Post-Polio Health

www.post-polio.org

"Not Going Is Not an Option"

Jann Hartman, Seattle, Washington, arojann@yahoo.com



Jann in Washington with Mt. St. Helen's in the background.



On an accessible pier on the Ohio River.

grew up believing in fairy tales and loved stories that ended "happily ever after." Even when I got polio in 1953 at almost 6 years old and spent most of that year in the hospital, I still believed that everything would work out for the best. I met my "knight in shining armor," we got married and had three wonderful boys.

John retired in 2005; we sold our home, bought an RV, and headed out. The plan was to travel south in the winter and head north in the summer. We hoped for many more golden years even with my post-polio syndrome causing some problems. Our plan was a good one, but as I have learned, "when we plan, God laughs."

Early in 2006, John was diagnosed with an aggressive cancer that had metastasized. Now, I became the caregiver as he got progressively worse. We stored our RV and moved in with my parents in Florida so they could help with John's care. It was a really stressful time for all of us.

John rallied a little after about the fourth round of chemotherapy, so we made plans to fly from Florida to Seattle. It was important to John that I would be settled with one of our boys, and our son had bought a house with a separate suite for us.

Friends and family became very important as John's days on earth counted down. I saw him hanging on as our 36th anniversary approached on Sept 12. He seemed very pleased to have made it, but my heart was



breaking knowing it would be

In Old San Juan, Puerto Rico.

our last one. He died four days later.

The grief I experienced was intense that first year. Even now, three years later, it comes and goes. You just have to allow yourself plenty of time. I also believe it is best not to make any drastic changes that first year, if possible. My life had changed almost entirely since our move to the Pacific Northwest, and that wasn't easy for me. It's a beautiful area, but not where I ever expected to end up. I joined a church and attend a great Bible study group. My new friends are very supportive and very dear to me.

Without John, I wondered how I would ever be able to travel. It is harder now, but not impossible. I was able to go to Hawaii, and I've visited old friends from high school and college in Pennsylvania. I attended the 10th Post-Polio Health International Conference at Warm Springs last year. I love spending time with PPS friends in Branson, Missouri; Arkansas; Wisconsin; and Vancouver, Canada. I am blessed

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POST-POLIO HEALTH INTERNATIONAL INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

PHI's mission is to enhance the lives and independence of polio survivors and home mechanical ventilator users through education, advocacy, research and networking.

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Worthy of Note

Congratulations!

William G. Stothers, president of PHI's Board of Directors, was honored by Access to



Bill Stothers

Independence with its Lead On Award earlier this year. Access to Independence, an independent living center in San Diego, gave the award "for a lifetime of selfless dedication to the rights and dignity of people with disabilities."

In accepting the award, Stothers noted that, while much has been accomplished, prejudice, discrimination and barriers remain. "We know we can do more. We know we can do better. The past 30 years shows that we can make a huge difference."

Disabled by polio at age 10, Stothers has been fighting barriers to access in education and in the workplace for 60 years. A working journalist since 1963 when he joined the staff of *The Globe and Mail* (considered Canada's national newspaper), he earned a journalism degree from the University of Western Ontario. He received a master's degree in East Asian history from the University of

California-Berkley and later worked for the *Toronto Star*, where, in 1972, he orchestrated one of the first examinations of independent living and disability rights issues ever in the mainstream press.

Stothers was a member of the Mayor of Toronto's Task Force on Disabled and Elderly that advocated for implementation of a citywide curb cut program. As a leader of the Action League for Physically Handicapped



Bill accepting the Lead On Award from Access to Independence.

"Not Going Is Not an Option."

to be able to visit my parents in Florida for a few months each year.

Last summer, we made my mother-in-

law suite even more accessible. I now have a lift for my car so that I can load my scooter. I also have a travel scooter that folds up, but I am not using it as much as I probably should. As I get braver, this too will get easier for me, I hope. I do not like to travel alone and go with friends whenever I can. But, for now, not going is just

continued from page 1



Jann and her travel scooter in Chicago.



