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Retired CEO and Spouse Give PDRS \$100,000 Gift

Funds Set Aside To Help Needy Parkinson Patients Purchase Their Medications

By Jack Egan

A retired Chief Executive Officer with Parkinson's disease and his spouse have made a \$100,000 special-purpose contribution to the Parkinson's Disease Research Society.

Richard Wellek, retired CEO of Varlen Corporation, and Susan Wellek have designated \$25,000 of the contribution to establish a discretionary fund to be used by Dr. Michael Rezak to help his indigent Parkinson patients pay for their prescription medications.

In announcing this gift of the Northbrook couple at the Society's September board meeting, Betty Ann Alter, PDRS president

said, "This is one of the largest gifts from individuals in PDRS history, and we appreciate it immensely."

Dr. Rezak, PDRS Medical Director and renowned Parkinson's researcher, thanked the Welleks for their compassion and generosity.

Patient Concern a Key Factor

The Welleks began planning the gift while talking about the increasing cost of Parkinson's medications with Sue Silvio, Dr. Rezak's nurse, after Dick's recent quarterly check-up. Sue said Dr. Rezak is concerned that some of his patients cannot



Even though Dick has given up aggressive, downhill runs, both he and Susan remain ardent skiers on trails near Aspen.

afford the medication and have to do things like cutting back on food or taking their medication every other day. Dick had already been impressed with Dr. Rezak's persistence in doing the research that led to his introducing the Parkinson's Early Detection Center. Now his attitude of patient concern was the motivating factor in moving forward with the gift

The Welleks, who are also PDRS board members, traveled remarkably similar parallel paths through their households

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Message from our President.. To Those In A Position To Help

By Betty Ann Alter

As my three-year term as PDRS president nears its end, I'd like to thank those who have taken part in our programs as well as those who have generously supported us with funds.

From recent events, we all know the importance of financial contributions.

For instance, the true character and heart of most Americans emerged after Hurricane Katrina's catastrophic strike a few months ago.

In those early days of realizing the incredible devastation and destruction the hurricane left behind, Americans worked together to find ways to help those survivors who desperately needed our assistance.

Chicago Responds

Chicago-area residents, from little children to senior adults, generously responded to the calls for cash contributions, food, clothing and even shelter for survivors.

Fortunately, many of America's friends in all parts of the world

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The Rezak Report

Michael Rezak, M.D., Ph.D., is Director of the PDRS Medical Advisory Board and an internationally renowned neurologist, researcher and Parkinson's specialist.

PHARMACOLOGICAL MANAGEMENT OF PARKINSON'S DISEASE

By Michael Rezak, M.D., Ph.D.

The medications available for the treatment of Parkinson's disease (PD) can be extremely effective in relieving the symptoms of the disease for long periods of time. Furthermore, some drugs currently on the market may have a role in slowing the progression of the disease (neuroprotection), although this still remains to be definitively proven.

What follows is a brief description of the currently available medications for PD along with some discussion as to their proper role in the course of treatment. It must be emphasized that all treatments for PD must be individualized for each patient. No "textbook" formula can be used and medications must be evaluated and then titrated to meet the specific needs and clinical presentation of each patient.

Amantadine (Symmetrel®)-This drug appears to exert benefits for PD by enhancing release of dopamine as well as from its modest anticholinergic effects. Clinically, amantadine is useful in early PD and appears to benefit tremor most. Recent evidence has documented amantadine's benefit in reducing l-dopa-induced dyskinesias. Furthermore, amantadine has been proposed to have possible neuroprotective benefits via its blockade of certain receptors in the brain that are believed to mediate dopamine cell death in PD.

Anticholinergics-This class of drugs can be helpful in the treatment of tremor in PD. Unfortunately, these drugs are fraught with side effects, which limit their use. The side effects can include, dry mucous membranes, blurry vision, urinary retention, hallucinations and memory difficulties. The key to using this class of drugs while minimizing the risk of side effects is to very slowly titrate (increase) the dosage until an appropriate response is achieved. The anticholinergic medications most commonly used include Artane® (trihexyphenidyl),

Cogentin® (benztropine), Kemadrin® (procyclidine), and Akinetone® (biperiden).

