

PPASS Times

Newsletter of Post Polio Awareness & Support Society of MN

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From Where I Sit

By Jane St. Onge, Chair

The "D" Word

I've been going to write about this for awhile but have always managed to put it on the back burner. The "D" word, depression, isn't easy to talk about. There's a stigma that accompanies anything to do with mental health. It's embarrassing to admit that I can't cope without medication. Is it a character flaw that I can't buck up and shake off the dark feelings and sadness without the help of a little pink pill?

Dr. Henry Holland (Dr. Henry Writes About Antidepressant Medications) notes "It is very true that many PPSers get depressed perhaps secondary to psychological factors such as loss of self esteem and a sense of usefulness, and possibly to biological factors such as the depletion of serotonin or dopamine. Whatever the connection, the various groups of antidepressant drugs seems to help many PPSers deal with pain, sleep disturbances, anxiety and mood change. . . .The doctors do not know exactly what is going on except that something is happening to almost the entire CNS system, but not exactly the same way for all of us. . . .Research done by Dr.

David Bodian in the late 40's and early 50's on autopsies of fatal polio cases revealed considerable brain involvement in the original infection and not just limited to bulbar, but spinal as well."

My depression started shortly after my symptoms of Post Polio Syndrome escalated and I had to leave my teaching job. I kept thinking with time I would feel better but that didn't happen. I found myself

Doing something about my depression made a positive change in my life. Now, I hope that talking about it might do the same for someone else.

withdrawing from social situations and avoiding people. It was hard to get out of bed and the crying jags continued. Taking an antidepressant has made a difference. I'm able to function like the old me. I was worried the pills would make me feel like a zombie, but that hasn't happened. There are a few side effects but they are manageable. Doing something about my depression made a positive change in my life. Now, I hope that talking about it might do the same for someone else.

Editor's Note: See Dr. Henry article on page 4

Group Happenings

Brainerd/Baxter Chapter

By Alvina Peterson

Greetings from the north-land! The Baxter/Brainerd Chapter has had a busy fall. Bob Jensen attended the PPASS MN Advisory Committee meeting in the Twin Cities on September 11th. On October 3rd our group traveled to St. Cloud to meet with the Chapter there. Our regular meeting was held on October 6th. June Elvig, a former member of our Chapter who has relocated to Seattle was our special guest. Plans have already been completed for the annual Christmas Party to be held on December 1st at Godfather's Pizza in Baxter. The theme this year is "Snowmen." We wish each of you a very Happy Thanksgiving as we think of the wonderful blessing of friendship we enjoy with others in our Chapters around the state.

St. Cloud Chapter

By Marilyn Satterness

Toni Reif opened our meeting by introducing and welcoming six members from the Brainerd/Baxter Chapter. Including our guests, 23 people were in attendance

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Group Happenings

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We received reports from Alan Kriz and Bob Jensen who attended a recent meeting of the PPASS MN Advisory Committee in Minneapolis.

Rosemary Marx encouraged all of us to share our personal polio stories, beginning with the onset of the disease, including our treatment, our degree and length of recovery, and the believe of many of us that we had overcome, our handicap and could leave the experience of polio behind us.

Many years later the delayed effects of polio came to all of us. Most of us were unable to find help from our doctors our understanding from friends or even family.

Fortunately, support groups began to develop and we found understanding and encouragement. The message continues to be: support one another, educate others, and learn how to relate to health care professionals.

At least two of us learned the hard way to avoid using mechanical exercise machines in the hope of increasing our strength.

One of the Brainerd/Baxter members has sometimes handled negative looks or comments from those who questioned her right to display a handicapped parking permit. Her response is to give them a note stating "post polio."

Following this sharing time, Toni demonstrated her new battery-operated scooter, called No Boundaries Easy Travel, which folds down to a size even acceptable on airplanes. It can also eas-

ily be disassembled.

West Metro Chapter

By Lois McIntyre

The speaker for our September meeting was Margot Imdieke Cross, a Disability Specialist for the State Council on Disability. She brought along many handouts including: Building Access Survey, applications for a disability parking certificate, ADA Guide for Small Businesses, a guide to Know Your Rights and Responsibilities, brochure explaining disability parking in Minnesota. All of these can be obtained by calling 651-296-6785 in the metro area, or 1-800-945-8913 from out state, or by going to <http://www.disability.state.mn.us> on the Internet.