Recommended Books

not an option.

Sands, Jennifer, *A Tempered Faith* (2003), *A Teachable Faith* (2006), and *A Treasured Faith* (2009). Three inspirational books from a 9/11 widow. www.jennifersands.com.

Krumroy, Jeri, Grief is Not Forever, (1985).

Advancement, he helped bring government leaders and transit officials in Toronto together to develop a public transportation program for people with disabilities, and in 1977, he represented the Mayor's Committee at the White House Conference on Handicapped Individuals.

Moving to the United States in 1978, Stothers joined the *San Diego Union*, where he rose to executive financial editor and later became the newspaper's ombudsman. He left in 1992 to become editor of *MAINSTREAM*, a national news and lifestyles magazine for people with disabilities. In 1998, he took on additional duties as Deputy Director of The Center for an Accessible Society and helped advance the Center's goal of focusing national media coverage on disability as a public policy issue.

Stothers is a principal of Exploding Myths, Inc., a media enterprise company headed by his wife, Cyndi Jones, also a polio survivor and long-time advocate for disability rights.

Joan L. Headley, Executive Director, PHI

Jann and tulips.



Question: I read with great interest the question and answer about knees collapsing in the Vol. 26, No. 2 (www.post-polio.org/ edu/pphnews/pph26-2sp10p7.pdf). I had polio at age 1. I'm told that I made a full recovery and that our local doctor used me as an example of a "miraculous" recovery.

Networking

A graduate of the U.S. Naval Academy, I am now 63 and have had a normal, active life. Several years ago I noted a weakening in my right leg that has slowly gotten worse. I attributed it to sciatica. I had surgery for a ruptured disc in 2002. Last summer after about a year of relative inactivity (just got lazy), my right leg started to buckle and deteriorate rapidly. It even looks smaller.

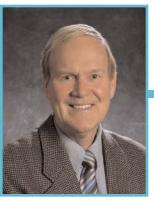
I saw a neurologist and first heard about post-polio syndrome (PPS). He felt it could be PPS combined with my back problem and with myopathy caused by my mild type 2 diabetes. I went through a period of rehab and regained some strength. I decided to do exercises at home and walk every day. The buckling frequency has decreased, but I have fallen a time or two. A recent MRI of my legs was shocking. My right leg muscles are almost gone, and the space filled in with fatty tissue. I am amazed that my life has been so normal. My body must have compensated incredibly without my realizing it.

The question is ... Can I regain some muscle mass and strength through exercise? I would love to work my legs harder, but have heard that I could damage my muscles since they may not have the capacity to recover. Should I experiment with a strenuous routine to see if I can improve strength, or do I risk doing damage and further deteriorating my legs?

A: Thank you for describing your history of polio and recent changes so clearly. Here are some thoughts about your situation and what you can do about it.

The large amount of fat seen in your thigh suggests a chronic gradual loss of muscle mass and is an expected result of muscle atrophy. It does not explain if the new atrophy is a result of nerve loss from your lumbar disc problem or from nerve loss due to PPS. Reduced activity will also lead to muscle atrophy from "disuse weakness," and this happens more quickly and dramatically in people who have recent and old nerve losses. Exercise can usually reverse much of the loss of muscle mass from disuse atrophy.

I would not recommend a "strenuous routine" of exercise. Instead, I would recommend you try a low-intensity, non-fatiguing exercise program to strengthen your thigh muscles. However, combine this with a careful monitoring (keeping a written record) of your walking activity, including a record of your "maximum walking capacity" done once weekly. This is best done on a level



Frederick M. Maynard, MD

surface and done either as a timed test (how far you can walk in 6 minutes) or as maximum distance walked before there is muscle fatigue (muscle not as strong as when activity started or aching pain in muscle develops). The former is better from a time management standpoint if walking distances are fairly long.

