Voices of Parkinson’s
Clinical Trial or DBS: The Luxury of Having Life-Altering Options
by Ralph A. Schwarz

Bad news: You’ve got Parkinson’s disease! Good news: There ought to be a cure within the next 10 years, so just ‘Hang in there!’ That was 17 years ago, and I wait with the millions afflicted with PD for announcement of a cure. Although researchers are making progress, the solution is not over the next rise. Even when a treatment is identified, getting from the microscope or Petri dish to the pharmacy or operating room requires 10 years or more: Procedures that assure effectiveness and safety, such as extensive clinical trials, data analysis, and approval by regulatory agencies, take a lot of time.

Finding people willing to participate in clinical trials is also difficult. People are reluctant due to risks involved, fear of the unknown, and, at times, the need to delay other beneficial treatments, such as taking certain Parkinson’s medications or having deep brain stimulation (DBS) surgery. And “informed consent” requires that the research participant understands foremost that, in the purest sense, the aim is to gather data that may help patients in the future and that he might not personally benefit from having been in the study.

But it would have been very difficult for me not to hope for personal benefits when I enrolled in a Phase 2 clinical trial six years ago. I had been considering DBS surgery to relieve my symptoms, but this trial showed promise and excluded those with DBS. The research involved the surgical implantation of genetic material transported by a neutralized virus into specific regions of the brain with the hope of protecting and stimulating growth of dopamine-producing cells. Two-thirds of the 51 participants would receive the actual treatment and the rest a placebo surgery. The procedure was categorized a “double blind” in which neither participants nor researchers knew who had received the genetic material or the placebo surgery. In fact, the surgical team itself knew which treatment arm to perform only when the patient was on the operating table!

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A Note from the Coordinator Diane L. Church, PhD

Business is booming at The Parkinson’s Center! Despite the winter doldrums and icy roads, people continue to be in touch by phone, email and drop-ins at the office. You keep me on my toes with your challenging and interesting questions, and it is an honor to be of service to you.

In this issue, I have included an article on how the various components of the APDA interact and support each other. Won’t you help support our local programs and national research efforts by joining the APDA NH Chapter and/or engaging in the American Parkinson’s Optimism Campaign? Whatever your specialty, you can make this campaign your own, because Optimism Sings, Optimism Bakes, and Optimism Hikes, Bikes, and Paddles!
The following months were a time of waiting, second-guessing, tests, scans and observations. Did I receive the treatment? Could I see or feel any changes, any improvements? Nearly two years later, I learned that I’d received the placebo surgery; the study had not produced the desired results and the researchers were going back to the laboratory.

With my exit from the trial, I was free to reconsider DBS. But recently, on the eve of again opting for DBS surgery, I received news that the trial has new life and is proceeding as a “Phase 2a study,” with different doses of material implanted into somewhat different locations in the brain. I am advised that, if results are positive when announced in two years or so, previous placebo-arm participants will be offered the actual treatment, again with the proviso that the participant has not undergone DBS.

Although my PD progression has been unusually slow these last 17 years, it is nonetheless advancing. Now, as six years ago, I face the same difficult decision: Do I put faith in an unproven/experimental procedure that might produce the long-sought “cure” or do I settle for the symptomatic improvements provided by DBS, which has already gone through all research phases and is now a standard treatment for PD? Do I wait two more years, in hopes of positive research results and the opportunity to receive beneficial genetic material (which, I am reminded, would be available to me as a placebo-ed research volunteer, but likely not to others for a decade or more)? Do I again wait, knowing that my decision-making may have cost me several years of the higher quality of life typically provided by DBS if the research doesn’t pan out?

Decisions involved in having brain surgery, whether experimental or not, or to participate in any clinical study are personal, potentially complicated, and should be based on the best unbiased data available. Not all clinical trials require such weighty decisions, but can affect participants’ lives and so require thoughtful reflection. Despite the difficulty in making these decisions, I believe it is a luxury to have life-altering options from which to choose.
Preparing for Your Neurology Appointment: Helping Your Neurologist to Help YOU!

On your mark!
An appointment with your neurologist will be most productive if you are prepared to share your information and concerns. Here is a checklist to help you get organized.