Having a disability parking certificate or handicapped license plate is a privilege and a necessity

and with it go many responsibilities. The certificate should not be displayed hanging from your rear view mirror while driving as it obstructs your vision. A person may have two certificates or one certificate and one set of license plates. People with permanent or long term disabilities are issued a blue and white certificate, valid for six years at a cost of \$5.00. A temporary certificate is red and white and good for up to six months. Commercial vehicle certificates are green and white and valid for three years. Certificates bear the international symbol of accessibility and are honored in all states. A parking certificate should never be given to another person to use. If you should see someone parking in a handicapped parking space that you think definitely does not need to park there, you may obtain their license number and the number on their certificate and call Margot at 651-292-2920 and she will run a check on it. Non-certified persons who park in disability spaces can be fined up to \$200. It is estimated that 20% of disabilities are non-visible. If you are a passenger in a vehicle and not going into a building or store, you should park in a regular parking space and leave the handicapped space for someone who needs it. A quarter million certificates have been issued and thirty thousand license plates. You may apply for a certificate or license plate at: MN Dept of Public Safety, Driver and Vehicle Services Division, 445 Minnesota Street, Suite 164, St. Paul, MN 55101 (651) 297-3377 or a Deputy Registrar's Of-

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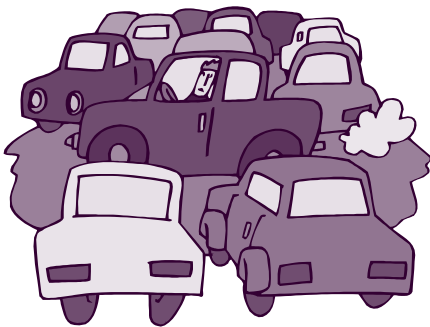
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fice.

The number of handicapped parking spaces in a lot is determined by the type of business. At a grocery store or other shopping area, 4% of the spaces should be accessible, medical or rehabilitation facility should have 10%, and residential should have 1%. Van accessible spaces must have an access aisle that is at least eight-feet wide. But don't expect



people to pay attention to this, I get hemmed in frequently with my van, no room to put the ramp down, even though there is a sign on my window that says "Please park 8 feet away". Sometimes they even park on the yellow lines. Accessible spaces for cars must have an access aisle that is at least five-feet wide.

Government buildings are required to have automatic door openers. Private businesses are required to remove physical barriers that are readily achievable, those easily accomplished without much difficulty or expense. Their goods and services should be accessible for people with disabilities.

The Air Carrier Access Act requires that airlines provide special seating to persons with disabilities.

Margot emphasized that we must

know our rights and "be in their face" about demanding what we need.

The time went far too quickly with so many subjects to cover and an abundance of questions so Margot will return for our December meeting.

"Whatever Works", was the theme of our October meeting and it is always interesting to see what implements people can devise to make daily living easier for them, some humorous but practical. Most of us with limited mobility have reachers to help us pick up items from the floor or grab an item from the cupboard, hang up or take down clothes but have you ever seen one that folds in half so you can carry it with you at all times, a little pricey but worth it for the convenience. One member keeps long kitchen tongs in every room of her house to always have one available. It might be a good idea to keep a basket handy next to your chair with small items you might need such as scissor, pencil, tablet, cell phone etc.

"Screwy Louies" (the round rubber hand gripper) or a strap wrench to help loosen jar covers or other objects too tough to move with weak hands or fingers. Hand and wrist supports give stability and strength to a weak wrist. Adding vinyl repair glue to the rubber sole of your shoe at the toe end might keep you from tripping. Nordstrom's Department Store allows a customer with two different sized feet to purchase two pair of shoes for the price of one. The rubbery shelf liner that can be purchased in most stores makes a good base for holding bowls or

other items in place. If you have trouble closing a door behind you, you can attach a cord with a large ring on the end to grip and pull it behind you. If you have people who regularly come to visit you and it is not always convenient to open the door for them, you can have a keypad attached that allows them to punch in the code and enter. An electronic clock performs the same duty. A theater in Moundsview gives free admittance to disabled persons.

One member that enjoys gardening is getting a battery powered wheelbarrow to help her move dirt, plants, and supplies around her yard. If anyone is interested in this unique tool, it can be purchased from a catalog called The Front Gate. Offset hinges can be used on a door frame to widen the door. Sister Kenny has a store where many assistive devices can be purchased and there are also many medical catalogs carrying these items, also Sears or J.C. Penney have catalogs. Hope these little tidbits of information have helped you think of something that might be of use to you.

