Celebrating the Life of Nathan Slewett, NPF Chairman Emeritus

The National Parkinson Foundation’s Chairman Emeritus, Mr. Nathan Slewett, passed away on July 7, at age 97. Mr. Slewett spent more than 40 years as a tireless volunteer leader and supporter of the National Parkinson Foundation and he left an indelible mark on the lives he touched through his personal philanthropy.

Last year, Mr. Slewett received two prestigious honors in recognition of his contributions to Parkinson’s disease research and treatment. The World Federation of Neurology (WFN) chose Miami as the location for its XVII World Congress on Parkinson’s Disease and Related Disorders in order to honor him for his work which was recognized as shaping Parkinson’s research. Coinciding with the opening ceremony of the congress, the Miami-Dade Board of County Commissioners declared December 13, 2009 as “Nathan Slewett Day” for his contributions to the Parkinson’s community, as well as the South Florida community.

Mr. Slewett became involved with NPF after relocating his family to Miami from New York, where he was a successful attorney and real estate developer. Mr. Slewett had planned to retire, spend time with his family and play golf. Instead, during the 1970s, he began fundraising for NPF on the golf course. He worked at the National Parkinson Foundation in Miami as a volunteer for over 40 years. According to Nathan, the driving force behind his decision to become involved with NPF was, “to pay back to society all the good things provided to me and my family.” He served as the volunteer President of the foundation for several years and was elected Chairman of the Board in 1992, and continued to serve as Chairman Emeritus until 2010.

CONTINUED ON PAGE 2
“To those who knew him, Nathan Slewett was a vital force of nature, stronger and more vibrant than his years would suggest,” said Joyce Oberdorf, President and CEO of NPF. “He was a visionary whose shrewd business sense and concern for others touched many people’s lives. We are indebted to Nathan for his unwavering commitment not only to research, but also to care for those living with Parkinson’s.”

Mr. Slewett succeeded at bringing in celebrities such as Bob Hope and Dick Clark to annual fundraising events. He took on this important role after befriending NPF’s founder, Mrs. Jeanne Levey, without compensation and without any personal or familial connection to the disease. His accomplishments during his tenure are remarkable—because of his leadership, the National Parkinson Foundation has: funded more than $155 million in research and support services since 1982; established a Centers of Excellence network housed at leading universities throughout the world; given many prominent researchers and scientists their start in the field through grant funding; and garnered international recognition.

Nathan’s leadership and philanthropy also benefited several other organizations. He was the founder of Boys Town/Jerusalem, a trustee of Temple Beth Sholom in Miami Beach and a member of the Society of Fellows of the Anti-Defamation League. He was recognized as Volunteer of the Year by the National Society of Fund Raising Executives and was awarded the 2001 Presidential Order of Merit by the University of Miami.

Although he did not live to see a cure for Parkinson’s disease, his legacy lives on in the many researchers and neurologists whose careers started because of Nathan Slewett. He will always have a place of honor at the National Parkinson Foundation, as well as in the heart of everyone who had the privilege of knowing him.

“Nathan did not just raise awareness and funds for Parkinson’s research and education; he inspired others to do the same with his boundless energy and commitment, coupled with his irresistible personal charm.

Although it is difficult to appreciate the full impact he has had on the search for a cure of Parkinson’s, his enormous contributions have clearly translated into improved quality of life for countless patients and their families. Nathan’s constant quest for excellence in education, research and patient care have inspired other organizations and support groups around the globe.”

Joseph Jankovic, MD, Medical Director of the NPF Center of Excellence at Baylor College of Medicine.

To honor the memory of Nathan Slewett, his family and friends have established a special Year-End Challenge Grant. They will match, dollar for dollar, up to $100,000 in matching funds, any year-end gift you make before December 31, 2010. For more information, please call 800-327-4545.

