



Parkinson Association of Southwest Florida, Inc.

Winter Newsletter 2012

2950 Tamiami Trail N, #20
Naples, FL 34103
(239) 417-3465

A Message from the Staff

Thank you for the opportunity to work with such terrific people! We are overwhelmed by the wonderful notes of thanks and appreciation that are coming in with the returns from the annual appeal letter. It's terrific to work for an organization that has members who take time out of their day to say thank you.

We wish you Happy Holidays and hope that you have a blessed New Year.

Sincerely,

Ruth Hubing,
Executive Director

Chuck Curry,
Administrative Asst.

Rasagiline Rejected as “Disease-Modifying” for Parkinson’s Disease

By John Campbell, MD



By a unanimous vote, the FDA voted in mid-October against an expanded indication for Rasagiline/Azilect, saying it found no compelling evidence that the drug delays progression of Parkinson’s disease. At the center of the debate was the ADAGIO Study – Attenuation of Disease Progression with Azilect Given Once Daily. A “delayed start” design, in which half of the participants start the drug from Day 1 and the other half are put on placebo, was used. Halfway through the trial, the placebo group is switched to the active agent. If the drug is truly disease-modifying, the theory goes, those who started on placebo should never catch up to those who started the drug once both are put on active therapy. The benefits beginning the drug earlier should persist. Benefit was seen for those who started early on the 1 mg dose, but none was seen for those who started on the 2 mg dose. That discordance led to the conclusion that the case had not been made for Rasagiline being disease-modifying.

Despite the vote, there is still confidence that other ongoing efforts will find a treatment that significantly delays the progression of the disease. Unfortunately, a good biomarker, as a surrogate of the disease process, is currently not available. It may be a while before we have such a biomarker to prove neuroprotection.

Possibly, Parkinson’s disease is not a clinical disease but rather a clinical syndrome. It is likely that there may be different causes for development of the disease we call Parkinson’s. The future of trials may be to divide out the genetic variations and test drugs for specific subgroups. Unfortunately, at this point, no drug is currently available that can clearly modify the course of any neurodegenerative disorder. Trials continue. I am optimistic that such a disease-modifying drug will eventually be demonstrated.

Dr. John Campbell, PASFI’s Medical Director, is Director of the Parkinson’s Disease and Movement Disorders Center at Collier Neurologic Specialists.

The mission of the Parkinson Association of Southwest Florida, Inc. is to promote quality of life for persons with Parkinson’s disease and their care partners.

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Organizational Donations

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Education Committee Events

January 18

2-4 p.m.

Hodges

Panel Discussion on non-medical treatments
and programs for PD patients.

January 27

10 a.m.- noon

United Church of Marco

Dr. Deutschman

Medication Do's and Don'ts for Parkinsonisms

February 15

2-4 p.m.

Hodges

Dr. Campbell's Annual Address

February 22

1-3 p.m.

United Church of Marco

Pre-planning panel discussion

March 7

2-4 p.m.

Avow Hospice

Pre-planning panel discussion

March 14

1-3 p.m.

United Church of Marco

Margot Escott

Peer Counseling

March 21

2-4 p.m.

Hodges

Annual Presentation

Mary Spremulli

*Voice Aerobics: A Whole Body Approach to
Strengthening Voice*

RSVP to 417-3465

Special Needs Trusts

How Do I Provide for my Family Member With a Disability?

By: Lisa B. Goddy, Esq. & Ed Wollman, J.D., LL.M. of Wollman, Gehrke & Solomon, PA, Naples, FL

We all know someone that we love and care for that may not be able to handle financial matters due to a disability, such as Parkinson's, Alzheimer's, Autism or other disability. A trust is often used to set aside funds to provide care for an individual as well as to preserve the individual's governmental benefits, such as Medicaid and/or Supplemental Security Income (SSI). However, a standard trust will not be sufficient to protect the assets set aside for the individual's future care and well-being. Instead, a "Special Needs Trust," also referred to as a "Supplemental Needs Trust" may be appropriate and necessary.

What is a Special Needs Trust

A Special Needs Trust ("SNT") is an investment vehicle that allows a disabled individual to safeguard his/her assets without disqualifying him/her from governmental benefits, such as Medicaid and SSI. The SNT holds assets for the benefit of the disabled individual, who is the beneficiary, and those assets may be used to provide services or items that will enhance the beneficiary's quality of life. At the same time, the SNT will not jeopardize the beneficiary's Medicaid and SSI, which will continue to cover his/her basic medical needs.