Get ready!
- If this is your first appointment, ask the neurologist’s office what types of information you should bring. These may include office notes from other doctors, MRI or CT images of your brain, and lab reports.
- Medication list: Document all prescription medications (including non-Parkinson’s drugs), over-the-counter medications, vitamins, and supplements; dosages; when medications are taken; and when you first start taking each. Are there any medications that you were on in the past that were discontinued? Have you experienced any side effects?
- List of Parkinson’s symptoms you are experiencing. Which are new? Which are most troublesome?
- Movement symptoms (walking, getting out of chair, moving in bed, etc)
- Fluctuations in your symptoms (typically correlated with medication cycle, eating, sleeping, and exercise)
- Dyskinesias (involuntary movements caused by Parkinson’s medications)
- Non-movement symptoms (swallowing, speech, nausea, constipation, urinary frequency and/or urgency, drooling, excessive sweating, dizziness upon standing, swollen ankles, sleep disorders, restless legs, and more)
- Changes in mental status (depression, anxiety, cognition, ability to make plans, hallucinations, compulsive or excessive behaviors such as shopping, gambling, or sex)
- List three items that you most want to discuss with the neurologist. (There may not be time to address everything during your appointment, so it is important to prioritize your needs.)

Go!
- Arrive early to allow time for parking, using the restroom, getting to the appropriate reception desk, checking in, and filling out paperwork.
- Bring along water, a snack, and any medications you might need in case your appointment is delayed.
- Ask a family member or friend to accompany you, to take notes and remind you of anything important that has not been discussed.

At your neurology appointment:
- You did your homework, so you are prepared when your neurologist asks about your symptoms and medications!
- Special requests: Ask early in the appointment about prescription refills, disability forms, handicapped parking permits, etc; often a nurse or secretary is available to work on these during your appointment.
- Address those three major concerns on your list of priorities.
- Ask for a referral to a physical therapist for help with balance, gait, strength, pain, and flexibility issues.
- Ask for a referral to an occupational therapist for help with handwriting, home modifications, driver evaluations, computer modifications, and adaptations to make dressing, grooming, cooking, and eating easier.
- Ask for a referral to a speech language pathologist for help with speech and communication problems (including vocal volume, clarity of speech, and increasing facial expressivity) and swallowing.
- Ask for recommendations regarding exercise and nutrition.
- Ask about participation in clinical research trials.
- Ask the best way to get in touch with the neurologist in between appointments: Contact with nurse or secretary, by phone or email?
- Ask where you can get more information about Parkinson’s disease. (HINT: Contact Diane Church at the APDA Parkinson’s Center at DHMC!)
Do Neurologists Make a Difference in Parkinson’s Disease Care?

A review of a recent research publication:


RESEARCH OBJECTIVE
To investigate whether patients received care for their Parkinson’s disease (PD) from neurologists, and whether patients treated by neurologists had improved clinical outcomes.

STUDY DESIGN
Identify new PD cases from 2002-2005 using the large Medicare beneficiary database (which includes 98% of Americans older than age 65). Use a variety of sophisticated statistical techniques to analyze the data.

Interesting research findings:

- Only 58% of 138,000 newly diagnosed Parkinson’s patients received care from a neurologist at any time in the four-year study period. The others received care for their PD from primary care physicians specializing in internal medicine, family practice and/or geriatric medicine.

- Women, some minorities, and most elderly individuals received neurologist care less frequently than did younger white male patients.

- Patients receiving Parkinson’s care from a neurologist had better health outcomes. They had a significantly lower likelihood of:
  - being placed in a skilled nursing facility
  - hip fracture
  - death

Possible reasons for improved clinical outcomes for Parkinson’s patients receiving care from a neurologist:

Perhaps neurologists are more likely than non-neurologists to:

- Be aggressive with the use of medications like levodopa, thereby helping the PD patient to remain more mobile.

  ▲ Greater mobility is associated with reduction of many medical problems such as poor blood circulation, pneumonia, and physical de-conditioning that leads to increased risk of falls.

- Use other PD medications in combination with levodopa, leading to greater patient mobility and the benefits mentioned above.

- Recognize and manage common PD-related problems such as anxiety, depression, psychosis, and autonomic dysfunction.
The researchers acknowledged limitations to the study that may be resolved with additional research:

The benefits of neurologist care might be overestimated or underestimated if different “types” of Parkinson’s patients are seen by neurologists and non-neurologists:

- Which patients were diagnosed with PD, and who made the diagnosis?
  - Neurologists may recognize and diagnose more cases of mild PD.
  - Non-neurologists may mistake more severe conditions (such as Parkinson plus syndromes, Lewy body dementia, or variants of Alzheimer’s disease) for Parkinson’s.