In October 2010, NPF launched a Parkinson’s disease toll-free helpline staffed by highly-trained Parkinson’s specialists, including social workers and nurses, with Spanish-language capabilities. “The Helpline is our way of saying that you don’t have to face Parkinson’s alone,” explains Joyce Oberdorf, President and CEO of NPF. “If you call, you will speak to a real person who understands your needs and will help break the isolation all too many patients and caregivers feel.” Each caller, whether they are newly diagnosed or have been living with PD for years, has unique needs and should have access to the right information at the right time. Now, through the Helpline, we are able to offer customized and personal information to patients and families.

On each call or e-mail, our specialists help establish connections to resources and local networks of support through our extensive network of 43 Centers of Excellence, 43 chapters and over 900 support groups. The Helpline allows us to reach out to underserved communities in rural areas or inner-cities who may not have access to information about Parkinson’s disease. Our specialists will help callers locate resources in their area, as well as send them an informational packet that will help callers be fully informed on their next visit to the general practitioner or movement disorder specialist.

The Helpline is not just for people diagnosed with Parkinson’s disease; it is also for their caregivers, family and loved ones. The Helpline can become part of a support system for anyone affected by Parkinson’s.

The NPF Helpline is made possible through the generous support of the Medtronic Foundation and thousands of people with Parkinson’s and their families.

Do you suspect that a loved one may have PD?

Our Helpline specialists are here to talk to you about the early warning signs of PD:

1) Tremor or shaking
2) Stooping or hunching over
3) Trouble moving or walking
4) Small handwriting
5) Loss of smell
6) Trouble sleeping
7) Soft or low voice
8) Having a serious or a mask-like facial expression
9) Dizziness or Fainting
10) Constipation

Remember that no single one of these signs means that you or a loved one has Parkinson’s disease, but early diagnosis of PD gives you the best chance of a longer, healthier life.

Call us now if your loved one shows several of these symptoms. We’re here to help!

For more information, visit:
www.parkinson.org/helpline.

The Helpline hours are
Monday - Friday, 9am - 5pm (EST).
You may also e-mail us at helpline@parkinson.org.

Please be aware that while we are happy to discuss any issue with you, calling our Helpline is not a substitute for going to a doctor. When making a medical decision, always consult a physician. We stand ready to discuss issues related to PD generally and possible places to go to get care or support, but we can’t diagnose or treat PD over the phone. When we offer names of people in your area, that does not specifically constitute an endorsement of them or the services they offer. NPF does certify certain centers, has affiliated chapters, and offers training to providers, and the Helpline specialist can help you find one of these if you request it.
NPF Awards $1 Million for Clinical Research

Each year, NPF, under the direction of our Clinical and Scientific Advisory Board (CSAB), supports cutting-edge research conducted by the world's top Parkinson's disease experts. The singular aim of NPF's research is to partner with our Centers of Excellence to discover the best treatment and care options for people living with Parkinson's disease.

In 2010, NPF awarded one million dollars to four research investigators in the United States, Canada and Australia. “These awards are part of NPF’s emphasis on clinical and comparative effectiveness research that is focused on improving care,” said Joyce Oberdorf, President and CEO of NPF. “Each project can have an immediate impact on the lives of Parkinson’s disease patients worldwide.”

NPF GRANTS FUNDED IN 2010:

**Biomarker Assessment of the PARS Cohort—Principal Investigator: Andrew Siderowf, MD, MSCE, Associate Professor of Neurology and Medical Director, University of Pennsylvania, NPF Center of Excellence, United States.**

The Parkinson At-Risk Syndrome (PARS) project is intended to identify individuals at risk of developing Parkinson's disease before they display symptoms. Dr. Siderowf has identified a group that he believes is at risk of developing PD. Even though they have no symptoms, Dr. Siderowf believes that those who will develop PD are currently losing neurons at a higher rate than they will once symptoms are present. NPF is funding lab tests that could be performed on these at-risk individuals to identify PD before people develop symptoms.

**Early Detection of Cognitive Changes in the Brain—Principal Investigator: Antonio Strafella, MD, PhD, FRCPC, Toronto Western Hospital, NPF Center of Excellence, Canada.**

Dr. Strafella’s study will use positron emission tomography (PET) in the hopes of establishing biomarkers for cognitive impairment in Parkinson’s disease, a model pioneered successfully in Alzheimer’s disease. Such biomarkers are a critical requirement for understanding disease progression. Dr. Strafella believes that the success of this project would make possible disease modifying therapies for cognitive decline: “By identifying the changes associated with early cognitive changes, we will be able to set the path for potential early treatments offering significant impact on the quality of life of people with Parkinson’s disease.”

