaring April as “Parkinson’s Awareness Month” for their city by signing a proclamation and presenting it to the local support group. You are welcome to participate by attending these presentations. More information about Awareness activities will be found on our website, www.parkinsonsne.org under events.

Council Bluffs, Iowa—Monday, April 13 at 7pm; 209 Pearl Street

Grand Island—Tuesday, March 24th at 7pm; 100 E. First Street

Hastings—Monday, March 23rd at 7pm; 220 N. Hastings Avenue

Kearney—Wednesday, April 1st at 10am; 18 East 22nd Street

LaVista—Tuesday, April 7th at 7pm; City Hall, 8116 Parkview Blvd

Lincoln— MAYORAL - Wednesday, April 15 at 4:15pm; 555 S. 10th Street, Room 208

Lincoln— Lt. Governor - Weds., April 8 at 10:30am; Warner Chamber, State Capital, 2nd Fl.

Omaha—Thursday, April 16 at 10:30am; City Hall, 1819 Farnam Street, 3rd Floor

Spencer—Tuesday, April 7th at 7pm; City Hall
SAVE THE DATE!

The Annual Walk-a-thon will take place on Sunday, May 31st at Miller’s Landing. Miller’s Landing is located by the Riverfront in downtown Omaha. The Landing will give us access to the new pedestrian bridge and local sites on the river. Look for the big blue balloon arch to mark the Parkinson’s walk location.

Registration will be at 12pm with the walk beginning at 1pm. Each participant can choose the short or long walk path. Food and fun will be provided before and after the walk along with exceptional entertainment and activities.

Don’t miss the opportunity to participate and make a difference in the movement to beat the disease!

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SPONSORSHIP REGISTRATION

Yes, I/we would like to support the 2009 Parkinson’s Invitational Golf Tournament. Please find our check enclosed that will match our sponsorship selection.

- □ CORPORATE SPONSOR: $ 600
- □ TEAM SPONSORSHIP: $ 440
  Attach list of team members to registration.
- □ EVENT HOLE SPONSOR: $ 150
- □ INDIVIDUAL ENTRY: $ 110

SPONSOR CONTACT NAME: ________________________________________

ADDRESS: _______________________________________________________

CITY, STATE, ZIP: _______________________________________________

PHONE: ___________________CELL: _____________________________

EMAIL: _______________________________________________________

PLEASE MAKE CHECK PAYABLE TO: "Creighton University - APDA"

MAIL REGISTRATION FORM AND CHECK TO:
MS. LISA A. BROVOLD
APDA INFORMATION AND REFERRAL CENTER
601 NORTH 30TH STREET, SUITE #2902B
OMAHA, NE 68131
SECOND ANNUAL PARKINSON’S SYMPOSIUM:
“Therapy Matters in Parkinson’s Disease”
Sandhills Convention Center
Friday, May 15, 2009
North Platte, Nebraska

We are excited to present the Second Annual Parkinson’s Symposium! A unique symposium focusing on therapy management for the Parkinson’s patient will take place on Friday, May 15th in North Platte, Nebraska. An exciting forum of speakers will be lecturing to both medical professionals and community participants. One conference setting will host physicians, nurses, pharmacists, physical, occupational and speech therapists, while another conference will target patients, spouses, family and caregivers.

Dr. Diego Torres, the newest Movement Disorder Specialist in Nebraska, will instruct the attendees on botox treatment for dystonia (cramps in feet, legs, etc.). A familiar face, Dr. John M. Bertoni, will present the process of diagnosing Parkinson’s disease and the management of it. Dr. Lillian Larson and Melissa Harmon, speech therapist, will provide a team approach in exploring the role of speech therapy. Physical therapist, Julie Knoll will discuss the importance and benefits of physical therapy in Parkinson’s disease. Kaylene Sodawasser, occupational therapist will wrap it up by sharing creative methods that help maintain daily quality of life.

Look for the brochure in April!