- Which Parkinson’s patients are referred to a neurologist?
  - Patients with more severe disease (greater immobility and balance problems) are more likely to be referred to a neurologist.
  - Those who are severely disabled or even bedbound may be less likely to visit a neurologist.

- The risks of placement in a skilled nursing facility, hip fracture, and death are different for those with mild PD vs. advanced/severe PD vs. other illnesses that might be mistaken for PD. These differences could skew the data regarding clinical outcomes of neurologist care, potentially over- or underestimating the effects.

- Our measurements of PD progression and disease severity may be inadequate.
  - Relevant outcome measures in the Medicare database were used in this study, including placement in a skilled nursing facility, hip fracture, and death.
  - However, relatively few people with PD enter skilled nursing facilities regardless of disease severity so the amount of data available is limited; numerous falls indicative of PD progression do not result in hip fractures so are not included in the analysis; and death may be due to PD-related health problems or an unrelated co-morbidity such as heart disease, diabetes, or stroke.

Why this research is important:

This research suggests that neurologist-based care for PD patients resulted in better health outcomes. If further research supports these findings:

- More widespread neurologist care will:
  - improve the quality of life for people with Parkinson’s
  - reduce health care costs by reducing the need for costly nursing home placements, hospitalizations for hip fracture, and other expensive treatments

- We may see changes in health care policy and practice such that:
  - referral of PD patients to neurologist care is supported and routine
  - increased and improved neurologic education will be provided at all levels of medical training, allowing primary care and other physicians to provide better care for Parkinson’s patients

“If you think research is expensive, try disease.”

Mary Lasker, 1901-1994
philanthropist and advocate for medical research

The APDA: Information & Referral Centers and Chapters Working Together for a Common Cause

The APDA National Office, Information & Referral Centers, and State Chapters work together to “Ease the Burden and to Find the Cure” for Parkinson’s disease. The APDA currently includes 53 Information & Referral Centers, 45 Chapters, more than 800 support groups, APDA National Young Onset Center, APDA Rehab Resource Center, and nine Centers for Advanced Research.

The American Parkinson Disease Association, Inc. places strong and wide-ranging emphasis on the grassroots organizing of Information and Referral Centers, Chapters, and Support Groups. It is this grassroots structure that distinguishes APDA from other organizations serving people with Parkinson’s disease.

The Parkinson’s Center at DHMC

The Parkinson’s Center at DHMC is the official APDA Information & Referral Center of New Hampshire, founded in 2006. It is supported by the American Parkinson Disease Association, Inc. and host institution, Dartmouth-Hitchcock Medical Center.

The Parkinson’s Center mission is to respond to the needs of persons affected by Parkinson’s disease and their caregivers by providing education, referral, support and public awareness programs. The Information and Referral Center serves as a regional “hub” that processes requests received by mail, email, phone or on-site visit.

Co-Medical Directors of the Parkinson’s Center are DHMC Neurologists Stephen L. Lee, MD, PhD and David J. Coffey, MD. The Parkinson’s Center Coordinator is Diane L. Church, PhD; her position is salaried at 20 hr/week. As Coordinator, Diane provides the following:

- Info and resources about PD to patients, families, healthcare professionals, students and the community
- Referrals to neurologists, movement disorder specialists, rehabilitation specialists (physical and occupational therapists, speech language pathologists), respite programs, community agencies, research centers and more
- Telephone and email hotlines
- Distribution of free literature from the APDA and materials from the Parkinson’s Center lending library
- Educational programs
- Newsletters
- Help in establishing and maintaining support groups
- Support for special initiatives, such as the Parkinson’s Wellness Program, Dancing with Parkinson’s, and the Parkinson’s Comfort Quilt Project
- Consultation and assistance to the all-volunteer APDA NH Chapter, which focuses on fundraising and public awareness
The APDA NH Chapter has two main functions: raising funds and raising awareness.

The New Hampshire Chapter of the APDA

The APDA New Hampshire Chapter was founded in 2008, and has two main functions: raising funds and raising awareness. The Chapter’s fundraising supports NH-based outreach, programs, and education in addition to APDA national research and education programs.