Walking - Is It All It's Cracked Up To Be

Larry Kohout would like all of us to give him a sentence, a paragraph or a page on "Walking - Is It All It's Cracked Up To Be?" There are those who put great stock in the ability to walk, here is your chance to weigh-in on the subject—one way or the other. Contact Larry with your thoughts: 952 835-9714 or via the internet at lkohout@mn.rr.com. Your ideas will end up in an article and your name will appear only if you want it to.

Coming Meeting Dates

Brainerd/Baxter Chapter

Nov Meeting Nov 3rd - We will be meeting at Perkins at 11:30, on the first Monday of the month.

Dec Meeting Dec 1st - We will have our Christmas party at Godfathers on the first Monday of December at 6:00 p.m. Spouses are very much welcomed. We will have a \$5.00 dollar gift exchange, with men giving to men and woman giving to woman. Also we will bring gifts to give to the Women's Shelter. We have given to them for the last two years and they really appreciate it. Nedra Torfin has a list of their needs.

St. Cloud Chapter

Nov Meeting Nov 7th - Meeting from 10:30 - 12:00 Unfortunately, our planned speaker has had a change of plans and can't be with us, but we are planning an informal discussion meeting.

Dec Meeting Dec 5th - Meeting from 10:30 - 12:00 We will be having an early Christmas party, again with an informal discussion.

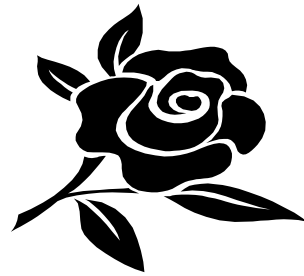
West Metro Chapter

Nov Meeting Nov 8th - Will be party time again as November is the month that we choose to celebrate all of the holidays in one big party. There will be no Monday meeting at the library in November; instead we will be meeting at the Olive Garden Restaurant in Brooklyn Center. The Address is 1601 James Circle North. Brooklyn Center, MN 55430. This is just a few blocks north and west of the intersection of Inter State 694 and Highway 100. The meet-

In Memory Of Karen Lee Ulmen

1964 - 2003

By her father, Tom Ulmen



ing is on the second Saturday at 1:00 p.m. All members of the group as well as spouses, caretakers, friends, and those you find along the way are all welcome. If you have not signed up and would like to make a reservation, please call Maxine Bremer at 952-939-0441.

Dec Meeting Dec 8th - After the big party month we will once again be back at the library. Margo Imdieke Cross will return for our December meeting to continue her discussion on accessibility and our rights. If You have some specific questions please contact Judy Baxley so she can coordinate them with Margo. You can reach Judy at 952 953-4432 or via the Internet at jude-mail@usfamily.net.

Dr. Henry Writes About Antidepressant Medications

By Henry Holland M.D.

Published by permission of Dr. Holland. This article was retrieved from the Library at the Lincolnshire Post-Polio Network at <http://www.ott.zynet.co.uk/polio/lincolnshire/library.html>

I am a little surprised at the concern about the use of antidepressant medications in the treatment of PPS. It rings of the ongoing stigma against individuals who suffer from so called mental illness. I have spent 37 years studying, researching, and treating mental illness. I have a significant family member who

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spent 20 years in a state mental hospital. When I first began my psychiatric training 31 years ago, schizophrenia was considered a mental illness with probable psychogenic causes. There was even a term used then, namely the schizophrenogenic mother. Today, we know clearly that schizophrenia is a biological brain disease involving disturbances of certain brain biochemicals affecting cognitive and perceptive function. There are changes on MRIs and probable genetic factors or predispositions. The same can be said of bipolar disorder (manic depressive illness) and major depression. Some studies indicate that over one third of PPSers before being diagnosed or shortly thereafter meet the criteria for the diagnosis of major depression.

The "boundary" between so called mental illness and physical illness is quite vague and may not exist. The very fact that many medications such as the various types of antidepressant drugs help us and many other individuals with chronic or reoccurring disorders should tell us logically that so called mental illness has definite biological factors and vice versa, that is, a condition such as PPS has definite emotional factors. I know what I have experienced. I have experienced loss of functional status, having to accept disability at a time that I would be at the zenith of my career, fear of what is happening to me and not knowing what really helps except rest, the logical anxiety that this PPS is progressive, and to hear or read that we are all going through this again (deja vu) and

the whole experience seems unfair and makes me angry. That anger can get projected when we have our feuds, bash our doctors, and assail various agencies. Don't get me wrong, most of the time our complaints have some merit, and we mostly support each other, but we have been individualists and in control so long that these life style adjustments are tough and can be depressing.