Walking is an activity that does require repetitive strong use of the thigh muscles and does lead to slow strengthening of these muscles in and of itself. A walking program alone may be best for strengthening your thigh muscles. One has to be careful that strengthening exercises don't interfere with, or necessitate a decrease in, your functional walking. Overuse weakness can occur in polioinvolved muscles, especially such as in your weakening and atrophying thigh muscles.

If you experience increased ache and/or burning discomfort/pain in the thigh muscles, or increased/ frequent involuntary twitching in these muscles or increased weakness (even of a temporary nature) then you MUST significantly reduce, but not stop, the intensity and/or duration and/or frequency of the exercise and/or walking. Given the relative complexity of the decision-making involved in the above rehabilitative steps, I would recommend seeking professional advice from a physical therapist or exercise physiologist who is familiar with post-polio issues. A professional can support and guide you through the above steps and help you plan for regaining as much strength as possible in your leg muscles.

Question: I have seen advertisements for products that claim to "cure" PPS. From all I know, there is no cure. Do these products have any beneficial ingredients that may help us?

A: One must always be skeptical of anything advertised as a "cure" for PPS, because it is a condition that almost certainly has many causes. Most advertised products are nutritional "super-supplements" and/or herbal remedies. What some of them may do is decrease or alleviate PPS symptoms in some people, particularly if they correct a deficiency that is producing their symptoms.

If disabling symptoms end and a polio survivor can exercise and become more active, they may even regain some lost strength and function. Remember PPS symptoms are not specific and can be imitated by many other conditions – from vitamin deficiency to depression to even early cancer. See *Post-Polio Health*, Vol. 25, No. 2 (www.post-polio.org/edu/ pphnews/PPH25-2sp09p4-5.pdf).

Regarding beneficial ingredients in advertised products: Most of these nutritional supplements contain some type(s) of antioxidants, which are compounds that have a neutralizing capacity on free radicals. Free radicals are circulating compounds in the blood and cells that are produced as a result of energy use by the body's cells and have a destructive effect on cell health. All diseases and injuries, including vigorous exercise, increase free radical production, and the body requires more antioxidants to neutralize them and maintain stable cell health (also known as homeostasis). Anything that promotes antioxidant capacity and activity within cells is probably good for health.

Some products contain glutathione (GSH) or promote its production. GSH is the most powerful antioxidant that occurs naturally in all cells and is made by most cells. Probably any supplement, as well as certain foods and lifestyle behaviors that promote the production of GSH, is helpful for maintaining good health. Nevertheless, specific studies are needed to document how valuable these are for health maintenance and potential disease treatment.

The best thing I can say about the use of the complementary and alternative medicine products, many of which are sold through marketing programs with questionable claims, is that they have little risk of harm and may have some benefit to individuals that can only be discovered by a "try it and see" approach. ▲ SEND YOUR QUESTIONS FOR DR. MAYNARD TO INFO@POST-POLIO.ORG.

Successful Bracing Requires Experience, Sensitivity

Carol Elliott, Downers Grove, Illinois, carolkelliott@aol.com



Conventional metal and leather KAFO.



A polymer system KAFO.

experienced polio in 1953 at age 2 that resulted in right lower limb paralysis. I have worn a KAFO (knee ankle foot orthosis) my entire life. An "orthotic" device is a brace or splint for support, immobilizing or treating muscles, joints or skeletal parts that are weak, ineffective, deformed or injured. A Certified Orthotist is a healthcare professional skilled in evaluation, design, fabrication and fitting of orthoses (braces) and other devices to straighten or support the body and/or the limbs.

Like most polio survivors who use assistive devices due to lower limb paralysis, I am well-acquainted with the need to find quality practitioners or orthotists. This presents a unique challenge to both groups.