The APDA NH Chapter is led by an all-volunteer Board of Directors, including people with Parkinson’s, family members, friends, and interested community members:

- President: Maureen Chamberlain
- Vice-President: To be filled
- Treasurer: Fred Britton
- Secretary: Mary Haynes
- Members-at-Large: Mary Blevens, PT, Fred Chamberlain, Rod Leavell, Sister Gloria Morin, RSM, Lisa Sommers, SLP, Laurel Trahan, CMC, Diane L. Church
- Advisor: Diane L. Church
- Website Developer/Honorary Member: Volodymyr Lyczmanenko (President, APDA MA Chapter)

Our APDA Chapter strives to:

- Raise funds for research
- Raise funds for local programs such as therapy, transportation, exercise, dance, and respite care programs
- Support educational events
- Secure media attention to raise public awareness and understanding about Parkinson disease
- Act as local representatives of APDA
- Assist support groups
- Encourage and support volunteer involvement
- Directly represent and advocate for the Parkinson’s community

HOW does the APDA NH Chapter raise money and awareness?

- Chapter memberships (see page 11)
- Fundraisers; (see Events on page 10)
- Raffles at fundraisers and events
- Corporate sponsorships
- Charitable and memorial donations
- Annual Parkinson’s Awareness Month (April) Candlelight Vigils
- Annual “Walk in the Park” (100% of proceeds support research at APDA Centers for Advanced Research)
- Participation in/donations to the Annual Parkinson’s Unity Walk in New York City’s Central Park (100% of donations support Parkinson’s research)

The Parkinson’s Center provides education, referral, support and public awareness programs.

Our non-profit APDA NH Chapter is financially responsible!

- We keep accurate records of all incoming and outgoing funds.
- Our Board of Directors monitors the use of funds.
- We submit semi-annual and year-end reports to the American Parkinson Disease Association’s National Office.
- We maintain a bank account.
- We record and acknowledge tax-deductible memberships, memorial donations, and contributions.

Our APDA NH Chapter welcomes you:

- Your ideas for fundraising are always welcome.
- Please volunteer to assist with an event.
- Board Meetings are open to all APDA NH Chapter Members. We invite you to become a Chapter Member by submitting the membership form on page 11.
- Board Meetings are held at 6:00 p.m. on the second Wednesday of the month at Elliot Senior Health Center, 138 Webster St., Manchester, NH. Meetings are sometimes cancelled, so please phone (603) 434-6252 to confirm.

The Parkinson’s Center, the APDA NH Chapter, and the APDA National Office work cooperatively to meet our goals and to ‘Ease the Burden – Find the Cure’ for Parkinson’s disease.
The Book of Exercise and Yoga for Those with Parkinson’s Disease: Using Movement and Meditation to Manage Symptoms (2nd ed, 2010), by Lori A. Newell, MA

Deep Brain Stimulation: A New Life for People with Parkinson’s, Dystonia, and Essential Tremor (2012), by Kevin L., Chou, MD, Susan Grube, RN, MSN, and Parag G. Patil, MD, PhD

Get Up and Move! Winning Against Parkinson’s (2008), by Gail Kitchens


Living with Parkinson’s: Diagnosis, Treatment, and Management (2011), by Gabriella Rogers (endorsed by Parkinson’s Australia)

Living with Parkinson’s Disease: How to Make the Best of It (2009), by Marilyn Elizabeth Shaff


Natural Therapies for Parkinson’s Disease (2010), by Dr. Laurie K. Mischley

Parkinson’s Disease: The Way Forward (revised 3rd ed, 2010), by Dr. Geoffrey Leader and Lucille Leader

Parkinson’s Disease: Top Tips to Optimize Function (2011), by Lucille Leader and Dr. Geoffrey Leader

Reverse Parkinson’s Disease (2011), by John Pepper

Songs, Science and Spirit (2012), by Heather MacTavish with Zubin Balsara

Swallow Safely: How Swallowing Problems Threaten the Elderly and Others. A Caregiver’s Guide to Recognition, Treatment and Prevention (2010), by Raya Sayadi, PhD, CCC-SLP and Joel Herskowitz, MD

Take Charge of Parkinson’s Disease: Dynamic Lifestyle Changes to Put YOU in the Driver’s Seat (2011), by Anne Cutter Mikkelsen with Carolyn Stinson

The World According to Honey Bear: A Doggone Good Read (2011), by Catherine Rodriguez, EdD (Written to teach children about Parkinson’s, through the eyes of a loving and insightful service dog.)

