

On the Same Page

Center for Movement Disorders and Neurorestoration: Grand Opening and Ribbon-Cutting May 5, 2011

At the April 19th ribbon-cutting ceremony for the opening of the Center for Movement Disorders and Neurorestoration, Michael S. Okun, M.D., an associate professor of neurology and co-director of the Center, made a powerful promise to patients: “Listen and help. Listen to the patient. Help the patient. Whatever it takes. Listen and help. Always in that order.”

Sitting in the audience, I was taken with the alignment of this commitment, which has been the guiding principle of the Center since its inception 10 years ago, and the recent launching of our “I Promise” campaign at UF&Shands, the central premise of which is that nothing we do is as important as the way each of us individually treats the people who come to us in need of care.

The UF Center for Movement Disorders and Neurorestoration started as an idea in 2001. Two physicians, a neurologist and neurosurgeon, returned to the home of their residency training with a vision for the future and institutional support to help transform this vision into reality. The Center has now grown, as Dr. Okun put it at the ribbon-cutting ceremony, “into one of the largest and most comprehensive interdisciplinary movement disorders centers on the planet.”

This success story is a shining example of how all of the missions of an academic health center — research, education, outreach and patient care — grow quite naturally from a core commitment to being centered on the patient.

At the ribbon-cutting, we heard from Dr. Okun, Kelly Foote, M.D., an associate professor of neurosurgery and co-director of the Center, and Michael Good, M.D., dean of the College of Medicine. Guided tours of the new Center space, which occupies the fourth floor of the UF Orthopaedics and Sports Medicine Institute, were also highlights of the afternoon’s festivities.

We were also honored by former Attorney General Janet Reno and her sister, Maggy Hurchalla, who graciously agreed to become the first patient and family member combination to go through the interdisciplinary clinical research center.

Dr. Okun conveyed that Ms. Reno had been inspiring our UF-based team for the past several years, and that it was very special that she was the first patient in the new facility.

Ms. Hurchalla, an award-winning leader in environmental protection at the state and national level, provided an eloquent encapsulation of patient and family member experiences. She recalled that on the day “in 1995 that my sister publicly announced she had Parkinson’s, I was making a speech at a large dinner event with mostly older people. After dinner, people kept coming up to tell me that they too had Parkinson’s. They said they admired her courage because they were afraid to tell people. They were afraid that their children would look at them differently and start planning for nursing home placement.” She continued, pointing out that “since she announced she had Parkinson’s, my sister served five more years as Attorney General of the United States. Her hand shook like mad, but she pointed out that her brain wasn’t shaking. Since that time she ran for governor of Florida in her little red truck ... and served on the Board of the Innocence Project.”

Ms. Hurchalla then went on to express, from a patient’s perspective, what amounts to a compelling case for an interdisciplinary clinical and research center like the Movement Disorders Center, and by

extension, academic health centers in general: “As we get older, we get to know far too much about far too many diseases. We discover that the wonderful GP of our childhood can’t know it all. Then we begin to discover that being a specialist is not enough unless you specialize within the specialty. It is no reflection on the medical profession that they can’t know everything. It’s no reflection on a neurologist that he can’t keep up with head trauma, epilepsy, neonatal neurology and all of the neurological diseases of aging. If you see a thousand patients that have a movement disorder and you see them in all phases of the illness, you are going to be better at solving their problems. If you are involved in teaching and research within your special specialty, you can keep up better with what’s happening at the edge of medical discoveries. Apart from the big breakthroughs, you can understand the little things that bother a patient that they are sometimes embarrassed to ask about.”

Ms. Hurchalla further pointed out the benefits of having all of the different highly specialized (and subspecialized) members of the health care team involved with movement disorders — neurologists, neurosurgeons, physical therapists, occupational therapists, psychologists, pharmacists and others — in one place.

For example, she extolled the Center's physician assistant, Janet Romrell: “She has saved my sanity in the face of a large and indifferent system of medical labs and drug stores that can’t ever seem to get it right. Before we came to UF&Shands, I seemed to spend half my life waiting in line and being told the prescription wasn’t ready. I think we should get frequent flyer miles for the amount of time we spend in drugstore lines. And it is not only that the Rx is right and it is ready — the whole question of drug interactions gets addressed in more than fine print.”

“Unfortunately,” Ms. Hurchalla summarized, “the ramifications of Parkinson’s are such that it takes a village to help. This new Center provides a place for the village.”

