



Caring for an Elderly Loved One Can Take a Financial Toll

By Pamela Yip, *Dallas Morning News*, March 18, 2011
pyip@dallasnews.com

It's a duty that many of us will eventually assume: that of caregiver of an elderly loved one.

I became one 11 years ago when I returned to California to care for my dad, who was dying of lung cancer, and learned firsthand what a challenging job it is.

But apart from the emotional demands, there's also a financial cost caregivers must contend with and should prepare for in advance.

"You need to throw out the anchor before the storm hits, because once the storm hits, it's too late," said Brian Fant, a Dallas elder-law attorney. "What usually happens is people wait until they absolutely are forced into being a caregiver before they even consider what preparation would be helpful."

There are 65.7 million caregivers, making up 29 percent of the U.S. adult population, according to the National Alliance for Caregiving. The numbers are expected to grow because of longer life expectancies.

Caregivers, on average, spend more than \$5,500 per year in

out-of-pocket expenses, said Sandra Timmerman, director of the MetLife Mature Market Institute. Long-distance caregivers shell out more than \$8,700 per year for incidentals such as transportation, food and supplies, she said.

As a result, more than half of those surveyed online in November by Caring.com, a caregiving website, are concerned about the impact of caregiving on their savings.

The demands of caregiving can also affect a caregiver's plan for working and retirement.

"Many times, when the caregiving becomes more intense, the caregivers feel it's better to go to part-time work or drop out of work altogether," Timmerman said.

That's what happened to Marilyn Herrin, who retired from her job in human resources in Virginia four years ago and returned to North Texas to care for her 96-year-old mother, Mary, and her 74-year-old brother, Bob.

"I was not ready to retire, with this economy the way it is," said Herrin, 68. But economics forced her to.

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MAY general membership meeting

speaker:

Elizabeth Creasy, RN

Brentwood Hospice
"End of Life Care for
Parkinson's Patients"

**Monday, May 9, 2011
1:00 p.m.**

University Park
United Methodist Church
4024 Caruth Blvd
(at Preston)
Dallas, TX 75225

Bring your
questions and
join us for
refreshments after
the presentation.

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Parkinsonism Society**

Dedicated to impacting and improving the quality of life for Parkinson's patients and their families

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Newsletter

Ann Staton, Editor

The DAPS newsletter is published monthly as an information guide only, and does not serve as legal or medical advice. We welcome your feedback, contributions or requests. Please send to or contact:

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Running for PD

by *Veronique Enos*

Associate Director

The Michael J. Fox Foundation

I just finished running the New York City Half Marathon on Sunday with a team of 30 Team Fox members to raise funds and awareness for Parkinson's research. It was great. I felt good. A few times I unconsciously said out loud, "I love my life," and once even, "I love you," which I hope wasn't too awkward for anyone in earshot. Would they understand I was speaking to my injured upper hamstring tendon?

It's just that there is something so delicious about hope. It changes everything. If something as simple as an injured leg feeling better could make me so happy, how could we measure the happiness of someone who was given a cure? When I think about it, really picture it—no more disease, no Parkinson's, healing in the body and spirit—it is such a powerful idea that I lack words.

In perspective, it's a small thing, but a year ago I badly pulled my hamstring at the top of my leg where it attaches to the bone. I'm grateful it stayed attached. I'm back out there, but still feel it as a steady burn when I run, and have to keep my distances shorter and my pace slower. It'll take time.

It's okay. This is just running we're talking about. My life is great. I am engaged to be married in June and doing well on all fronts. I've done lots of shorter races, I got a bike, started swimming. I run slower and smile bigger at the finish line because I am able to run at all. And I wear my Team Fox singlet, to raise awareness for Parkinson's research while I run.