Yoga for Movement Disorders: Rebuilding Strength, Balance and Flexibility for Parkinson’s Disease and Dystonia (2009), by Renee Le Verrier

Also by Ms. Le Verrier: A, B, C…X, Yoga, Z (2009) (Introduce your children or grandchildren to yoga through the ABCs as you practice yoga to ease the symptoms of Parkinson’s.)

Visit the Lending Library online: patients.dartmouth-hitchcock.org/parkinsons/lending_library.html and type “Parkinson’s” in the search box to view all of our holdings.

American Parkinson’s OPTIMISM

We’ve Got Optimism… And It’s Contagious!

Join APDA as we launch our new national Optimism campaign to increase awareness of Parkinson’s disease across the country and raise money for education, support services, and to help find a cure. With Optimism events, there are no limits to the ways you can get involved.

And together, we can accomplish anything!

Start your own event today! www.Optimism4Parkinsons.org
Walk-in-the-Park 2011
A great success in a great location!

Nearly $4,000 was raised for Parkinson’s research.

Please join us on Saturday September 15, 2012 for our Third Annual Walk-in-the-Park at Greeley Park, Nashua.

A. Sister Mary Flatley (left) and Sister Gloria Morin enjoyed the bright sunshine!

B. Donnalee Lozeau, Mayor of the City of Nashua, welcomes the NH Chapter APDA and Walk-in-the-Park participants to Greeley Park.

C. “Margie’s Marchers for Hope”: Margie Clark (in hat), Shelby O’Malley, and Julie Chute made it a “family affair” for the second year in a row!

D. Mary Blevins (left) and Mary Haynes greeted walkers at the registration table.

E. Fred Chamberlain and grandson Jimmy Burke

F. Maureen Chamberlain, her sister Kathy and niece Sierra (left to right)

G. Rod Leavell (left) and John Ghiorzi

H. Allison Aldrich and Hunt Smith provided entertainment (www.huntandallison.net)
Memos from Maureen

The winter of 2011-2012 is slipping away. Snow has avoided ski slopes and cross country trails. My husband and I drove to Colorado in early December to spend Christmas with our granddaughter, Sarah, a 5 year old believer, our son, Steven, and daughter-in-law, Nadja. It was a difficult trip because of Steven’s illness. I took six weeks leave of absence from the NH Chapter APDA and returned in January to a seriously neglected website. Life does not always stay on our preferred time table and now we need to make up that lost time. Fortunately, two people have volunteered to keep the website updated with great information, practical advice, and notices of exercise classes, events, and support group meetings in New Hampshire.

The NH Chapter has printed envelopes to put in funeral homes, doctors’ offices, and assisted living facilities to make it easier for families to donate in honor or in memory of a loved one with Parkinson’s disease. We will be seeking the assistance of support groups to monitor replacement of the envelopes in the communities near you.

One major goal for 2012 is to increase membership in the NH Chapter of the APDA. We need your participation if we are to develop and fund local programming, such as dance and exercise classes, educational events, respite care, travel costs for people who no longer drive, and more. Your tax-deductible dues are just $20 per household for the calendar year, and can go a long way to help the Parkinson’s community. For example, if 120 households make membership contributions, we could fund 100 hours of professional respite care for our hardworking family caregivers. We have printed membership cards for those who join. Please help us to help you.

Maureen M. Chamberlain
NH Chapter President, APDA

ANNOUNCEMENTS AND EVENTS

From the APDA Parkinson’s Information and Referral Center at Dartmouth-Hitchcock Medical Center
For information, please contact Diane L. Church at (603) 653-6672 or send email to Diane.L.Church@hitchcock.org or the person noted for a specific announcement.

Saturday, March 10, 9 a.m. - 2:30 p.m. “Challenging the Changes,” an educational event in honor of Parkinson’s Disease Awareness Month, Dartmouth-Hitchcock Medical Center, Lebanon, NH
- Presentations by Dawna Pidgeon, PT and Keistan Blandin, PhD
- Dance workshops with Kate Gamble
- Support Group Leaders and Board Members Meeting: join us during lunch in a quiet and private room to share thoughts and experiences
- Announcement of Support Group Leader of the Year Award
- Raffle by the NH Chapter APDA $1.5 per person includes continental breakfast and box lunch

Space is limited. Pre-registration must be received by March 2.