How did this village come about for patients with Parkinson’s disease, parkinsonisms, dystonia, Tourette’s, Huntington’s, ataxia, and other basal ganglia diseases? Dr. Foote recounts it this way: “On a spring night almost 10 years ago, I rode in a car with Michael Okun from Emory University in Atlanta, GA, to Gainesville, FL, in what would prove to be the first of many trips we would make together. The next morning we stood together, side by side — a rather unorthodox presentation style — to deliver a presentation about our vision for a movement disorders center at the University of Florida. Who knew that over the next decade or so we would stand side by side giving talks around Florida and then around the world together. How improbable was it that a neurosurgeon and a neurologist would share a podium, bound together by a common vision, and stand shoulder to shoulder to deliver a unified and simple message: patient-centered, scientifically-driven, multidisciplinary care ... We were a group of friends with varied training and expertise, who had all bought into a common vision of a better way to take care of patients and study their disorders. It was powerful, and it was exciting.”

Across time, Dr. Okun and Dr. Foote developed what they described as a winning formula for their evolving village: “Support and promote people. Help them to achieve excellence and renown in their given specialties. Celebrate individual accomplishments as victories for our team. Embrace the philosophy of center over self.”

This team now includes 35 faculty and staff, including: **Hubert Fernandez, M.D.**, who helped establish a world-class clinical trials center at UF and then moved on to take over leadership of the movement disorders program at the Cleveland Clinic; **Ramon Rodriguez, M.D.**, a movement disorders neurologist and dystonia expert, who accepted the clinical trials baton from Dr. Fernandez and has established one of the most productive neurology clinical trials programs in the country; **Dawn Bowers, Ph.D., Russ Bauer, Ph.D., and Cate Price, Ph.D.**, the Center's primary collaborators in Neuropsychology; **Christine Sapienza, Ph.D., Jay Rosenbeck, Ph.D., and**

Michelle Troche, Ph.D., from Speech Pathology; **Herb Ward, M.D.**, and **Mark Gold, M.D.**, from Psychiatry; **Frank Bova, Ph.D.**, from Neurosurgery; **Steve Robicsek, M.D., Ph.D.**, from Anesthesiology; **Kenneth Heilman, M.D.**, from Neurology; **Meredith DeFranco** from Physical Therapy; **Lisa Warren, Sherrilene Classen, Ph.D.**, and **Portia Gardner-Smith** from Occupational Therapy; and **Tim Day** and **Kevin McDonald** from Shands Rehab.

Dennis Steindler, Ph.D., **Brent Reynolds, Ph.D.**, **Ron Mandel, Ph.D.**, and their basic science teams are world leaders in stem cell and viral vector gene therapy research, and have been working toward a cure for Parkinson's disease; **Tetsuo Ashizawa, M.D.**, and **Sub Subramony, M.D.**, have brought an NIH-funded, internationally-acclaimed hub for ataxia and Huntington's disease care and research. **Aparna Wagle Shukla, M.D.**, was recruited into Neurology from Toronto Western Hospital to bring to the clinic real-time physiological analysis and transcranial magnetic stimulation research for movement disorders. **Yuqing Li, Ph.D.**, was recruited to the University of Florida (Neurology), as the Tyler's Hope scholar, with the goal of creating the world's best and most comprehensive laboratory for DYT-1 dystonia research. **Todd Golde, M.D., Ph.D.**, and colleagues have joined the Center and created a strong bridge between the Center for Movement Disorders and Neurorestoration and the Center for Translational Research in Neurodegenerative Diseases. The two Centers have been making key recruits to UF, including **Nick McFarland, M.D., Ph.D.**, (recruited from Mass General into UF Neurology), who along with **Christopher Hass, Ph.D.**, (Applied Physiology and Kinesiology), have opened a comprehensive clinical research effort for PSP and atypical parkinsonisms, and **Jada Lewis, Ph.D.**, one of the world's best at creating animal models for neurodegenerative diseases. Additionally, **David Borchelt, Ph.D.**, (Neuroscience) will link his research in Huntington's Disease, and **Karen McFarland, Ph.D.**, to both Huntington's disease and to ataxias. **Christopher Batich, Ph.D.**, in the College of Engineering will continue his efforts to define the role for metal deposition in neurodegenerative diseases; **Samuel Wu, Ph.D.**, (Biostatistics) and **Chuck Jacobson** will continue their efforts to collect and analyze data from one of the world's largest movement disorders databases (UF-INFORM); **Keith White, Ph.D.**, from Psychology and **Bruce Crosson, Ph.D.**, from the Brain Rehabilitation Research Center will continue to unlock the imaging correlates of Parkinson's disease; **Pedro Fernandez-Funez, Ph.D.**, recently recruited into Neurology, has been developing a fly model of pesticide exposure in Parkinson's disease. This year the Center welcomes researchers from all over the University to begin new collaborations such as the addition of **Christou Evangelos, Ph.D.**, (College of Health and Human Performance), who was recruited from Texas A&M to study upper extremity function and will be working with Parkinson's disease and movement disorders patients.