**Comparing Physical Therapy Outcomes: LSVT-BIG® vs. Aquatic Methods—Principal Investigator: David J. Houghton, MD, MPH, University of Louisville, NPF Center of Excellence, United States.**

Dr. Houghton will lead an investigation of an advanced aquatic therapy by testing outcomes against the well regarded land-based therapy LSVT-BIG®, a rehabilitative therapy for people with Parkinson’s. In a well designed, randomized comparative effectiveness study, these two approaches will be compared with each other, rather than against a placebo therapy. This analysis will have policy implications as aquatic therapy is not currently covered by Medicare.

**Comparing PD Management Strategies: Comprehensive Service Delivery vs. Standard Care—Principal Investigator: Robert Iansek, PhD, Victorian Comprehensive Parkinson's Program, NPF Center of Excellence, Australia.**

Dr. Iansek will test coordinated care at a single hospital versus physician managed care for impact on both quality of life and cost. Dr. Iansek is evaluating the care of every patient in his clinic with a large, multidisciplinary team. Dr. Iansek’s hypothesis is that quality of life would be positively impacted by his approach. NPF, long a supporter of multidisciplinary care, is pleased to fund a large clinical trial intended to prove the benefit of this model.

Since 1982, NPF has funded more than $155 million in care, research and support services. NPF will announce the next round of grant funding in April 2011.
Welcoming New Senior Staff

Robin Boettcher, Vice President, Chapter and Community Partnerships

Robin Boettcher joined NPF this September in a new position as Vice President, Chapter and Community Partnerships. She previously served as a National Field Director for the Leukemia & Lymphoma Society (LLS), working with a variety of chapters throughout the country in all operational areas, including strategic planning, finance, fundraising and staff and board development.

“Robin will take the lead in developing a strategic vision of NPF’s chapter partnership and engage staff and volunteer leaders in creating a new chapter services agreement,” said Joyce Oberdorf, President and CEO. “She brings to NPF a wealth of experience, from management and strategic planning to finance and board development, but specializes in helping local organizations become more effective in service delivery and fundraising.”

Shannon O. Sullivan, Vice President, Strategic Development

Shannon O. Sullivan joined NPF in 2009 as Director of Major Gifts and in 2010 was named Vice President, Strategic Development. In this role, she leads NPF’s fundraising and development initiatives.

Prior to joining NPF, Ms. Sullivan was Director of Development for the Department of Psychiatry at the University of Miami Miller School of Medicine. She began her work in healthcare philanthropy as the Director of Development for Accelerate Brain Cancer Cure, a non-profit organization dedicated to finding a cure for brain cancer. Prior to these roles, she spent close to ten years working on capacity building and technology integration for educational, non-profit organizations, including the E-rate program, NetDay, and the Beaumont Foundation of America. At the Beaumont Foundation of America, she helped the Salvation Army develop and implement a national strategy to integrate technology into client educational and life skills curricula.

Ms. Sullivan is a graduate of Dartmouth College in Hanover, NH and holds a MBA degree from the University of Houston in Houston, Texas.

NPF CENTER AND CHAPTER LEADERSHIP CONFERENCE

December 2-4, 2010 in Houston, Texas

At this annual conference, NPF staff, center directors, center coordinators and chapter leaders from NPF’s 43 Centers of Excellence and 43 chapters across the country gather together to share ideas, present posters and discuss best practices in Parkinson’s care. This event is for NPF affiliates and is not open to the general public. For more information, please call 800-327-4545.
Can cholinesterase drugs help falling in PD?