Though there isn't any equivalent, I have had the smallest glimpse at feeling the uselessness, waste, and frustration when a body is unable to perform what the spirit asks it to. So, more than ever, when I consider the daily losses that PD and other degenerative diseases bring, I shudder, and wish for them to heal. In the people I know with PD and other complicating situations—including my father who has lived with debilitating arthritis for 25 years—strength of character seems to rise to compensate for the body. But it shouldn't have to in this way, and I'll keep bargaining for disease to release its grip.

So, I've decided to end my stubbornness, thinking I have to be running a marathon in order to reach out to you. Whether or not I can make it to 16 or 26 miles this season has nothing to do with the enormous need there is to keep progress moving forward for Parkinson's treatments. What matters is whether Harry can take part in his granddaughter's wedding, JoAnn can keep playing harp and teaching lessons, Kenneth can work as a doctor, and Jeffrey can care for his children. My work at the Foundation

Veronique Enos joined The Michael J. Fox Foundation in March 2001, shortly after its inception, and has grown with the organization into her current role as a Major Gifts Officer in Development. Veronique serves as a major gifts fundraiser, and is a contact and resource for Foundation supporters and interested parties on the west coast.

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Gene Therapy Raises Hopes for Parkinson's Treatment

by Amy Dockser Marcus – amy.marcus@wsj.com

The Wall Street Journal, March 17, 2011

An experimental gene therapy used on people with Parkinson's disease has helped to significantly ease patients' motor-function problems, opening the way for a possible new treatment for the neurological disorder.

In a study published Wednesday in *Lancet Neurology*, 45 patients with moderate to advanced Parkinson's disease were enrolled in a clinical trial run by Neurologix, Inc., which is developing the gene therapy.

In the Phase 2 trial, 22 patients were randomly assigned the therapy and 23 underwent a "sham surgery" designed to make them believe they might have received the treatment. Patients, caregivers and the team evaluating the results were not told what group patients fell in.

After six months, the patients who received gene therapy showed a 23.1% improvement in their motor score, against a 12.7% improvement in patients receiving the fake surgery. The motor score takes into account symptoms of the disorder including tremors, muscle spasms, and problems in walking and balance.

Michael G. Kaplitt, vice chairman for research and neurological surgery at Weill Cornell Medical College and one of the designers of the trial, said researchers were working with the Food and Drug Administration

to launch a Phase 3 trial—the next step before seeking approval to market the treatment. Dr. Kaplitt is a co-founder of Neurologix.

People with Parkinson's disease lose brain cells that make dopamine, which regulates a circuit in the brain controlling movement. Current treatments use drugs that act like dopamine, but as more neurons are lost, the drugs lose effectiveness.

The gene treatment works differently, changing the way cells function in the part of the brain involved in motor function. A gene called glutamic acid decarboxylase, or GAD, is delivered to the cells via an inert virus. The gene makes a chemical called gamma-aminobutyric acid, or GABA. Patients with Parkinson's also lose GABA, which causes problems in the circuit that helps control movement.

Scientists hailed the result but did not see it as a cure. "It does not get to the root cause of the degeneration. But it is an exciting step forward because it should reverse symptoms," said David Standaert, director of the UAB Center for Neurodegeneration and Experimental Therapeutics at the University of Alabama at Birmingham.

Dr. Standaert said there were still concerns about gene therapy, which unlike existing treatments cannot be reversed. "This is changing the chemistry of that area of the brain permanently," he said.

VOLUNTEER CORNER

Let's all put our hands together to thank Shirley Hand, Charlene Noe and Jann Horswell for their fine job in providing the lovely table at every DAPS Meeting. The General Membership is to be commended for the wonderful assortment of goodies each month. This takes a joint effort of many people to come together. Shirley always brings such great decorations, plates and napkins, and Jann is always there to help arrange! Charlene is in charge of the drink table and does a wonderful job! It takes lots of volunteers to make this Society "Work" and DAPS is blessed to have the best ones! Thanks for your commitment.