The effects of aging, muscle overuse, joint pain and soft tissue damage, weight loss or gain for polio survivors require constant adjustments to their braces. Sometimes this results in a doctor's prescription for a new leg brace. Often, the polio survivor is faced with the challenge of trying newer materials and technologies to "correct" weight-bearing realignment issues. Some people want what they have always been comfortable with, even if it means rejecting an upgraded leg brace because it might require

JOE RAMICONE is the past president of the Midwest Chapter of Prosthetists and Orthotists, a member of the American Academy of Orthotists and Prosthetists and a member of the Illinois Society of Orthotists, Prosthetists and Pedorthists. He has served as a volunteer practitioner at the 2002 Paralympic Men's and Women's Slalom and Giant Slalom downhill skiing events in Salt Lake City, Utah, and was the key organizer for the First Swing Golf Clinic for physically challenged individuals in Chicago in 2003. In 2010, he was involved with The Great Lakes Adaptive Sports organization, a track and field competition for youths with various physical disabilities that held local and national championships.

CAROL ELLIOTT is a freelance writer/editor and contributor to *Post-Polio Health*. She deeply respects and appreciates the good work of orthotists everywhere.

a painful "breaking-in" period and getting used to a "new normal." Some people might prefer the orthotist to "accommodate" their preferences with an exact duplicate of the braces they have grown up with over the years.

Having worked with many, I think a good orthotist should be experienced and sensitive. Over the years my orthotists have been a diversified group. The one quality that I consistently admire is their genuine desire to fabricate what would be the best orthosis for the patient's unique situation – a real challenge in the older polio survivor. Most importantly, I look for orthotists whose goals and mine are the same: a brace that makes me feel secure and comfortable.

Joe Ramicone, the orthotist I have seen for the last four years, fits that criteria, and I asked him some questions that may be useful to other polio survivors who find themselves in need of orthoses.

PHI: Do you find that most polio survivors have fairly definite preferences about trying upgrades? Are they willing to leave the old behind? How do you best approach polio individuals who have worn KAFOs all their lives?

JR: Most polio survivors have a good idea of what they want in a new orthosis. The most common request

The American Board for Certification in Orthotics, Prosthetics and Pedorthics is the accrediting agency for Certified Orthotists and Certified Prosthetists. Those certified have a strong science background and formal instruction in biomechanics, kinesiology, pathomechanics, material science and gait analysis. Practitioners must have a minimum of a bachelor's degree in orthotics and prosthetics or a bachelor's degree in another field and have completed a 12-month accredited residency program. To check out the credentials of an orthotist, go to www.abcop.org.

is to see what is new and then to be fit with a device similar to what they've had. At this point in my career, when it comes to the polio survivor, I change very little in a new orthotic design. Most of my trials with new technology have not ended up with a better outcome. I believe that polio individuals want a newer technology, but also like the familiar feeling of their existing KAFO.

One example is the use of a polymer KAFO to replace a conventional, or metal and leather, KAFO. The polymer system is a more modern approach to fabricating an orthosis. It is has the advantages of being lighter and easier to adjust or change over time. Most of the polio survivors that I have tried to convert feel that the polymer system is too hot and not as rigid as their metal and leather design. I am always willing to try new technology, but in the case of a long-time user, I will express what I have learned from previous experience and need to hear from them that they are willing to make a change.

PHI: What do you teach new orthotists treating polio survivors for the first time? How do you help them therapeutically differentiate between fabricating a "textbook" KAFO, versus a uniquely customized bracing system that fits the patient's needs for familiar comfort?

JR: I instruct the resident orthotist to observe the patient walking with and without their orthosis. We perform a muscle and range of motion test and then observe

their bodies looking for redness, callusing or other signs of excessive pressure that may be caused by their existing orthosis. We want to insure that the new orthosis fits comfortably. We will also evaluate the person's upper extremity dexterity and cognitive ability to insure that the patient can independently don and doff the orthosis.

I then ask the resident to listen to what the individual expects from the new orthosis. We discuss the functional deficits that we see and the orthotic modalities to treat those deficits. For example a polio individual may need to have a KAFO with a locked knee for stability when walking. There are many different joints that will accomplish this goal. Some require two hands to use, and others will employ a trigger release that can be activated with one hand. We then solicit the person's input regarding vocational and recreational goals and urge him or her to play a role in the design of the new orthosis.