Investigators from the Oregon Health & Science University, NPF Center of Excellence, recently tested the hypothesis that augmenting a chemical in the brain called acetylcholine by using a drug called Donepezil (Aricept®) may be beneficial in the prevention of falling in Parkinson’s disease patients. The mechanisms as to how this drug works remain unclear. It is possible that this drug, which is also utilized for memory and cognition, may also enhance the ability for patients to pay attention, to better process information and it may improve their ability to dual task. Interestingly, patients in the very small Oregon study fell half as often as patients on a placebo drug. There are other medications that have similar mechanisms of action to Donepezil, such as Rivastigmine (Exelon®), and studies on many more patients will be needed to explore this approach to treatment.


How can I tell if it’s time to ask for medication changes? Should I be asking my doctor about the timing of my medication? Does the interval really matter?

Parkinson’s disease can prove complex to manage both for patients and for practitioners. Patients may struggle in knowing when to ask for more medications, or alternatively to ask for different medications. Patients should keep a few things in mind when approaching the question as to the “need for medications.” Parkinson’s disease is slowly progressive, and therefore if your symptoms are changing and your medication management is not changing, it may be reasonable to inquire about different approaches in management. It is important to keep in mind that these changes may include doses, intervals and changes in drug combinations. The key point to remember is that it is critical to clearly articulate your symptoms to your doctor, as changes in medication management should be tailored to changes in symptoms. Finally, there is a myth in Parkinson’s disease management that holding back medications until later in the disease course will somehow preserve relative effectiveness of pharmacological approaches. There is little to no data to support this viewpoint, and holding back medications may hasten complications, and possibly diminish quality of life. Most experts will advise their patients to take the minimal amount of Parkinson’s disease medications to effectively control symptoms and improve quality of life.

The National Parkinson Foundation continues to remain deeply committed to the outstanding care of patients with Parkinson’s disease. The free web-based forums located on our website (www.parkinson.org) offer immediate and free access to experts in the field. In this issue, we highlight some of the most popular questions asked by patients and families. We invite everyone to visit us, read the daily posts, and to ask any question that may be on your mind(s). We have appreciated the direct interaction with the Parkinson’s disease community, and we look forward to continuing the dialogue.
We have found through many years of caring for persons with Parkinson’s disease that both patients and practitioners commonly discount the importance of medication timing, choosing instead to focus on specific drugs and particular dosages. This is a correctable mistake, and one that may have important quality of life implications. As your Parkinson’s disease changes over time, so should your medication regimen. Ask your doctor at each visit about adjusting medication intervals as well as dosages. Most patients will need to move beyond three times a day dosing, and ultimately require medications at strict intervals. Such regimens can help to avoid the wearing-off phenomena, which is waning of the effects of a dose of levodopa prior to the scheduled time for the next dose, resulting in decreased motor performance, and other medication-related motor complications.

Q Should I get a flu shot this year? Should my family get a flu shot?

A There have been a lot of stories in the news about Parkinson’s disease and the flu. Recently, Richard Smeyne published an NPF-sponsored study in which an animal model of Parkinson’s disease was generated by injection of a flu virus. Julia Henry and colleagues recently reviewed all the neurological manifestations of the flu virus over the last two centuries, and discovered that there have been surprisingly few cases of Parkinson’s disease. Therefore the main benefit of taking the flu shot is not in preventing Parkinson’s disease, but rather in preventing a respiratory syndrome that could lead to aspiration pneumonia and worsen Parkinson’s disease. We are currently not aware of any reason for Parkinson’s disease patients and family members not to get a flu shot, and we strongly encourage you to discuss it with your doctor. Additionally, by vaccinating all family members of Parkinson’s disease patients, this may also lessen the chances of flu spread, further protecting the Parkinson’s disease patient from respiratory complications.


What’s Hot in Parkinson’s Disease?

Dry Cleaning Solvents and Potential Environmental Risks for Developing Parkinson’s Disease

Pesticides, Agent Orange, and potential environmental risk factors for the development of Parkinson’s disease continue to make the news. The recent report by Goldman and colleagues from the Parkinson’s Institute, a NPF Center of Excellence in Sunnyvale, CA, may open some eyes to environmental exposures and Parkinson’s disease risk.