The March Newsletter was mailed on Tuesday, February 22, with the nimble hands of Jann Horswell, Tamea Jolly, Helene Morris, and Bob Staton. Great job everyone!

The DAPS office was filled with volunteers on Wednesday, March 10, stuffing, labeling and stamping the Tour of Holland Non-Event Fundraiser Invitations. Fun was had by all, including DAPS' President, Jean Blomquist; Rosemary Francis; Jann Horswell; Tamea Jolly (Ann's sister); Helene Morris; Joyce Susman; and Cindy Weatherall.

Before retiring, Herrin would usually come to Texas two times a year, but that eventually became three and four times.

“The costs were getting so cumbersome,” she said. “It was horrible. Physically, it was getting draining for me.”

Now, Herrin lives in Mesquite on an annuity from a pension and Social Security benefits, and makes regular trips to care for her mother in Dallas and her brother in Garland.

Her mother, who has severe rheumatoid arthritis and macular degeneration, is in rehabilitation to strengthen her legs so she can return home. Her brother has chronic obstructive pulmonary disease and is bipolar.

Experts advise that you think long and hard before retiring to become a caregiver.

“People have to think about it because it cuts back their own lifetime wealth,” Timmerman said. “They would lose their wages that they’ve been building up and accumulating.”

Workers also lose their employer’s matching contribution to their 401(k), and “some leave before they’re even vested, and they don’t really think about the ramifications,” she said.

Have “the talk”

Talk to your parents about their current assets and income, debt and spending, the percentage of their assets that are liquid, and their plans for covering medical and long-term care needs.

Have this conversation while your parents are still healthy and able to handle their own affairs.

Try broaching the topic indirectly by talking about your own finances or those of someone you know.

You want your parents to understand that you’re doing this not out of greed, but out of concern and a desire to be prepared if something were to happen to them. You want to plan with them, so you need to know what financial resources they have that you could tap to meet their needs.

Estate planning

Make sure you have the proper estate planning documents prepared. Particularly important is the financial power of attorney that your parents would sign, giving you the power to handle their financial affairs if they become incapacitated.

“It doesn’t remove the parents’ right to make financial decisions,” Fant said. “It allows their children to come alongside of them and make financial decisions.”

Talk to your parents’ bank and see if it has a specific form for financial power of attorney.

“Sometimes they will have their own form, but a bank is obligated to recognize the notarized power of attorney,” Fant said.

Know what’s covered

Know what Medicare and Medicaid will and won’t cover when it comes to caregiving.

Generally, Medicare doesn’t pay for long-term care. It pays only for a medically necessary skilled nursing facility or home health care, if you meet certain conditions.

Most long-term care assists people with activities of daily living, such as dressing, bathing and using the

bathroom. Medicare doesn’t pay for this so-called custodial care.

Herrin’s mother has a home health aide who comes daily to bathe her and do light housekeeping, and a nurse who comes weekly to take her blood pressure and prepare her medications. Both services are paid for out of her mother’s own funds.

Medicare is paying 100 percent of her mother’s rehab costs for the first 20 days, Herrin said. After that, it covers 80 percent.

Medicaid, the nation’s public health insurance program for low-income people, is the largest source of financing for nursing home care and community-based long-term care. It pays for the aide who comes daily to bathe Herrin’s brother and do some light housekeeping and grocery shopping.

Find help

Many community organizations offer free services that can help you through this trying time. Take advantage of everything for which you qualify.

Being a caregiver is a demanding but rewarding role. While it’s important to make plans in advance, it’s difficult to be prepared for every contingency.

“Aging is not like child care,” said Kay Paggi, an elder-care consultant and geriatric care manager in Richardson. “With a child, you kind of know: college, summer camp. But with elder care, there’s just no way of predicting.”

Running *continued from page 2*

includes opportunities for conversation with people who are daily performing the work and passion of their lives while living with Parkinson's disease. They reach me, and a portion of my running is always dedicated to them.