Not only does this team work together clinically, in research and education; but the village also came together in designing the new Center. Of particular note, thanks goes to **Miles Albertson** (UF Facilities Planning and Construction), **Michelle Wahl/Becky Legate** (Faculty Group Practice), **Janet Kearney** (Neurology), and **Danielle McGee** (administrator for the Center for Movement Disorders and Neurorestoration, who worked closely with the architect (Ponikvar and Associates) and the builder (Ajax Construction) on a committee that met weekly for two years to develop the concept. This committee addressed every detail, no matter how small. Every aspect of the Center was designed to exemplify a patient and family-centered concept. The nuts and bolts of the Center include 21 exam rooms dedicated to physical, occupational and speech therapy; diagnostic modalities using electronic gait and balance testing; on-site X-ray, MRI and CT scans; and an operating suite featuring advanced brain-imaging technology, 3-D stereotactic mapping and imaging. But there are some key features beyond the nuts and bolts. As Dr. Okun remarked, "Compliments of James Oliverio and UF's Digital Worlds Institute, along with Jill Sonke and the College of Fine Arts, the patients will see images of dancers projected on the walls. Images that lift us up, and remind us that some who can't walk in life, can dance. We say, let them dance ... You will notice that on all the walls of the Center there are many pieces of beautiful art. All of this art was created by our patients. This art symbolizes that this Center belongs to the patients, and that the patients and the families who fight these diseases are

winning; and that their lives have substance and they have meaning. Their brushstrokes and their stories serve as our inspiration.”

During its first decade, the message of the Center was also heard by leading Foundations and by philanthropists, who embraced its vision and accelerated its progress. Early in the Center's development, the National Parkinson Foundation (NPF) funded a Center of Excellence at UF. NPF President Joyce Oberdorf continues to be exceptionally supportive. As well, the Staab family — Rick, Michelle, Tyler and Samantha — who have created Tyler's Hope for a Dystonia Cure, have given generously to support the Center's research on dystonia. As Dr. Okun stated, “The Staab family has taught us about courage and resolve in the face of tragedy, about vision, and about hope. They have galvanized the entire Gainesville community [on dystonia]. Their cause has become our cause ... We intend to find a cure for dystonia.” This Center will serve as the headquarters for Tyler’s Hope.

Other donors have also provided important support for the Center; Sally Muller and the Smallwood Foundation trustees have supported the Center’s vision for a comprehensive interdisciplinary fellowship training experience at UF; the Criser family has supported a vision for the interdisciplinary Tourette experience, now led by Dr. Irene Malaty; the Allen family supported the development of our interdisciplinary Progressive Supranuclear Palsy and Atypical Parkinsonism Program under the direction of Drs. Nick McFarland and Christopher Hass; the generosity of the Donnellan family brings hope to patients with multiple sclerosis and other related disorders; and the Greene family, who have supported the interdisciplinary Parkinson’s Disease Program.

I will conclude by returning full circle to the Center’s commitment to patient-centered care, and their goals, as expressed by Dr. Okun:

“Today as we open the doors we change the orbit of the American health care system for Parkinson’s disease, dystonia and movement disorder patients. We shift from a physician-centered model to true patient-centered care. The patient is the sun, and we shall orbit around the patient.

Starting today, when a patient arrives at the University of Florida, he or she can see specialists from neurology, neurosurgery, psychiatry, psychology, physical therapy, occupational therapy, speech therapy, rehabilitation services and social work — all potentially in a single day. Today they will have access to over 50 ongoing research studies — access to hope — all in a single day.

If your mother was just diagnosed with Parkinson’s disease, or you found out that your daughter had progressively debilitating dystonia, and you were to ask a knowledgeable person, ‘If I could take her to any center in the world to be evaluated, where should I take her,’ the answer to that question is going to be, ‘the University of Florida.’”

Forward Together,

David S. Guzick, M.D., Ph.D.
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