Dopamine Receptor Agonists-This class of drugs exerts its influence by mimicking the action of naturally occurring dopamine and thus directly stimulates the dopamine receptors in the basal ganglia. Originally, these drugs were used as an adjunct to l-dopa, however recent data has confirmed their effectiveness when used as monotherapy for up to five years in early PD. This latter fact is extremely important because these drugs have a much lower probability of inducing dyskinesias and motor fluctuations compared to l-dopa, perhaps related to their longer half-life. Thus, whenever possible, beginning symptomatic treatment with a dopamine receptor agonist rather than with l-dopa is now an accepted principal of treatment. In the United States the currently available dopamine receptor agonists for the treatment of PD include Parlodel® (bromocriptine), Permax® (pergolide), Mirapex® (pramipexole) and Requip® (ropinerole). Furthermore, there is evidence suggesting a neuroprotective role for dopamine agonists, further underscoring the desirability of this class of medications in early PD. Finally, it should be noted that recent reports suggest that prolonged use of the ergot containing agonist, Permax® may result in a serious side effect, heart valve injury. This side effect is presumably due to the propensity of ergot containing drugs (e.g., Permax® and Parlodel®) to result in fibrosis

of various organs. Although the likelihood of this side effect appears low, it must be taken seriously and patients remaining on Permax® should have serial echocardiograms as a precautionary measure.

Special mention must be given to Apokyn® (apomorphine), a new potent dopamine receptor agonist injectable drug, recently approved by the FDA for the treatment of acute intermittent "off" episodes that are otherwise difficult to manage. Patients who receive Apokyn®, must be pre-treated and receive on-going treatment with the anti-emetic drug Tigan® (trimethobenzamide). The first dose of Apokyn® is given at the physician's office so that an appropriate dose can be titrated and side effects observed.

Typically, a caregiver is trained to give the subcutaneous injection since the patient is too "off" to manipulate the syringe. This drug should be considered a "rescue" medication and used in those patients that manifest the most stubborn and unpredictable "off" episodes.

Levodopa (Sinemet®, Stalevo®)-This is the most efficacious drug available to treat the symptoms of PD. Upon its release in 1968 it was thought to be virtually curative. However, as years of experience have shown, despite its significant benefit for symptoms it has been shown to have a propensity to induce dreaded dyskinesias and motor fluctuations. Therefore, delaying its use until it is deemed

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at difficult times on their trek from childhood to adults. Today, the two act as an impressive team.

Dick grew up in Aurora and went to West Aurora High School. His dad was an immigrant and his parents were older. They were very loving people with a strong work ethic, working six days a week with no vacations. His father was living out the theme: "Try to pull yourself up so you can provide a better life for your children."

So Dick pretty much raised himself like a latch-key child and became very independent. While in high school he got a job in a small Aurora manufacturing company to earn spending money and to save for college.

Susan was born in Chicago and went to schools there until she moved with her family to Skokie as a teenager and then went to Niles Township High School.

Strength and Perseverance

Her father had significant impact on Susan when he lost everything he had in his retail business and then showed strength and perseverance in taking what he had been dealt and making the most of it.

Susan's paternal grandmother lived with the family after her husband had passed away. She was extremely hard working, refined and interesting. Susan said, "If Women's' Lib had been around during her grandmother's formative years, she would have been in the forefront of that movement."

Both Dick and Susan went to the University of Illinois and they met in their freshman year. Dick went into Industrial Management. Susan earned her degree in Elementary Education and became a schoolteacher. The two were married in the summer after graduation.

Stationed in England

Dick had a commission in the Air Force and was sent to England and stationed near Cambridge, about 65 miles Northwest of London. Susan went with



The Wellek family team: (left to right) Dick, Deborah, Susan, Marcy and Jeff.

him and two of their three children were born during their three-year stay.

As Dick was leaving the service, he realized he did not have a career plan but he had a destination. Both he and Susan wanted to return to Illinois where family was centered and "where the children could grow up with grandparents," said Susan.

Dick went back to work for the same small manufacturing company in Aurora where he had worked in every department on every machine on breaks during high school and college. He was with that company until 1968 when a customer hired him to be a sales engineer. He traveled extensively, but with three young children, it grew increasingly difficult for both Susan and Dick, so he rejoined the small manufacturing company he had started with and was named sales manager.

Elected CEO in 1983

Within a year and a half, the small company's founding owner died. A year after that, the company, where Dick then was a senior executive, was sold to Varlen Corporation. Dick was asked to run the acquired company as a new subsidiary and it soon became Varlen's biggest

company. That led to a senior executive position where he successfully ran a group of companies. He then was elected Varlen's Chief Executive Officer in 1983 and held that position until retiring in 1999.

