Parkinson’s Progress report

VOLUME VII ISSUE I Winter 2011

Coordinator
Lisa A. Brovold

Nebraska Chapter
Mary Egger, President
Mary Jane Petersen, Secretary
Bev Baker, Treasurer

Parkinson’s Progress report is published quarterly as an information guide only. The newsletter does not serve as legal or medical advice.

Correction: The August newsletter erroneously listed James Poole as Vice President for the Chapter. This is not correct and there is no Vice-President at this time.

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Happy Holidays!

Peace and Joy to all of you this special time of year;

May 2011 be full of hope and success in everything held dear.

Your gift of friendship and support are deeply treasured

-Lisa and Danica
Once a year, the facilitators of all 27 support groups state-wide meet together for a time of enjoyment, education and networking with their colleagues. On Thursday evening, an Appreciation Banquet is held in their honor and the Above and Beyond awards are bestowed upon deserving facilitators for all their service to the Parkinson’s community. With every facilitator worthy of receiving the award, it is a difficult decision to choose only two to present it to per year. This year’s recipients of the Above and Beyond awards were Rod and Lorraine Osler from Hastings and Virgil and Elaine Chochon from Columbus. Lorraine Osler has served the Hastings support group along side Flossie Saathoff for over 25 years. She began attending the group with her first husband who had been diagnosed with Parkinson’s. Even long after his death, Lorraine continued to dedicate her time to the support group. Eventually she remarried and the Parkinson’s community was blessed with Rod’s quirky sense of humor and compassion.

Virgil and Elaine Chochon followed Theresa Noonan as the Columbus support group facilitators in 2006. Virgil has Parkinson’s disease and leads his group by his example. He is a leader in raising awareness in the Columbus community, seeking funding support from area business and banks. Elaine quietly supports Virgil and the group through her caring ways and organizational gifts. The Parkinson’s community is fortunate to have such leaders in our midst.

Our theme for the Appreciation Banquet was “Come as You Dream to Be”. So many of our facilitators came dressed in costume of who they would like to be.
The Care Partners Gathering
Lauritzen Gardens Outing

Many of you are not aware that the Parkinson’s Information and Referral Center hosts a Care Partners Gathering every **Second Wednesday** of the month. The Gathering is a time for care partners, those who have spouses or other relatives with Parkinson’s disease, to meet together for support and insight into their unique life situation. It is an opportunity to share and care as well as enjoy each other’s company. The group not only meets for these special purposes but to let loose and have some fun! They do this through different outings and activities such as the Lauritzen Gardens field trip shown above or a holiday white elephant exchange below.

The Care Partner Gathering meets at 10am at the Chapter office, 501 North 87 Street, Suite 207 on the **second Wednesday** of the month. Parking is in the rear of the building. Though the group is mostly women, we challenge the men to come and be involved. For more information, please contact Mary Mick at 571-4648 or Lisa Brovold at 449-4535. Hope to see you there!

**Share and Care Time Together**

*We know how to have FUN!!!*
Every year for the past three years, the Parkinson’s Information and Referral Center has hosted two separate symposiums for the Parkinson’s community across Nebraska. The symposium is unique as it has two conferences running simultaneously; one for medical professionals and one for the community.

The symposium held in North Platte was located at the Sandhills Convention Center. This year’s symposium was another wonderful success, focusing on the basic care issues of Parkinson’s. A panel of four people with Parkinson’s spoke at both of the conferences, providing their own personal account of their journey with Parkinson’s. Both audiences found the panel to be very informative and appreciated the personal perspective. Drs. Cardenas, Kluger and Widnell provided further insight into diagnosing, managing and recognizing the symptoms and progression of Parkinson’s Disease. The North Platte Symposium is sponsored by the Hand in Hand fundraiser, APDA Nebraska Chapter.

The Omaha symposium entered its seventh year and was another huge accomplishment. With both conferences almost filled to capacity, it was the best attended symposium. The topics focused on the treatment options for the disease and the popular physicians from University of Nebraska Medical Center provided the majority of the education. Dr. Mohiuddin from Creighton presented the rare insight into the complications that Parkinson’s has on the heart. The APDA Nebraska Chapter supports the Omaha Symposium through donations given by you.

