

Advocacy continued from page 1

Opportunities for advocacy

It is up to each of us to make our needs known and advocate for new and improved policies, programs, and services to better meet these needs. Waiting “to be asked” what we need has not worked in our favor. You CAN make change happen. Start today. Choose activities that make the most of your skills, experiences, interests, and availability.

Support the Parkinson’s Action Network (PAN) which lobbies for greater federal funding for research, improved access to care, and finding a cure for Parkinson’s disease. Register to receive email action alerts (www.actionpd.org), keeping you up-to-date on legislative issues,

and automating the process of emailing your elected officials and urging support of a particular bill.

Volunteer to help your local Parkinson’s chapter or support group by doing clerical work, maintaining their web sites or Facebook pages, helping organize walks and patient education conferences, and fundraising. Taking on these tasks frees up staff to work on

bigger projects and saves valuable resources that can be applied to provide direct services and programs for patients and their families.

Show your support for the
Global Parkinson's Pledge
 "to make Parkinson's a priority health, social, and economic issue around the world, and to advance the cure."
 Sign the on-line petition at:
www.parkinsonspledge.org

Speak to community groups and write letters to the editors of your local newspapers to raise awareness of PD and dispell common myths, emphasizing the toll it takes not just on individuals and those who love them, but on society as a whole.

Jean regularly talks to Arizona State undergrads who plan on becoming physical therapists. She tells them what it’s like to live with PD and how her disease has progressed. As future therapists, it is important for them to understand this. Interacting with a real person with Parkinson’s — shaking, and losing her thought in mid sentence — conveys a personal perspective they don’t get in a textbook.



Jean speaking to future physical therapists

Empowerment continued from page 1

Benefits of empowerment

Empowerment can help you:

- ✓ Gain greater input into decision making regarding your care.
- ✓ Set your own treatment goals, prompting you to better adhere to your treatment plan and realize improved outcomes.
- ✓ Feel more in control of managing your PD, reducing stress and anxiety.
- ✓ Feel hopeful rather than helpless.

Choosing Dr. Right

Choosing the right doctor and developing a good relationship with him or her is critical to your quality of life. Surveys reveal that the stronger the personal connection between patients and doctors, the better the care patients receive. Look for a doctor who:

- ✓ Will partner with you, doing things with and not to you.
- ✓ Has a good bedside manner and good technical skills.



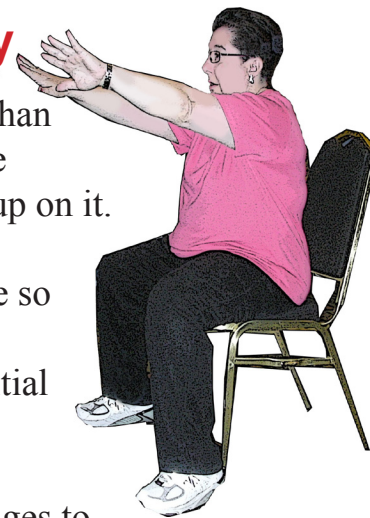
Sheryl and Dr. Cynthia Comella

- ✓ Communicates in terms you understand.
- ✓ Listens to and takes your concerns seriously, treating you with respect.
- ✓ Is compassionate, supportive, and cares about your well-being.

If you are not satisfied with your doctor, find a better match. Sheryl broke up with two doctors before she met her MDS of 12 years. The first was an internist who attributed the tremor in her left pinky to Sheryl being “a middle-aged woman anxious about becoming an empty nester.” The second was a general neurologist who told Sheryl that at age 44, she was “too young” to have PD, and treated her for essential tremor instead. He obviously had not read Michael J. Fox’s “coming out” story featured on the cover of People magazine in his own waiting room, but Sheryl had.

Listen to your body

You know your body better than anyone else. When you sense something is wrong, follow up on it.



At one point walking became so painful that Sheryl opted for physical therapy. After an initial evaluation, the therapist told Sheryl her pain was due to “irreversible” structural changes to her spine caused by poor posture related to PD. “You understand that you have a ‘progressive, incurable’ disease, don’t you?” she asked.

Her solution was that Sheryl learn to use a cane. **Sheryl’s** was to find a physical therapist who could help her, and she did. In the process, Sheryl experienced a miracle: the “irreversible structural changes” to her spine disappeared.