Date/Time | Spring Event
---|---
Wednesday, April 8 10:30am | State Proclamation Signing  
Lt. Governor Sheehy  
Warner Chamber, State Capital Building  
Lincoln, Nebraska

Monday, April 13 9:00am | Embracing the Heartland  
KGBI 100.7 FM  
Lisa Brovold, Coordinator will discuss Parkinson’s Disease  
With September Turner

Monday, April 20 1:00pm | Parkinson Empowerment Program  
Teleconference:  
“Depression in the Parkinson’s Patient”  
Thomas Magnuson, MD  
Contact (866) 626-7347 or online at www.parkinsonsne.org

Friday, May 15  
All Day | Second Annual Parkinson’s Symposium  
“Therapy Matters in Parkinson’s Disease”  
Sandhills Convention Center  
North Platte, Nebraska  
Contact (866) 626-7347 or go online to www.parkinsonsne.org
One of the questions that I frequently receive from patients is why other people they know who have Parkinson’s disease are using different medications than they are. Sometimes patients even request that they be allowed to try specific medications because they know someone else who had good results. The choice of which medication is appropriate for a patient depends on several factors. The good news is that we have more medications to treat Parkinson’s disease than we do for any other neurological disorder. There is a great deal of research in this area, and not only are we discovering new medications, we are learning more about the medications that we already have which in many cases is causing us to rethink the way we have traditionally approached Parkinson’s disease. What this ultimately means is that there are several ways to initiate and continue the progression of therapy. This allows us to tailor therapy more closely to the specific needs of a particular individual.

At the time of diagnosis, several factors are taken into consideration when choosing how and when to initiate drug therapy. One such factor is the age of the patient. Some medications can lose effectiveness over time, and that may mean that therapy with those medications, even if they are some of the best at controlling symptoms, may be delayed in younger patients so that they are still available as symptoms become increasingly troublesome. Individual patient’s needs are also taken into account. For example, having a job that requires fine motor skills may mean that therapy is more aggressive in the beginning.

Many of the medications that we use to treat Parkinson’s disease can have effects on other diseases and other medications that are being taken by a patient. Sometimes that limits what we are able to safely use for one individual. Or conversely, it may make the choice much easier if a drug for Parkinson’s disease can be used to treat multiple problems. For instance, many patients with Parkinson’s disease also have a condition called Restless Leg Syndrome (RLS) that causes unpleasant sensations in the calves, thighs, or feet. The drugs of choice for RLS are the same dopamine agonists (ropinirole, pramipexole) that are used to treat Parkinson’s disease. Therefore, it makes sense to try to treat both problems with one drug.

Some of the medications we use can make other conditions worse. Since the majority of patients with Parkinson’s disease are diagnosed later in life, it is a frequent occurrence that additional diagnoses are present, and other drugs are being used. People who have glaucoma, bowel problems, irregular heartbeats, and men with prostate enlargement can experience worsening of symptoms when exposed to some medications used to treat Parkinson’s disease. As a consequence, for some patients we have fewer medications from which to choose.

Additionally, even though certain symptoms are classically thought of as being a part of Parkinson’s disease, (mainly tremor, rigid muscles, slowed movement, and balance disturbances), not all patients experience the same symptoms in the same way. Some drugs are better for certain symptoms than others. For instance, one group of medications may be useful in helping to alleviate tremor, but may have little effect on rigidity or slowness. Conversely, some medications work very well across the entire spectrum of symptoms. It would make little sense to use a drug that only targets tremor to treat someone who had multiple symptoms knowing that a second drug would have to be initiated. Similarly, that drug would be of no use in someone who did not experience tremor as part of their disease. The goal is always to use the least number of drugs at the lowest possible doses to get the best outcomes. In doing so, unwanted side-effects and drug interactions are limited.

At this time, there is no cure for Parkinson’s disease, and how the symptoms progress is different from patient to patient. As time passes, the dose of a drug may need to be increased, a drug may need to be taken more often, or a new drug may need to be added. None of these approaches are right or wrong. The choice is up to the prescriber and the patient.

The way physicians approach Parkinson’s disease may soon change. New study data indicates that before long we may be able to slow down the progression of the disease in those who are newly diagnosed. The treatment of Parkinson’s disease has already changed substantially over the last couple of decades, and our knowledge is continuing to grow. It is important for patients to understand that treatment must be individualized, and the right drug for one person may be the wrong drug for another.

Michele A. Faulkner, Pharm. D., is a faculty member of School of Pharmacy and Health Professions, Department of Pharmacy Practice at Creighton University, Omaha, Nebraska.
A Place to Belong...