PHI: Have you fabricated braces for a polio survivor who has never worn a brace before – someone who has been ambulating independently for years, but is now experiencing new muscle weaknesses and fatigue due to postpolio syndrome? What type of bracing do you recommend for the first-time brace wearers, and how has this experience played out for them?

JR: Yes, I have fit "first braces" on polio survivors. The design is based on their pathomechanics and muscle weakness. We want

to control the joints and motions that lead to instability and at the same time allow motion that is beneficial. The usual design is a polymer design. Most first-timers do well with this polymer, also known as a plastic system.

PHI: How has your volunteer experience with disabled athletes strengthened your ability to assess orthotic needs as people are faced with the challenge of improving mobility in their lives?

JR: The key to a successful outcome is to design an orthosis with the least amount of control and restriction that still accomplishes the goal. I tell resident orthotists to manage only what needs to be managed, and leave the rest alone, which is easier said than done.

Each individual has a different vocational and recreational activity level. For example, an individual who does not do sports, but just wants to be able to move about at home or office may do well with an all-aluminum KAFO. It is lighter than a steel design but not as durable. A very active individual may require a carbon fiber orthosis. This material is light and strong but not easily adjustable.

Some people may also be able to adapt to part of their deficit or not require orthotic management during specific activities. It is important to review the rationale for the orthotic design with each person and allow them to tell you what they need the orthosis to do.

Promoting Positive Solutions



Stephanie T. Machell, PsyD

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts. Her father was a polio survivor. **Question:** My husband died a year ago and I am lonely. When I am lonely, I eat too much. Do you have any suggestions for me?

Response from Stephanie T. Machell, PsyD:

I'm very sorry for your loss. Losing a spouse is one of the most difficult and stressful experiences anyone can have. A good friend who recently lost her husband told me that thinking of herself as an individual after so many years of being part of a couple was difficult. She felt that her husband had become an integral part of her. But even so, the loss of his physical presence in her life was terribly painful. Such a loss creates a void that even good friends and family may not be able to fill.

Food is often used to fill such a void. In the words of Doug Heffernan from *The King of Queens*, "Food is always there, and it's always good." When you feel lonely, it's all too easy to go to the kitchen and get something to eat. It gives comfort and doesn't demand anything in return. It can evoke memories of happier times, maybe even of times shared with your husband. Because food provides such easy and reliable comfort, emotional eating can be a hard habit to break, especially at a time when you have little or no energy to look for alternatives.

This comfort is almost always shortlived. Eating too much of even the most delicious food doesn't solve the real problem of loss and loneliness. The feelings return and may be joined by guilt or shame about overeating.

But right now, the most important thing is to give yourself permission to grieve. Tell yourself that each person grieves in his or her own way, and however you are grieving is just fine. If food helps, let it for now. It's not a permanent solution, but if it gives some comfort in the short run, let it be. Perhaps set a deadline to reexamine your eating patterns, and until that deadline, give yourself permission to eat without guilt.

Setting a time each day to grieve can help. Block out two hours each day, look at photos, listen to music that reminds you of your spouse, write about him and really feel the loss and sadness. At other times of the day when you feel a wave of grief, remind yourself to save it for your two-hour designated time. Do this until two hours feels too long and you start to get a little bored.

You can also try to find other ways of comforting and nurturing yourself. Giving yourself permission to do the things that matter most to you and give your life light and color can be difficult after a loss, but it is a big part of healing your pain and loneliness. Supportive friends and family may help ease your loneliness. Animals offer unconditional love and comfort that often goes beyond that of our human families.

Reading, sewing, knitting, listening to music, artwork or other hobbies or interests are ways of connecting with yourself or with others through clubs or classes. Religious practices and meditation can help you connect with a higher power and help you cope and make meaning of your loss. Journaling, either in words and/or pictures, can help you get in touch with and release your feelings. It can be healing to get out in nature, even if it's just sitting on the porch or in your car looking at a beautiful view.