Wednesday, April 25, 11:30 a.m. - midnight “Dining to Donate” at Applebee’s Restaurant, Hooksett, NH, just off I-93, Exit 9
Pick up a coupon at the March 10 event or the April 12 Candlelight Vigil, or contact Rod Leavell at (603) 345-9056, rleavell@comcast.net. Give your coupon to the waiter/waitress before you order and 15% of your total will be donated to the NH Chapter APDA. You can have lunch, afternoon snack, or dinner at the Hooksett Applebee’s, any time between 11:30 a.m. and midnight to qualify.

Saturday, April 28
18th Parkinson’s Unity Walk, Central Park, New York City
All donations to the Unity Walk are distributed to the major U.S. foundations for Parkinson’s disease research, including the APDA. Consider donating to our team: “New Hampshire Granite State Steppers,” or create your own team! All donations are tax-deductible. More info at www.unitywalk.org.

Tuesday and Fridays, May 1 - June 8, 11:30 a.m. - 1 p.m., with pre- and post-assessments the weeks before and after Parkinson’s Wellness Program (six-week program), Dartmouth-Hitchcock Medical Center, Lebanon, NH
Exercise, balance, gait training, and education program led by DHMC’s Rehabilitation Medicine specialists to help those with PD achieve a better quality of life. “Medical Eligibility Form” is required to ensure that the program is appropriate and safe for you. $250 per person; partial scholarships are available.

Saturday, October 13, 9 a.m. - 2:30 p.m. Symposium for People with Parkinson’s, Caregivers, and the Community
SERESC Conference Center, Bedford, NH
Details in the next Parkinson’s Companion.

SAVE THE DATES!

Saturday, September 15, starts at 10 a.m. 3rd Annual Walk-in-the-Park for Parkinson’s Research, Greeley Park, Nashua, NH
All proceeds are donated to APDA Parkinson’s research programs. Details in the next Parkinson’s Companion; see photos of last year’s Walk-in-the-Park on page 9 of this Parkinson’s Companion.
2012 Membership Drive
Join the New Hampshire Chapter of the APDA!

Please help your NH Chapter of the APDA reach its goals of raising funds and increase awareness to help fight Parkinson’s disease.

We hope to develop and fund local programming, such as dance and exercise classes, educational events, respite care, travel costs for people who no longer drive, and more. But we can’t do it without your help!

Please join us:

- Lend your financial support to the work of the Chapter through payment of modest annual dues ($20 per household).
- Share in the efforts and fun to help us reach the important goals of the Chapter. You might volunteer at a fundraising event, participate on a committee, help educate the community about Parkinson’s, and more! We welcome your ideas.
- Attend Chapter Board Meetings: held on the second Wednesday of most months, 6:00 p.m., Elliot Senior Health Center, Manchester, NH. All Chapter Members are welcome to attend. The Chapter leadership appreciates your input and support.

How does someone become a member of the New Hampshire Chapter of the APDA?

Kindly complete the form on this page.

Please make checks payable to NH Chapter APDA

Mail to the following address:
NH Chapter APDA
PO Box 183
Londonderry, NH 03053

We are a nonprofit 501(C)(3) organization. All donations and dues are tax deductible. For more information, contact Maureen at (603) 434-6252 or email mchamberlain.apdanh@gmail.com.

Name______________________________________   Date ______________________
Address__________________________________________________________________
(Please affix address label if you prefer!)

Phone # [_____] __________________   E-mail ___________________________________

Please indicate your level of support:

Household Membership $20 annual
Household Membership with Additional Donation Please indicate total: $
Other donation Please indicate amount: $
Corporate Sponsorship $25_______ $50_______ $100_______ Other_______

Do you belong to a Support Group? Please tell us which one ______________________

How would you like to see your membership dollars used?___ ______________________

Do you have a fundraising idea that might help us achieve our goals? ______________________

Do you have skills, time and/or resources that you would like to contribute to our efforts?
  ____Chapter Board membership
  ____Becoming an event coordinator, assistant or volunteer
  ____Helping with public relations and advocacy
  ____Other (please describe) _______________________________________________________

Thank you for your interest and support!
Attention: Diane L. Church