**Adams**
Karma Boddy - Co-Facilitator
Diane Nieven - Co-Facilitator
Gold Crest Retirement Center
200 Levi Lane
(402) 988-7115
3rd Tuesday at 6:30pm

**Beatrice**
Harold Brown – Facilitator
Good Samaritan
1306 S. 9th Street
(866) 421-0816
1st Monday at 10am

**Broken Bow**
Glenda Ward - Facilitator
Prairie Pioneer Center
1314 South “B” Street
(308) 872-3974
2nd Thursday at 7pm

**Columbus**
Virgil Chochon – Facilitator
Columbus Community Hospital
4600 38th Street
(402) 564-1438
2nd Thursday at 1:30pm

**Fairbury**
Lana Likens – Facilitator
Jefferson Community Health Ctr.
2200 “H” Street
(402) 729-3351
1st Monday at 10am

**Gering-Scottsbluff**
Jack & Donna Johnson-Facilitators
Northfield Villa
2550 21 Street
(308) 235-2513
4th Wednesday at 2pm

**Grand Island**
Connie Van Wie - Co-Facilitator
Charlotte Brown - Co-Facilitator
1st Presbyterian Church
2103 West Anna Street
(308) 382-3713/384-5997
3rd Sunday at 2pm

**Hastings**
Flossie Saathoff - Facilitator
First St. Paul Lutheran
918 W. 4th Street
(402) 462-9970
4th Wednesday at 2pm

**Kearney**
Andy & Nevabelle Howe – Facilitators
First United Methodist Church
4500 Linden Drive
(308) 234-1570
2nd Tuesday at 2pm

**Lincoln**
Judy Johnson – Co-Facilitator
Emie Wedergren - Co-Facilitator
Madonna Rehab Center
54 and South Streets
(402) 435-8946/304-1950
4th Sunday at 2pm

**Early Onset**
Bruce & Kristi Griffith - Co-Facilitators
(402) 449-2584 - Kristi
Call for day/time

**McCook**
Wally & Gloria Gummers – Facilitators
Community Hospital
1301 E. “H” Street
(308) 276-2651
3rd Monday at 7pm

**Norfolk**
Phil & Bonnie Sykes – Facilitators
Lutheran Hospital Nebraska Rm.
2700 Norfolk Avenue
(402) 371-6613
1st Tuesday at 2pm

**North Platte**
Carolyn Fear – Facilitator
First United Methodist Church
1600 W. “E” Street
(308) 534-7404
1st Monday at 7pm

**Omaha**
Ron & Maxine Kantor – Facs.
Creighton Univ. Med. Center
601 N. 30 Street, Dining Rms A-C
(402) 393-9169
3rd Thursday at 11:30am

**Caregiver’s Gathering**
Mary Mick - Facilitator
APDA Nebraska Chapter Office
501 N. 87 Street, Suite 207
(402) 449-4535

**Exercise Only – Omaha**
Melanie Clark, RPT – Co-Facilitator
Linda Fuchs, RPT – Co-Facilitator
St. Leo’s Church, 102 and Blondo
(402) 391-4052 or 533-8242
Every Tuesday at 11am

**Evening**
Lisa Brovold
APDA Nebraska Chapter office
501 N. 87 Street, Suite 207
(402) 449-4535
4th Monday at 6:30pm

**Sioux City, Iowa**
Marilee Lynn - Facilitator
Sioux Land Senior Center
Hamilton Blvd & West 4 Street
(712) 389-2954
3rd Monday at 1pm

**Spencer**
Ray & Nellie Faye Hagberg–Facilitators
Our Savior Lutheran Church
101 S. Whipple
(402) 589-1576
3rd Tuesday at 2:30pm

**York**
Rita Maloley – Facilitator
York General Hospital
2222 Lincoln Avenue
(402) 362-0440
3rd Tuesday at 2pm

**Caregiver’s Gathering**
Mary Mick - Facilitator
APDA Nebraska Chapter Office
501 N. 87 Street, Suite 207
(402) 449-4535

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St. Leo’s Church, 102 and Blondo
(402) 391-4052 or 533-8242
Every Tuesday at 11am

**Fitness Works**
Jacey Gengenbach, NSCA - CPT
1032 S. 74th Plaza
(402) 934-8881
Monday: 12pm - 1pm*
Tuesday: 6pm - 7pm*
Saturday: 9am - 10am*

* $10 charge/session

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Gering, Scottsbluff and Cheyenne Support Groups
Feeling stretched caring for a loved one?

Powerful Tools for Caregivers is an educational program designed to provide caregivers with tools needed for taking care of themselves.

During six weekly sessions attendees will learn how to:

- Reduce Stress
- Improve self confidence
- Balance life
- Better communicate feelings
- Make tough decisions
- Locate helpful resources

When a caregiver takes care of themselves, the care receiver also benefits.