The research effort we are undertaking at The Michael J. Fox Foundation is making a profound difference. MJFF has done much to tackle hurdles within the drug development pipeline, accelerating progress, resulting in more promising treatments moving into clinical trials and closer to patients. At this time, in addition to funding critical research across all likely routes to a cure, the Foundation is turning special attention to barriers within clinical trials, and setting up tools to make clinical trial enrollment easier for all parties, with the goal of bringing about new and better treatments faster, and ultimately a Parkinson's cure.

I want to support this work through Team Fox and I know that together, when we do what we can, we'll make the effort count. For now, though it's not a marathon, I'm running every shorter race I can, trying to get my tendon healthy, and preparing to be back out in a Team Fox marathon when it's right. My wonderful fiancé, John Kaefer, took up running and completed his first marathon in NYC this fall, raising money for Team Fox in my place. He did a terrific job, and I'm impressed and grateful.

When I measure this year that I couldn't run marathons, I find the same year where my relationships became strong—I got engaged, and became close to my soon to be step-son. In this

year, I was able to work hard at my job, spend time with my family; I got a bike and went on adventures, and cheered other people's victories. I thought about the meaning of success, balance, and priorities. I

experienced loss, but also felt gratitude and joy in life. In the end, I will measure this year as a time of leaping progress. Looking back, it may go down as a great growth spurt, though it didn't seem so at all in the living of it.

Similarly, when I look back over the long history of PD research, I see that, though we still have no cure, we have progressed in our knowledge and practice, bringing us closer to a variety of new treatments on multiple routes. We have climbed so far. There will be a day, when only a few more leaps will bring us the rest of the way to a cure. It might take more time, more than even feels reasonable. But we are getting closer to realizing our dream.



While running Sunday's half marathon, my tendon did not burn for first time in 14 months. The respite helped me picture a day when the problem might be fully resolved. And then I pictured a day when bigger resolutions will happen, an answer to PD, and to other struggles and diseases. It's an amazing consideration. I know it is good to believe. Most of us wish for peace, healing, and progress for the ones we love. Let's keep that up. I feel it working. And when we look around, there is success happening now, even in the midst of the struggle.

You can view Veronique's Team Fox page at <http://tinyurl.com/49aazeb>.

Memorials • Honors • Donations

March 2011

In memory of Jerry Fyrer

From: John & Linda Doden

In memory of George T. Higginbotham

From: Amy Robinson

In memory of Mary Preskitt

From: Izell & Jenny Bankston

In memory of Ted Schuessler

From: Lionel & Jean Blomquist

In memory of Herman "Hy" Schwartz

From: Lionel & Jean Blomquist
Dr. & Mrs. Mark Fleschler

In honor of Stella Novit's 97th Birthday

From: Jan & Charles B. Hart

Donation to DAPS

From: Marilyn Arras
Shirley Bothwell
Nancy O. Clarke
Irving PAGE
March General Meeting
Plano PAGE
Glauco & Sharon Rizzo
Skillman PAGE
Southwest Dallas County Parkinson Group
Michael Weber

"Destination Argentina" Event

From: Jon & Judy Atwood in memory of Gary Atwood
Ruth Beam in honor of Ann Staton
Tom & Virginia Benke in honor of Lionel Blomquist
Donald R. Bennett in memory of Barbara Bennett
Marcie J. Black in memory of Rebecca Black
Kendall