These symposiums will be offered again in 2011. Be looking for the details in the next newsletter or via email. You can also go to the website: www.parkinsonsne.org for more information.

<table>
<thead>
<tr>
<th>Date/Time</th>
<th>Spring Events</th>
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<tr>
<td>Monday, February 14</td>
<td>Parkinson’s Empowerment Program</td>
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<tr>
<td>1:15pm CST</td>
<td>Teleconference</td>
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<td></td>
<td>“Dental Care”</td>
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<td></td>
<td>William Parr, DDS</td>
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<td>Contact (866) 626-7347 or online at <a href="http://www.parkinsonsne.org">www.parkinsonsne.org</a></td>
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<tr>
<td>Friday, April 8</td>
<td>Parkinson Empowerment Program</td>
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<tr>
<td>10:00am CST</td>
<td>Teleconference:</td>
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<tr>
<td></td>
<td>“A Dialogue with David Iverson”</td>
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<td></td>
<td>David Iverson, Writer, Correspondent and Co-Producer</td>
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<tr>
<td></td>
<td>2009 PBS Frontline documentary “My Father, My Brother and Me”</td>
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<tr>
<td></td>
<td>which explored his family’s battle with Parkinson’s disease.</td>
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<tr>
<td></td>
<td>Contact (866) 626-7347 or online at <a href="http://www.parkinsonsne.org">www.parkinsonsne.org</a></td>
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When they hear the words “Parkinson’s disease,” most people immediately think of tremor. However, those of us who work with people who have the disease, and certainly those who experience the symptoms know that rigidity, slow movement and impairment of posture are also frequently encountered by affected persons. But there is one symptom frequently encountered that is often not recognized as part of the disease by patients, or even by their medical advisors. In fact, it is a symptom that may actually precede the diagnosis of Parkinson’s disease. That symptom is pain.

The frequency with which people who have Parkinson’s disease experience pain is estimated to be anywhere from 40-80%. Of course, it stands to reason that because older persons are affected more often than younger persons, pain is not an uncommon occurrence as it is often encountered within the age group most likely to have the disease. This is one of the primary reasons that the pain of Parkinson’s disease is overlooked or attributed to something else entirely. In addition, pain is not something that you can see. Clinicians rely on patients to tell them that they are hurting. However, because patients typically have no idea that the pain might be a symptom of their disease, they fail to mention it, and simply suffer in silence.

There are many types of pain experienced by Parkinson’s disease patients. Certainly the most common of these are muscle cramps, and stiffness or tightness in the muscles (especially in the neck, the back and the legs), dystonias (sustained muscle contractions that cause twisting and repetitive movements or abnormal postures resulting in pain, especially common in the feet), and neuropathic pain (pain originating from the malfunctioning of the nervous system, often experienced as burning or tingling). The site of the pain may or may not coincide with the sites of the obvious symptoms of Parkinson’s disease.

Certainly, some pain is known to be due to the underlying disease, because it appears or becomes worse when medications used to treat the abnormal movements begin to wear off or lose their effectiveness. If that is the case, the best option is to adjust the medications being used to treat the Parkinson’s disease so that symptoms remain under more constant control, thus keeping the pain at bay. It is important to keep in mind that sometimes the medications used to treat Parkinson’s disease have a tendency to make the pain worse. Therefore, when a Parkinson’s patient experiences pain, the first thing that should be done is an evaluation of their medications to see if they gain relief or experience a worsening of pain after they are medicated. If neither is true, then other options for pain control should be considered.

Aching, cramping and pain in the joints are common in Parkinson’s patients, because lack of mobility, unnatural posture, generalized stiffness and abnormal movements associated with walking stress those areas. It is quite common for patients to experience what is known as “frozen shoulder,” which is an extreme reduction in the normal range of motion caused by muscle strain and scarring of the soft tissues. Arthritis in the spine is another common finding. Ultimately, besides controlling the pain that already exists, the goal is to maintain or restore mobility so that the musculoskeletal problems described here are avoided. The best way to maintain mobility is a formal exercise program that includes stretching.