Not Going To Change

One thing the Welleks did not expect in Dick's retirement was his Parkinson's diagnosis. As soon as it was confirmed by Dr. Rezak's second opinion, Dick told Susan, "We're not going to let this change our lives. I intend to do everything I've always done until I can't."

Even though Dick is always positive, physically active and disciplined, he confessed that he has given up two things he enjoyed: racing Porsches and aggressive, downhill skiing.

Dick's three adult children have rallied around him, each independently shouldering a set of responsibilities: Jeff focused on research, chiefly what's new in Parkinson's treatments; Marcy educates Dick about nutrition and alternative medicine; Deborah, a psychotherapist, takes responsibility for Dick's mental outlook.

"We're a team and we're all in this together," Susan concluded.

New PDRS Donation Cards Praised for Brilliance, Beauty

“These cards are brilliant and beautiful. They look hand-crafted and very individualized and very personal. They have impact”

That’s the way Myra Sanderman, a North Shore writer, describes the new PDRS donation cards introduced earlier this year.

Myra, a Highland Park resident who writes children’s fiction, went on to say, “Many organizations have donation cards but those cards tend to have a corporate design and focus on promoting the organization. The exclusive PDRS cards are more charming and inviting.”

Artist had Parkinson’s

Myra first saw the cards when Sara Klugman, a long-time friend and PDRS board member, brought them to a bridge game. The cards are illustrated with artwork produced by Sara’s mother, an artist who had Parkinson’s disease for more than 30 years.

“I was attracted to them immediately,” Myra said, “because I recognized one of the four cards had a photo of her mother’s artwork...a piece that Sara has hanging in her home. She is so proud of it and I always admired it.”

The other three cards in the series also depict the tedious technique of Stitchery in which Sara’s mother relied on needles and thread, rather than paint and canvas, to create intricate designs.

Inspirational Messages

“I use the cards for sending notes if there’s a death in someone’s family or for a special occasion,” Myra explained.



“It just seems easier, almost inspirational, to write a message on these cards rather than on store-bought ones.” “I’ve always supported Parkinson’s research,” Myra said. “By using these cards, my financial support continues. And knowing the artist makes them important to me.”

(Editor’s Note: The 5x7 inch cards, packaged with envelopes in sets of six, can be purchased from Sara 847/433-1595 or Eileen 847/657-5672.)

Picture-Perfect Day For Second Annual Par for Parkinson's

Everyone was a winner who participated in the PDRS's Second Annual "Par for Parkinson's" golf outing that raised more than \$80,000 in mid-August.

The scramble event at the attractive Glen Flora Country Club in Waukegan was actually oversold. Late entries that came in after the 120 available slots were filled played early morning rounds and returned to the club later in the day for cocktails and dinner.

What started as an overcast morning turned into a picture-perfect day. "We had nothing but sunshine, clear blue

skies and a breeze off Lake Michigan, keeping the temperature in the 80's," said Jack Orlov, co-chairperson for the outing.

"Golfers went out of their way in raving about the course's layout and condition, clubhouse facilities and the helpful attitude of the club's staff," Orlov said.

After the scramble ended, additional friends of PDRS joined the golfers for cocktails, hors d'oeuvres and dinner. The clubhouse patio was a popular cocktail setting as guests lingered there to enjoy the weather.

Following dinner, Dr. Michael Rezak made a short presentation, focusing on the on-going Parkinson's research funded by PDRS. He also thanked everyone for participating in the day's activities.

In addition, Dr. Rezak praised the Glen Flora staff, from catering to the Pro Shop which donated an attractive set of fairway woods and irons for the live auction.

Awarding the big raffle prize capped the evening. Golfer Mike Sauer walked off with the major prize, a 42" HDTV Plasma TV.



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necessary is the standard of care today.

This drug is always combined with carbidopa to prevent the systemic side effects related to the peripheral metabolism of l-dopa (nausea, vomiting, blood pressure changes and sweating). Carbidopa/levodopa (Sinemet®) is available in an immediate release form and in a long acting form, Sinemet CR®. Sinemet CR® is most appropriate in the earlier stages of PD and allows for a reduction in dosing frequency. Sinemet CR® should be replaced with the immediate release drug when motor fluctuations are present.