Goldman and colleagues cleverly chose to study twins from the WWII Veterans Cohort. By utilizing twin pairs (half were identical twins) researchers limited the potential effects of genetics on the development of Parkinson’s disease. One person from each twin pair was required to have been diagnosed with Parkinson’s disease. A very careful occupational and hobby history was then extracted, with the chief weakness of this study lying in how the histories were obtained. First hand histories from patients were sparse with spouses and siblings providing second hand proxy histories in most cases. The main study weakness was somewhat balanced by the employment of an occupational hygienist. An occupational hygienist is a carefully trained professional that can independently determine exposures, hazards, or risks in a workplace environment. The hygienist and the researchers examined six solvents, and determined that only trichloroethylene (TCE) was associated with an increased risk (6.1x) of developing Parkinson’s disease in men. Additionally, men exposed to TCE or to another chemical called PERC (tetrachloroethylene) had an 8.9 times increased risk of developing Parkinson’s disease in men. Additionally, men exposed to TCE or to another chemical called PERC (tetrachloroethylene) had an 8.9 times increased risk of developing Parkinson’s disease in men. Interestingly, n-hexane, xylene and toluene, which have all been thought to be potentially associated with the development of Parkinson’s disease, did not show an increased risk in this cohort. All of the studies of environmental exposures should be interpreted with caution, and patients and families should look for common themes among multiple research reports, as the potential for error in these types of population-based studies can be high. TCE exposure will therefore require more study, and also study within the female population of Parkinson’s disease patients.

The next question a patient or family member should ask about TCE is what kind of work might lead to an exposure.

The following is a list of potential places one might come in contact with TCE:

- Grease remover
- Paints and strippers
- Decaffeinated coffees
- Dry-cleaning
- Carpet cleaners and spot removers
- Typewriter fluid
- Adhesives
- Computer part cleaners
- Textile plants
- Anesthetics in an operating room setting

The following is a list of the highest risk occupations associated with TCE exposure:

- Electricians
- Industrial machinists and repair crews
- Dry cleaners
- Health care workers

Patients and families should appreciate that there is a difference between acute TCE exposure and chronic TCE exposure. Acute high-dose exposure seems to depress the central nervous system, and may lead to breathing problems, heart arrhythmias, coma and a host of other problems. Acute TCE may also prove to be a nasty skin irritant. When we talk about TCE exposure and Parkinson’s disease, we are referring to chronic long-term exposure. Chronic exposure has also been associated with unsteadiness, dizziness, headaches, memory loss and many other symptoms. Patients and families should be aware that the risk factors for Parkinson’s disease seem to now be extending beyond genetics, and may be inclusive of environmental exposures.

Read Dr. Okun’s monthly column, “What’s Hot in PD?” online at www.parkinson.org.

AUTHOR: MICHAEL S. OKUN, MD, NPF National Medical Director

Resource for Caregivers: How do I get organized?

November is National Family Caregiver Awareness Month

Caring for someone with Parkinson’s disease (PD) means lots of medical records, medical and family contact lists, as well as financial documents. In order to avoid getting overwhelmed, below are some easy tips on how to get and stay organized by creating a simple binder with four main document categories: Family, Insurance, Finance and Property.

Peter Adams who was a caregiver to his mother who had PD.

FAMILY DOCUMENTS
- List all names and contact information for family members, close neighbors, relatives or co-workers who need to be notified in case of emergency.
- Include important in-house locations of items such as an extra house key, electrical breaker box, water cut-off, thermostat and alarm system.
- For example, just reviewing, “Where is the fire extinguisher?” may bring important things to your attention, such as no fire extinguisher or working fire alarms in place!

Also good to include in this section:
- Copies of (updated) wills and trusts
- Birth certificates
- Social security card
- Military discharge papers
- Marriage license, divorce decree
- Passports
- Disability verification
- Advanced directives to physicians
- Durable power of attorney
- Written instructions regarding funerals, burial or cremation, etc.