<table>
<thead>
<tr>
<th>Location</th>
<th>Day</th>
<th>Dates and Times</th>
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<tbody>
<tr>
<td>4-Hour workshop Lincoln, NE</td>
<td>Tues</td>
<td>April 21 5:30 - 9:30pm</td>
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<tr>
<td>Mills County Extension Svcs. 415 Main St., Malvern</td>
<td>Tues</td>
<td>April 14 - May 19 9:00 - 11:30am</td>
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<tr>
<td>Bellevue, NE Location to be announced</td>
<td>Thurs</td>
<td>April 16 - May 21 9:00 - 11:30am</td>
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<tr>
<td>Fountainview Senior Living 5710 S. 108 St., Omaha (Near 108 &amp; Harrison)</td>
<td>Tues</td>
<td>May 26 - June 30 9:00 - 11:30am</td>
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If you are engaged in caring for another person there is NO CHARGE to take the 6 – week Powerful Tools for Caregivers classes.

Pre-registration is required and class space is limited. For information or to register, call: 402-522-7934

Leave a name and number so a Powerful Tools for Caregivers representative can return the call, answer any questions or concerns, and take registrations.
INFO...

Young Onset Activities

Saturday, April 18

A tour of Boys Town, including Father Flanagan’s home, Hall of History, Meditation Gardens and the Visitor’s Center. The tour will begin in the Visitor’s Center with a free boxed lunch being provided at 12:30pm. A youth tour guide will join you and show you around the Town. The tour should end around 3:30pm.

Saturday, May 16

Come and enjoy the beauty of Spring at Lauritzen Gardens. There is no admission cost and a gourmet boxed lunch will be provided to everyone who RSVPs. Following the lunch in the dining room, you will be able to stroll at your leisure and talk with the other members of the group. Our own Monnie Lindsay is a Lauritzen docent, so she will provide the inside scoop!

Contact Colleen Wuebben at 397-0327 or Katie Domayer at 551-0602 for more details.

Caregiver’s Gathering

A group for caregivers was started a year ago in Omaha. It has grown from three people to 12 people. The group meets the second Wednesday of the month at 501 N. 87 Street, Suite 207, which is the Nebraska Chapter office on the corner of 87th and Dodge. The meeting begins at 10am. Parking is provided in the rear of the building.

New Group in Grand Island

Connie Van Wie and Charlotte Brown hosted their first meeting in Grand Island in January. It was so successful that they invited Lisa Brovold to speak at their next meeting. On Sunday, March 15, she addressed a large, receptive audience at the First Presbyterian Church. The support group will meet regularly on the second Sunday at 2pm. Interested individuals should contact Connie at (308) 382-3713 or Charlotte at (308) 384-5997 for the 2009 schedule.

New Exercise Class

In Omaha, Jacey Gengenbach, NSCA, CPT, with Fitness Works, has begun exercise classes specifically designed for people with Parkinson’s. The classes cost $10.00 a session. The sessions are as follows:

- Monday 12pm - 1pm
- Tuesday 6pm - 7pm
- Saturday 9am - 10am

The classes are held at Fitness Works, 1032 S. 74 Plaza in Omaha. For more details call Jacey at (402) 934-8881.

New Group in Adams

A new support group has recently started in Adams, Nebraska. Adams is located southeast of Lincoln (between Lincoln and Beatrice). Karma Boddy and Diane Nieveen of Gold Crest Retirement Center are the co-facilitators. The first meeting had close to 20 people in attendance. The group will meet on the 3rd Tuesday of the month at 6:30pm at Gold Crest. Call (402) 988-7115 for more information.

Thank you for your generous gifts and donations to the Nebraska Chapter of the American Parkinson Disease Association. All contributions are used in Nebraska for supportive services and across the country for Parkinson research.

You can make a tax-deductible donation by sending a check to:

Nebraska Chapter/APDA
501 N. 87 Street, Suite 207
Omaha, NE 68114

Fun at the Facilitators’ Meeting

Nebraska Facilitators
APRIL
PARKINSON’S AWARENESS MONTH
(Check the website for activities)

May 31, 2009
Walk-a-thon
Miller’s Landing on the Riverfront - Omaha

June 27, 2009
Golf Invitational Tournament

Hand in Hand, Linking Lives for Parkinson’s
April 2010