Most of the medications that we typically use for other painful conditions are used to treat the pain associated with Parkinson’s disease. When the pain is muscular or bone/joint related, there is often an inflammatory process at work. Over the counter medications called non-steroidal anti-inflammatory drugs, or NSAIDS (such as ibuprofen and naproxen) can be useful in such an instance. However, many older people, and some younger ones too, have high blood pressure. Using these medications can render drugs used to control blood pressure less effective, or they may bring about high blood pressure in someone who has not previously been diagnosed with the condition. This is an example of why we must keep in mind that medications available over the counter are
Similarly, prescription medications, such as those in the codeine family (known by the brand names Tylenol #3®, Lortab®, Percocet® and Oxycontin® among others) may be prescribed for more severe pain. These medications, although certainly effective, can be troublesome for patients with Parkinson’s disease, because they can add to the drowsiness many people experience due to their disease or to the medications they use to control their movement-related symptoms. These pain medications can also cause excessive dizziness, and increase the risk of falls in a population already susceptible to this problem. In addition, some patients experience profound constipation when they use medications from this class, thus worsening a problem experienced by many people with Parkinson’s disease. Symptoms of dementia and psychosis (particularly hallucinations) may also be made worse by these drugs.

Antidepressant medications and medications used to control seizures in people who have epilepsy may play a role in controlling pain that originates from the nerves. It is important that drug interactions be evaluated before such medications are used. However, it should be noted that depression has been shown to make pain syndromes worse for some patients, so the use of antidepressants may have a dual effect on the problem. Drowsiness and dizziness are common with these medications as well.

Patients with Parkinson’s disease need to be made aware that pain is a symptom associated with the disease, and routine questioning by health care professionals should be a part of the monitoring process. If you, or someone you know that has Parkinson’s disease is experiencing pain, talk to your doctor or pharmacist about the options.

Youth affects people of all ages, not just the elderly. To help meet the needs of those who are diagnosed at an early age, there is a Young-Onset group that meets on a monthly basis. The group’s focus is to educate, encourage and equip people with the disease to live life to the fullest. Their motto is, “Learn all you can about Parkinson’s, then live like you don’t have it.” If you are interested in learning more about the Young Onset group, contact either Katie at 551-0602 or Colleen at 397-0327.
A Place to Belong...  

**Adams**  
Karma Boddy - Co-Facilitator  
Diane Nieveen - 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  
(402) 228-2680  
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**  
Lorraine Osler - Facilitator  
First St. Paul Lutheran  
918 W. 4th Street  
(402) 463-8081  
4th Wednesday at 2pm

**Kearney**  
Nevabelle Howe – Facilitator  
First United Methodist Church  
4500 Linden Drive  
(308) 234-1570  
2nd Monday at 2pm

**Lincoln**  
Judy Johnson - Co- Facilitator  
Lori Johnson - Co - Facilitator  
Madonna Rehab Center  
5401 South Street  
(402) 435-8946 or (402) 430-2273  
4th Sunday at 2pm

**McCook**  
Wally & Gloria Gummere – Facilitators  
Southwest Public Health  
404 West 10th Street  
(308) 276-2651  
3rd Monday at 7pm

**Nebraska City**  
Kim Meredith  
Morton House  
1500 14th Avenue  
(402) 873-5551  
4th Wednesday at 10:30am

**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**  
Sherwin & Betty Terrill-Facilitators  
16778 Sage Street  
(402) 889-1608 or  
(402) 889-1610  
Last Wednesday at 10am

**Seward**  
Alicia Brown - Facilitator  
Greene House  
600 Church Street  
(402) 643-9111  
4th Tuesday at 10am

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

**Wallace**  
Karen Gibson—Co-Facilitator  
Karen Goucher—Co-Facilitator  
United Methodist Church  
118 S. Wallace  
(308) 387-4580/387-4221  
3rd Monday at 7pm