INSURANCE INFORMATION CHECKLIST
- Life (including any accidental death policy in place at work, credit union, etc.)
- Health
- Homeowner
- Automobiles, boats, recreational vehicles
- Disability
- Long-term care, Professional liability coverage, if applicable

FINANCIAL DOCUMENTS
- Bank accounts and persons authorized to sign transactions
- Safe deposit boxes
- Credit union accounts
- Location of checkbooks and account records
- Credit and debit cards, including location of payment records for the previous year
- Investment accounts

PROPERTY INFORMATION CHECKLIST
- List and locations of mortgage papers on any real estate property
- Titles and license receipts for automobiles, boats, recreational vehicles
- Receipts for any major property improvements
- Receipts for any major vehicle repair/maintenance expenses

Visit www.parkinson.org/caregivers for more information. Did you know that NPF hosts an online forum exclusively for caregivers?
Visit forum.parkinson.org today!

Visit www.parkinson.org/caregivers for more information. Did you know that NPF hosts an online forum exclusively for caregivers?
Visit forum.parkinson.org today!

Visit www.parkinson.org/caregivers for more information. Did you know that NPF hosts an online forum exclusively for caregivers?
Visit forum.parkinson.org today!
Seth Dunn’s mother was diagnosed with Parkinson’s disease in the mid-1990s and his father became her primary caretaker. After watching his mother’s gradual decline, Seth decided to start a fundraiser to raise money for Parkinson’s research in the hopes that other families wouldn’t have to go through what his family had gone through. This past June, he hosted the annual “Ponies Against Parkinson’s” in California. Since 2002, Ponies Against Parkinson’s has raised nearly $14,000 for the National Parkinson Foundation.

Since Seth lives near a horse-racing track, Hollywood Park in Inglewood, California, he decided that would be the perfect spot for a fundraiser. Each ticket includes a pre-event happy hour at his company, transportation to and from the track in a rented bus and admission to the track. When he started out seven years ago, he filled one bus with 60 people; by 2009, he filled three buses with 150 people.

Seth’s mother was an avid reader and she always read the Parkinson’s literature that she received from the National Parkinson Foundation. Seth knew that NPF was the right charity to partner with, stating, “Whether it’s 100,000 dollars, or 10 dollars, we don’t know what will put us over the tipping point to find a cure for this devastating disease.”

“We are proud that Seth identified NPF as a charitable partner for Ponies Against Parkinson’s. Singlehandedly, he has created a fun event to honor his mother that his friends, family and colleagues look forward to every year,” said Shannon Sullivan, NPF’s VP of Strategic Development.

The event is a day of laughter and community spirit that he wishes his mother could see.

“For me, seeing a group of people enjoying themselves while raising money for Parkinson’s disease is well worth the effort,” Seth explains.

He claims that as long as the track stays open, he will host the event. He hopes to involve more of NPF’s California chapters in June 2011. Mark your calendars to pony up!
time to love, laugh and give...Please remember the National Parkinson Foundation in your year-end giving. Your gift will support critical research and education efforts to help improve the lives of individuals living with Parkinson’s disease.

There are many ways to give:
- Make a donation online at www.parkinson.org.
- Honor a loved one with an honor or memorial gift.
- Encourage your friends to give by hosting a Team Hope for Parkinson’s community fundraising event.
- Donate stock or mutual fund shares to receive an end-of-the-year tax deduction.
- Join our Legacy Society by recognizing NPF in your will, trust or estate.

We deeply appreciate your ongoing support of our mission. From all of us at the National Parkinson Foundation, happy holidays and best wishes in the new year.

Escape to Miami in January and make a difference for people living with Parkinson’s disease!

Run with Team Hope for Parkinson’s in the ING Miami Marathon & Half-Marathon on January 30, 2011 to benefit the National Parkinson Foundation.

For more information, please visit: www.parkinson.org/marathon.
ASK THE DOCTOR:
A team of Parkinson’s specialists answer medical questions about Parkinson’s disease.

ASK THE PHARMACIST:
Mark Comes, RPh, fields questions about medication management.

ASK THE SPEECH CLINICIAN:
A team of experts answers questions regarding speech and swallowing.

PREGÚNTELE AL MÉDICO:
Ramon L. Rodriguez, MD contesta preguntas con respecto a la enfermedad de Parkinson y materias relacionadas.