There are two different types of SNTs depending on whether the assets belonged to the disabled individual (a self-settled SNT) or the assets belonged to someone else, such as a parent or grandparent (a third-party SNT). This article will only address the latter.

A third-party SNT is a trust that holds assets that originally belonged to a third person (e.g., a spouse, parent or grandparent) for the benefit of the disabled individual. The third-party SNT may be created upon the third person's death pursuant to a Will or Revocable Trust, or the SNT may be created in advance as a separate stand alone irrevocable trust. The stand alone SNT is a great way for caring relatives and friends to make gifts to the disabled individual at any time.

Let's look at a couple of examples.

1. **Parent-Child.** A parent of a disabled child creates a third-party SNT inside the parent's Revocable Trust, to make sure that the child is taken care of after the parent is gone. Medicaid and SSI will

continue to assist the child, and the SNT that the parent established will provide supplemental items and services not covered by Medicaid and SSI to improve the child's quality of life. Any remaining assets in the SNT upon the child's death can go to other family members instead of paying back Medicaid and SSI.

2. **Husband-Wife.** Husband, who has Parkinson's, lives in a nursing home and is receiving Medicaid. If Wife happens to die first, she would not want to leave her assets to Husband and then disqualify him for Medicaid. She may need to create a third-party SNT inside her Will for the benefit of Husband. The SNT would be designed as a discretionary trust so that the assets may be used to supplement, and not supplant, the Medicaid assistance that Husband is receiving.

What is Important when Drafting a Special Needs Trust?

The selection of a trustee is important. A trustee must carefully determine what needs-based governmental benefits the disabled individual is receiving. Medicare and Social Security Disability Insurance (SSDI) do not have financial criteria for eligibility but Medicaid and SSI do. The trust distributions to the disabled beneficiary must be structured around the eligibility rules. Most family members are able to do the job with reasonable guidance from the attorney who drafted the SNT. However, there may be times when another source of help may be necessary from a corporate trustee who is knowledgeable about the Medicaid and SSI rules. Therefore, the selection of a care management team, including the trustee, the guardian, the health care providers, the financial advisors, is advisable.

Due to the complex eligibility rules for Medicaid and SSI, a properly drafted SNT is essential in order to accomplish a parent's or a spouse's desire to provide for his/her loved one with a disability. There are other alternatives when considering the use of a SNT. Plan early and surround yourself with a complete team of advisors when making decisions for your loved one with a disability.

Save the Date

JANUARY

Fashion Show



Saturday, January 14, 2012

Naples Sailing and Yacht Club

The 4th Annual Fashion Show will feature the newest in fashion and include a surprise or two! This would make a wonderful gift item to give a relative, neighbor or special friend.

FEBRUARY

Poker Walk


Sunday, February 26, 2012

North Collier County Regional Park

The 11th Annual Poker Walk will consist of a short walk in the park followed by breakfast and raffle drawings. Come out and get some fresh air with friends and family.

APRIL

Tulip Tuesday



Tuesday, April 3, 2012

April is Parkinson Awareness month. The tulip represents our flower of hope in honor of Dr. James Parkinson who described the symptoms of the disease in 1817. We will be delivering tulips the first Tuesday in April.

Golf Challenge



Saturday, April 28, 2012

Bonita Bay Club East

The 14th Annual Golf Challenge will kick off with the helicopter golf ball drop and 50/50 raffle. Join us for lunch and the scramble.



Community Support Groups (SG)

Open SG

Tuesday

1pm- Bentley Village

Thursday

10:30am- PASFI office

PD 101 SG

1pm- Last Thursday of each month PASFI office

Widowed SG

Wednesday biweekly

3pm- PASFI office

Call for dates

At Home SG

Telephone Group

For those unable to leave the home, this group is offered over the phone. Call to enroll.

Sons & Daughters Support Group

9am- Fourth Wednesday of each month at PASFI

Women with PD Support Group

Call for dates and times.