Stalevo®, a combination drug consisting of carbidopa, entacapone (Comtan®, see section below) and levodopa was recently released onto the market. Stalevo® is available in three levodopa dosage forms, 50 mg., 100 mg. and 150 mg. By combining carbidopa and entacapone with levodopa, the metabolism of levodopa in the GI tract is limited and thus more levodopa is allowed to enter the brain where it can be converted to dopamine. Combining levodopa with entacapone also extends the half-life of levodopa, allowing less fluctuations in blood levels. The fluctuations in blood levels is thought to be related to the development of motor fluctuations and dyskinesias.

Motor fluctuations are a challenging complication related to the use of l-dopa that occurs in some patients. Motor fluctuations can sometimes result in severe oscillations in motor functioning such that a patient

may rapidly alternate from having severe parkinsonism ("off" state) to manifesting marked involuntary movements (dyskinetic state). The development of motor fluctuations has been well documented to be related to the dose and duration of use of l-dopa in the setting of the progressive loss of dopamine neurons. Nevertheless, it must be emphasized that although it is appropriate to delay l-dopa use for as long as possible, this drug (in the forms noted above) remains the "gold standard" medication for the treatment of PD.

Catechol-O-Methyltransferase Inhibitors (COMTI)

-This is the newest class of medications added to the drugs used to treat PD. Tasmar® (tolcapone) and Comtan® (entacapone) inhibit the enzyme catechol-O-methyltransferase in the gastrointestinal tract. By doing this, more l-dopa is allowed to enter the brain instead of being metabolized before getting to the brain. It is estimated that approximately 20% more l-dopa can reach the brain when one of these drugs is added. It should be noted that Comtan® and Tasmar® will have no benefit unless you are taking l-dopa concurrently (see Stalevo® above). These drugs are most useful in treating "wearing off" phenomenon (an early motor complication of l-dopa therapy). Side effects of the COMTI drugs include diarrhea, urinary discoloration and dyskinesias. It should be noted that the use of Tasmar® has been greatly restricted by the FDA because of several deaths due to liver damage in patients not being properly monitored for liver enzyme elevation. The

FDA has mandated strict monitoring criteria as well as requiring a signed informed consent when prescribing Tasmar®. Thus, Comtan® is the more widely used COMTI because of ease of use and the absence of any reported liver problems. Comtan® is available as a separate drug or in a combined form, Stalevo®.

Eldepryl® (Selegiline)-This drug is the only monoamine oxidase inhibitor (MAOI) approved in the treatment of PD. By inhibiting MAO, the major breakdown enzyme of dopamine, levels of dopamine are increased in the brain and thus can improve symptoms. Additionally, a number of studies have documented a small but definite neuroprotective benefit when used in the early stages of PD. Although the issue of neuroprotection is controversial for Eldepryl®, its use in early PD can certainly be well justified by existing research. Even though it is an MAO inhibitor, no special diet needs to be maintained if one follows the recommended dosing, i.e., 5 mg twice a day. This drug should not be taken late in the day as it may cause insomnia.

Finally, it must be emphasized to the patient with PD that adjusting medications to meet your specific need is the "art" in treating your PD. In order to avoid serious side effects this must be done in conjunction with your physician. By carefully reporting your response to medication changes, you and your physician form a team whereby your medications can be optimized.

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also responded to the humanitarian call for help...help in coping with a disaster that has left damages estimated at hundreds of billions of dollars.

Our hearts go out to those who lost family or friends and to those whose families have been uprooted and now are living in a new location.

At the same time, our plea goes out to those readers who now are also in a position to support PDRS' ongoing research programs, particularly the Parkinson's Disease Early Detection Center (EDC).

Located in our backyard at Glenbrook

Hospital, the EDC has been a lifelong goal of Dr. Michael Rezak, Director of the PDRS Medical Advisory Board. This is the only facility of its type.

EDC Purpose

The EDC purpose is, through testing, to identify measures that can clearly differentiate very early PD. This is vital for future studies trying to slow down or stop the progression of PD as well as for identifying those people at high risk for developing PD in the future.

So for those contemplating making year-end contributions as part of their tax-plan-

ning, please consider a gift of any amount to the Parkinson's Disease Research Society. We would be grateful to receive your support for the work we are doing to find a cure for this dreaded disease.

An addressed envelope is provided in this issue.

It has been a privilege and pleasure to work so closely during the last three years with Dr. Rezak, his team and the PDRS board.

Thanks again for your past support.
Enjoy the Holidays.