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

**Exercise Only – Omaha**  
Melanie Clark, RPT – Co-Facilitator  
Linda Fuchs, RPT – Co-Facilitator  
St. Leo’s Church, 102 and Blondo  
(402) 391-4052 or 553-8242  
Every Tuesday at 11am

**Carepartner’s Gathering**  
Mary Mick - Facilitator  
501 N. 87 Street, Suite 207  
(402) 449-4535  
2nd Wednesday at 10am

**Early Onset**  
Katie Domayer – Co-Facilitator  
Colleen Wuebben - Co-Facilitator  
(402) 551-0602/397-0327  
Call for day/time

* $10 charge/session
<table>
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<tr>
<th>Name</th>
<th>Contributions</th>
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<tr>
<td>Doris I. Angeroth</td>
<td>Beverly Clark, Charles &amp; Patricia Tatta, Deb &amp; Bob Franklin, Denny &amp; Meg Sullivan, Eldon &amp; Lynn Angeroth, Elton &amp; Daphne Miller, Ethelyn Knoernschild, Freddie &amp; Joan Miller, George &amp; Pam Sevick, Gerry &amp; Judy Bailey, Inella Eickholt, Joann Blum, Jon Ulven, Judy, Julia, Nancy, Deanna, Larry &amp; Debra Mesward, Mabel Jacobson, Maria Tweedy, Mark &amp; Ginger Unverzagt, Mary Ann Simpson, Michael &amp; Elaine Brown, Ogden Salon, Ozzie &amp; Donna Moonen, Patricia Frascht, Patricia Murphy, Patrick &amp; Doris Montang, Richard &amp; Catherine Connell, Rodney &amp; Janie Montang, Roland &amp; Eileen Hilty, Shirley Remmenga, Sunshine Fund, Tolora Lee, Tracy Vallier, Vernon Wulff</td>
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<td><strong>Harold Force</strong></td>
<td>Em Wunderlich, Grace Force, Jerald Wunderlich, Linda Schramek</td>
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<td>Margaret Garcia</td>
<td>Ann Burda, Dennis Clare, Joseph Garcia, Scott &amp; Michelle Fisher</td>
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<td>Orville Hanke</td>
<td>Charles &amp; Patricia Portenier, Donald &amp; Patricia Stienike, Johanna Homan, Keith &amp; Florene Skeels, Larry &amp; Karen Berstler, Lewis &amp; Shirley Hilligas, Wanda Sobotka</td>
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<td>Russell Leonard</td>
<td>Stuart &amp; Carol Leonard</td>
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<td>Dolores Meader</td>
<td>Michael &amp; Susan Pryor</td>
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<tr>
<td>Gene Neuswanger</td>
<td>Rosie &amp; Bernie Meyers, Vicki Perlmeter, John Robinson</td>
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<tr>
<td>Richard (Dick) Osterhaus</td>
<td>Jim &amp; Coleen Vincent, American Printing Company</td>
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### Gifts

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| | Ronny & Lynn Meyer  
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| | United Way of the Midlands |  

Thank you to all of our friends who donated in memory or honor of a loved one. Your financial gift allows the mission of the APDA Chapter and Center to continue to ease the burden of those in Nebraska.

Your generous donation allows more people with Parkinson’s to be educated about the disease and to have a better quality of life.

### Honorariums:

| **Earl Anderson** | Ray & Nellie Faye Hagberg |  
| **Lola Anderson** | Russ Corey Chiropractic |  
| **Timothy P. Jasa** | Helen Jasa |  
| **Stewart Kahn** | Allen Kahn |  
| **Pete Kiscoan** | Brian & Kathy Mallatt |  
| **Wally Gummere** | Lisa Gummere |
In April, the Center and Chapter of the APDA will make a huge effort to raise awareness of Parkinson’s throughout Nebraska. Please look for the activities and opportunities to become involved in this effort. We need everyone’s participation to make a difference where we live!