Caregivers SG

Tuesday

7pm- Homewood Residence

Class Schedule

Pre-Registration required for new participants

Exercise Classes

Monday

1pm- Fleischmann Park

1pm- Bonita Springs Community Center

1:30pm- Terracina Grand

Tuesday & Thursday

1pm- Balance Skills & Drills at Bentley Village

1:30pm- United Church of Marco Island

Wednesday

1pm- Carlisle

1pm- Bonita Springs Community Center

1:30pm- Terracina Grand

Friday

1pm- Fleischmann Park

Dance Classes

Call for locations and times.

Speech Classes

Call for dates and times.

Equestrian Challenge

Call for details.

**PASFI's Phone Number:
(239) 417-3465**

Directions

Bentley Village

704 Village Circle, N. Naples
888-697-4043

Bonita Springs Community Center

26740 Pine Ave, (Old 41)
Bonita Springs

Carlisle

6925 Carlisle Court
(off Airport Road, south of
Orange Blossom)

Fleishmann Park

South of Coastland Mall on
Fleishmann Blvd. at Goodlette-
Frank Road

Homewood Residence

770 Goodlette Road N, Naples

PASFI Office

2950 Tamiami Trail N, #20
Naples, FL 32103

Terricina Grand

6825 Davis Blvd., Naples
(corner of County Barn)

United Church of Marco Island

320 N Barfield Dr., Marco

Eye On Fashions

4th Annual Fashion Show

January 14, 2012
Naples Sailing and
Yacht Club



The Parkinson Association of Southwest Florida (PASFI) is proud to announce its fourth annual fabulous fashion show, "Eye On Fashions". This year's show will feature eclectic fashions from Petunia's on 5th Avenue and updated women's wear from Evelyn and Arthur of Bonita. We are also excited to have Dr. Pascucci and Eye Consultants of Bonita participating. They will be highlighting eyewear for the fashionable woman and do makeovers using high fashion frames. We are looking forward to having our audience participate.

The fashion show benefits PASFI, which provides services for those with Parkinson's and their caregivers/families. Parkinson's provides all of their services free of charge including exercise classes, art therapy, informational seminars, and connections with community agencies and other support groups that will help those with Parkinson's and their families. All of the proceeds from the fashion show will go toward these services.

This year's show will be held at the Naples Sailing and Yacht Club on Saturday, January 14th, 2012, beginning at 11:30. Complimentary parking will be provided by the Marino Group. Tickets are \$75.00 and include a lovely lunch, beautiful fashions, raffle prizes and a chance to support a group that helps many in our community. If you have questions or wish to purchase tickets, please contact the PASFI office at 239-417-3465. The deadline for ticket purchase is January 6th, 2012.



**Volunteers are the lifeblood of our organization.
Please consider volunteering for one of our many
committees.**

Lace Up Your Sneakers!

The Parkinson Association of Southwest Florida, Inc. will hold their 11th Annual Poker Walk on Sunday, February 26, 2012 at the North Collier Regional Park located at 15000 Livingston Road in Naples. Registration is \$20.00 and will begin at 8:30 a.m.; the walk will step off at 9:00 a.m. A continental breakfast and raffle drawings will follow the walk. Who knows, you might get lucky and win one of our wonderful prizes donated by local businesses or maybe even the 50/50!

Whether you walk individually or as a team, we hope that you will join us for what has become an enjoyable and fun filled event. Last year, walkers raised over \$32,000.00. The funds raised enable PASFI to fulfill its mission of promoting the quality of life for persons with Parkinson Disease and their care partners. PASFI offers a comprehensive array of services including specialized exercise programs, dance, equestrian, speech therapy, support groups, day care assistance and more. These services are offered free of charge to those living with Parkinson Disease in Collier and southern Lee counties.

If you need additional information, would like to register or join us as a sponsor, please contact PASFI at 239-417-3465.



The Social Committee Invites You to Party with Us!

January 11	Bar-B-Q Lunch
February 8	Valentine Party
March 14	Island Party
April 11	Annual Dinner at Cypress Woods
May 16	Ice Cream Social

RSVP's are Required for all Events!
PASFI office: 417-3465

Do You Receive Our Weekly NewsFlash?

We send out a weekly *NewsFlash* to keep all our friends and members up to date on the latest at PASFI.

To receive our email newsletter visit our website at www.pasfi.org or email us at pasfi@aol.com and add your email address to our list!

The NewsFlash is updated to the PASFI website each week.

Parkinson Association of Southwest Florida, Inc. promotes quality of life for persons with Parkinson Disease and their care partners.



Parkinson Association of Southwest Florida, Inc.
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