There are support groups for widows where you can connect with other women who are dealing with the loneliness you feel. This can be helpful if you feel that your family and friends don't understand what you are experiencing. Reading books about others who have had losses can also help you to feel less alone.

If you find that none of this helps, or if you are feeling hopeless or overwhelmed by all you are dealing with, you might consider seeing a mental health professional. In therapy, you can talk about what you're going through as well as learn and practice new coping skills.

Question: A man in our support group who has lived alone for many years is in the hospital. He had stopped cooking for himself, and he is anemic and very run down. He receives supplements and three meals a day and therapy to build up his strength. Another member of our group with the same issues (also lived alone for many years) recently moved to a nursing home. How do we know when it's time not to live alone?

Response from Rhoda Olkin, PhD:

This is a great (and possibly anxiety provoking!) question. Of course, polio survivors are not alone in wondering when it's time to move from living alone to another type of living situation. But we have additional considerations as polio survivors. Let me outline the main reasons people stop living alone, whether the decision was their own, or that of a concerned relative. A. FALLING. This is one of the main reasons older people move into group living situations. Studies suggest there might be a correlation between depression and falls – and of course we can't know which might cause the other, only that there is a relationship between the two. I know that when I get anxious or upset, I seem to cut my hands in the kitchen more. Conversely, after a fall I feel fragile and vigilant.

No one knows how often polio survivors fall and what the typical damage is. Perhaps we fall more than people without disabilities, due to fatigued limbs, crutches on wet floors or less agility to recover from stepping on a paper clip on the floor. But certainly any damage we incur from falling can be more serious. We might protect our bodies less when we fall, and atrophied limbs might be more prone to breaking. (And last time I fell when using crutches, I stupidly held onto the crutches and thus fell like a giant tree, flat on my face!)

Additionally, damage to a "good" limb can leave us more disabled. For example, if I hurt my left leg and it couldn't be weight-bearing, my mostly paralyzed right leg couldn't pick up the slack, and I wouldn't be able to use crutches, transfer from wheelchair to the toilet, bed or shower; I would be more immobilized than a person with two healthy legs would be if one leg was injured.

Similarly, if I injured my right hand, not only would I have trouble writing (as would any right-handed person), but I couldn't use my wheelchair (right-arm control) or crutches, and thus my mobility would be limited to walking (i.e., about 25 steps per day).

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Rhoda Olkin, PhD

Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and single mother of two grown children. continued from page 9

So evaluation of our falling history and potential is something we all should be thinking and talking about with our care providers. And please, install grab bars before you need them, and consider a lifeline call button that calls the people you designate in the order you prefer.

B. RISK TO SELF. I hope I'm not the only one getting absent-minded as I age! It's one thing to lose my glasses, misplace my crutches, forget to pick up my dry cleaning. It's another thing to leave the stove on until the pot catches on fire, not understand the implications of fire, be unable to take medications as directed or forget to eat. These are more dangerous situations that call for closer monitoring. There are some work-arounds, such as Meals on Wheels, and daily check-in calls. These help, but cannot address all of the issues that can arise.

C. GIVING UP DRIVING. This is a hard one, as most of us think we are better drivers than others think we are. Remember the episode of *Everybody Loves Raymond* when Debra felt that Frank wasn't safe to drive the kids anymore? The ramifications in the family were enormous. Driving is equated with independence for many people, and to stop driving seems like giving up.

Much of the United States requires navigation by car. So stopping driving limits one's social sphere. Not only is it hard to go to the grocery store, library or doctor's office, but also to visit friends and family. A more communal living situation addresses many of these issues. Additionally, transportation may be provided to organized outings to cultural events. **D. BEING LONELY.** Sometimes we curtail our activities without realizing how much we've done so. Maybe due to fatigue, you pass on going to a movie with friends one evening, or skip a dinner because it's a long drive or say no to going to the farmer's market because it's too much walking. Or perhaps you are just a "people person," and you like a lot of social interaction in your life. I love walking into an empty house, but if I were more of an extrovert I might hate it.