"Destination Argentina" Event cont'd

From: Edna G. Buentipo in honor of Sarah Atwood
Annabelle Catterall
Mary Margaret Davis in memory of George F. Davis
Pauline Diskey in memory of Gene Diskey
Dr. & Mrs. Dwight German in honor of Parkinson's Research
Elsie Hayes in memory of Dr. Robert Hayes
Vonciel Hickman in memory of Lester E. Hickman
JoAnn Jenkins in memory of Tommy Taylor
Dotty & George Kilpatrick in honor of Jean Blomquist & Ann Staton
Pam Kovacs, Friends Place Adult Day Services
Marsha Kreitman in memory of Jacob Kreitman
Dee & Kitty Maxey in memory of Jerry O'Connor & Chester Maxey
Fred & Molly Mooney
June V. Mohn in memory of Newton Mohn
Marvin & Edwina Murph
Charles & Pat Patterson in memory of Gary A. Atwood
Jerry & Gene Pinnell in honor of Lionel Blomquist
Sherrie Pulliam in honor of Brad Sledge and in memory of Lillian Sledge
David T. Rayshell in memory of Virgil Noe
Vinita Jones Richards in memory of Gerald S. Jones
Frances S. Schwartz in memory of Herman "Hy" Schwartz
Mark F. Schweinfurth
Bob & Ann Staton in honor of the DAPS Board
Joyce Susman in memory of Beril Susman
Norma Winton

Please RSVP by

Friday, April 29

866.227.9788 ext. 5835

PARKINSON'S DISEASE

"UPDATE FROM THE EXPERT"

Monday, May 2, 2011

11:30 a.m. – 1:00 p.m.

Sponsored by:

Teva Neuroscience

Featured Speakers:

Susan Imke FNP, GNP – C

Kane Hall Barry Neurology

Bedford, TX

Robert Hutchman MD

Pres./CEO & Medical Director

Reseda, CA

Grapevine Convention Center

1209 S. Main, Grapevine, TX 76051

817.410.3459

Lunch will be provided.

You are welcome to bring one guest with you.

NO CHARGE speech therapy and group exercise

CARROLLTON:

St. Andrews Christian Church

3945 N. Josey Lane

Group Exercise:

Wednesday...9:45 a.m. to 10:45 a.m.

Speech Therapy:

Wednesday...10:45 a.m. to 11:30 a.m.

DALLAS:

Baylor Institute for Rehabilitation

909 N. Washington (ph: 214-820-8854)

Water Therapy

Wednesday...11:00 a.m. to 12:00 p.m.

Dallas Yoga Center

4525 Lemmon Ave., 3rd Floor

Yoga for Parkinson's:

Friday...11:00 a.m. to 12:00 p.m.

Juanita J. Craft Recreation Center

4500 Spring Ave.

Group Exercise:

Friday...10:00 a.m. to 11:00 a.m.

Lakeside Baptist Church

9150 Garland Rd.

Speech Therapy:

Wednesday...10:30 a.m. to 11:15 a.m.

Group Exercise:

Wednesday...9:30 a.m. to 10:30 a.m.

Partners-in-Care Group:

2nd Wed...10:30 a.m. to 11:30 a.m.

Preston Hollow United Methodist Ch.

6315 Walnut Hill Lane

Speech Therapy:

Tuesday...11:30 a.m. to 12:15 p.m.

Group Exercise:

Tuesday...10:30 a.m. to 11:30 a.m.

Thursday...10:30 a.m. to 11:30 a.m.

Partners-in-Care Group:

First Tuesday...10:30 a.m. to 11:30 a.m.

Skillman Church of Christ

3120 Skillman St., FLC 2nd floor

Mezzanine

Group Exercise:

Monday...9:15 a.m. to 10:15 a.m.

DUNCANVILLE:

Trinity United Methodist Church:

1302 S. Clark Rd.

Speech Therapy:

Thursday...1:00 p.m. to 1:45 p.m.

Group Exercise:

Monday...6:30 p.m. to 7:30 p.m.

Thursday...2:00 p.m. to 3:00 p.m.

Support Meeting:

Last Monday...6:30 p.m. to 8:00 p.m.

GARLAND:

South Garland Baptist Church

1330 E. Centerville Rd.

Speech Therapy:

Thursday...9:30 a.m. to 10:15 a.m.

Group Exercise:

Monday...10:30 a.m. to 11:30 a.m.

Thursday...10:30 a.m. to 11:30 a.m.

Discussion Group:

Monday...9:30 a.m. to 10:30 a.m.

Partners-in-Care Group:

Thursday...10:30 a.m. to 11:30 a.m.

IRVING:

First United Methodist Church

211 W. Third St.

Group Exercise:

Tuesday...10:00 a.m. to 11:00 a.m.

PLANO:

Custer Road Methodist Church

6601 Custer Road

Speech Therapy:

Thursday...11:00 a.m. to 11:45 p.m.

Group Exercise:

Monday...9:45 a.m. to 10:45 a.m.

Thursday...9:45 a.m. to 10:45 a.m.

Partners-In-Care Group:

Monday...9:45 a.m. to 10:45 a.m.

RICHARDSON:

Arapaho United Methodist Church

1400 W. Arapaho at Coit

Group Exercise:

Tuesday...10:00 a.m. to 11:00 a.m.

Wednesday...10:00 a.m. to 11:00 a.m.

Friday...10:00 a.m. to 11:00 a.m.

Partners-In-Care Group:

1st Wednesday...10:00 a.m. to 11:00 a.m.

Parkinson's Disease Support Group

Texas Health Resources offers a Parkinson's Disease Support Group on the 3rd Thursday of each month at 6pm. It meets at the Texas Health Presbyterian Hospital Dallas campus, in the Beasley Conference Room, Main Building, First Floor. The address is 8200 Walnut Hill Lane, Dallas, TX 75231.

NEW PROGRAMS IN 2011

• Dance for Movement Disorders.

This class meets every Tuesday at 2:00 pm at the Finley Ewing Cardiovascular & Fitness Center (CVC), 5721 Phoenix Drive, across Greenville from Presbyterian Hospital, in Studio 3, Upstairs. This weekly class is cosponsored by the Movement Disorders Education and Resource Center and the **Dallas Area Parkinsonism Society (DAPS)** and is offered free of charge to individuals with movement disorders.

• Caregiver Support Group.

This group meets on the 4th Tuesday of each month at 2:00 pm in the classroom across the hall from Studio II at the Finley Ewing Cardiovascular & Fitness Center (CVC).

• Essential Tremor Support

Group. This group meets at 1:30 pm in the Beasley Conference Room, Main Building, on the 2nd Wednesday of each new quarter (January 12, April 13, July 13, October 12).

Caregivers are welcome to attend any of our support groups and exercise classes. For more information on our programs, or to RSVP for a support group, please contact us at 214-345-4224 or DallasMovementDisorders@TexasHealth.org.



Dallas Area Parkinsonism Society

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Dallas, Texas 75240

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MARK YOUR CALENDAR

general meeting

Monday, May 9 - 1:00 p.m.

Speaker: Elizabeth Creasy, RN, Brentwood Hospice:
"End of Life Care for Parkinson's Patients"

University Park United Methodist Church
4024 Caruth at Preston

open board meeting

Monday, May 16 - 1:00 p.m.

University Park United Methodist Church

next month

Monday, Jun. 13 - 1:00 p.m.

Speaker: Dr. Padraig O'Suilleabhain
UTSW Neurologist

University Park United Methodist Church.

disclaimer: The contents or opinions expressed in this Newsletter are those of the individual writers or presenters and do not constitute an endorsement or approval by DAPS staff. Please consult your personal physician regarding your individual medical problems.

Tom Thumb Reward Card

Link your Tom Thumb Rewards card to number **3071**, and a percentage of what you pay to Tom Thumb will be donated to DAPS!

Kroger Cares Card

Have the cashier scan the barcode before your Kroger Cares card is scanned. A percentage of what you pay will go to DAPS!

DALLAS AREA PARKINSONISM SOCIETY



For change of address or corrections, please indicate the changes on this page and mail or fax it to DAPS, or email: daps125@sbcglobal.net