Moving to a communal living situation doesn't have to be seen as a failure to live alone, but rather as a preference for a more social lifestyle. Everyone I know who has made the transition is happy they did so, but most of those same people dreaded the move beforehand. So how you feel about the thought of moving is probably different than how you would feel after the fact.

E. BEING ALONE. This is not the same as loneliness. Sometimes circumstances conspire to leave us without family or friends close by. Marriage/partnership, by the way, is the main predictor of going to a nursing home; people with spouses/partners are much less likely to do so. This makes sense. Companionship is a buffer against stress, and there is someone else to notice you left the stove on.

But if you don't have a partner, your kids have moved far away, you commuted to work in a city so your work friends live all over, you don't know your neighbors, then, despite friends and family, you are alone on a daily basis. In that case, all the factors in A - D are more problematic.

F. CHOICES. We may get stuck thinking in black and white terms: living

 \triangleright

Thank you

For recognizing your friends and loved ones with contributions to support the unique mission of PHI and IVUN. PHI strives to publish an accurate list. Please contact us if we made an error.

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For Mrs. Miki Zimring's speedy recovery

independently in our own homes versus warehoused in a nursing home. Those aren't the only choices. We could live with each other. Or move to a retirement community. There are communities with stepped levels of care. Board and care facilities are smaller homes with only about ten people who live together.

Threaten to live with your kids and I'll bet they can come up with even more choices all of a sudden! But visiting places long before we are even thinking about moving is probably a good idea, so that the image in our heads matches what is really available. And new choices are becoming available.

This is a scary topic for most of us, and we often avoid it until it's inevitable. But you can take control of your future. Before it's forced on you, decide how you wish to live, and communicate your choice to your family and friends or some trusted other. You will feel better making the decision yourself than having someone make it for you. But if the time has passed when you can decide for yourself, trust that being in a more secure environment with other people around will help you feel safer day to day. (P.S. Have I taken my own advice yet? No way! There's lots of time still ...) ▲ PHI Thanks its Members for their support. If you are not yet a Member,



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POST-POLIO HEALTH INTERNATIONAL INCLUDING INTERNATIONAL VENTILATOR USERS NETWORK

4207 Lindell Boulevard, #110 Saint Louis, MO 63108-2930 USA Non-Profit Org. U.S. Postage PAID Jefferson City, MO Permit No. 210

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Not Going Is Not an Option ... pp. 1 & 3 Successful Bracing ... pp. 6-7 Promoting Positive Solutions ... pp. 8-10 and more.

Moving? Change of address? Notify PHI before you move by calling 314-534-0475 or email info@post-polio.org, and tell us your old and new addresses. **Away Temporarily?** Send us your "second" address and dates you will be there, and we'll do our best to send your newsletter.

Maximize Your Year-End Charitable Contributions

As you plan your year-end charitable giving, don't overlook the benefit of a tax deduction for appreciated stock. Donating stock to Post-Polio Health International may be more advantageous financially for you than donating cash.

If you hold publicly traded stock that has increased in value and you choose to donate it to a charity, you may take a charitable deduction for the fair market value of the stock, provided that you have owned the stock for one year or more. This amounts to a "doubling up" of tax benefits. First, you can take the charitable tax deduction on your tax return (assuming that you itemize deductions), plus you will avoid capital gains tax on the appreciated value of the donated stock.

This strategy for charitable contributions allows you to donate to your favorite charity and avoid capital gains treatment on the appreciated stock.

Donations of appreciated stock should be transferred directly into the charity's investment account. (If you sell it and donate the cash, you will have to pay capital gains tax on the gain.) Before making any charitable contribution, you should check with your tax professional regarding your particular tax situation and other limitations that may apply.

Please contact Joan Headley at 314-534-0475 for further details on PHI's investment account at Edward Jones.