Everyone who has ever lost someone precious or lost a part of their self-esteem or been ill with a chronic disorder knows what depression is like. We take antidepressants and other psychotropic or brain directed drugs because they help some of us. True, the doses are usually lower than for treating most biological depression in people without PPS. But we do not tolerate most any drug or stress very well. We require less pain meds and even less anesthesia than most. Maybe the antidepressant drugs do help our "depression" in lower doses. I simply do not know, but it would not bother me in the least if they do work that way on us. I feel better and when you feel better, you are usually less depressed.

So if you take Prozac, Paxil, Zoloft, Elavil, Pamelor, Effexor, Klonopin, Ativan, Valium, Xanax, Ambien, Desyrel, Wellbutrin, and on and on, and you feel better, I say be grateful because I am.

I have said enough.

Henry Holland, Richmond, Virginia, USA. Henry4FDR@aol.com

One Psychologist's Perspective on the Experience of Polio

Part 9

By Margy Hull Ph.D.

This article was first published in the spring of 1997.

I embark with trepidation upon my voyage of exploration of this month's coping mechanism, *humor*. I am, I confess, one of that distinct minority of people who enjoy analyzing why something is funny. I know that the right brain, the real expert in humor, rolls its eyes at the humdrum logical analysis of the left brain and asks why we have to ruin a good thing. Therefore I promise not to analyze any particular jokes, but only to try to figure out why we love humor so, why it is so good for us, and how we can use it in our coping with the experience of polio.

It amazes me how young we humans learn to laugh at things. Is there anything as deliciously infectious as the belly laugh of a baby? Robert Ornstein and David Sobel in their book *Healthy Pleasures* see laughter and humor as usually arising from the "sudden perception of incongruity between what we expect and what we see." Could it be that the sophisticated humor of Seinfeld, Cosby, and Ellen are just slightly more complex variants of peekaboo and flinging one's spoon from the highchair? From cradle to grave, we love the life of the party and who can resist listening when someone says,

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One Psychologist's Perspective

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“Did you hear the one about...?”

Ornstein and Sobel describe the results of scientific studies which show what laughter does to our bodies, proving that we love to laugh for a good reason. After an initial heightening in arousal and alertness, there is a release of endorphins that lowers blood pressure and promotes a state of

“Did you hear the one about...?”

well being and relaxation. Our immune systems are stronger after a hearty laugh; we are less likely to feel pain and we feel it less intensely.

What else does humor do to deserve its standing as one of the best coping mechanisms? One quality it has when used well is that of breaking down walls of separation between us. Jokes are always funnier when shared. The fact that the other “gets it” immediately creates a common bond, a fellow feeling that improves whatever task we are engaged in together. Humor is an equalizer that tends to erode status distinctions and adversarial relationships. I would bet that Clinton, Dole, and Gingrich would have never come to an agreement on last year's budget were they not all pretty sharp in

the humor department; I would love to have heard some of their repartee in that room.

For those of us with polio, this ability to break down walls is helpful in several different ways. When I was a child and first ill, I stayed in a ward with about ten other “patients” (I use the term loosely because patient they weren't) who ranged in age from 6 to 60, both sexes, from varying cultural and educational backgrounds. Wisecracks permeated all conversation on that ward, and I see now that it was a key factor in helping us overcome the inevitable tensions created by our differentness. For those of us who look different because of our disability, humor breaks the ice of strangeness and reminds others we are just people after all. Being disabled has brought me into rather intimate contact with all sorts of people I might otherwise have had little to no contact with, from cab drivers to home health aides to people working in the backs of restaurants (I'm thinking of the many people through the years who have led me through the trash cans to get to the freight elevator). Humor is a universal language that enriched those experiences making them memorable, even treasured.

Another quality of humor comes from its origin in the right brain, which delights in the fresh perspective of incongruity. When combined with self observation, humor lovingly brings us up short and points the way to alternatives in ways of doing things and relating to others, of explaining things about them or ourselves that we otherwise would

find unacceptable. Being on the look out for something to laugh at keeps us kind of loose and spontaneous, ready to see the back scratcher's potential for turning on the light or our misplaced dignity as a foolish barrier to barbecued chicken at picnics.

Finally humor, the kind that is laughing *with* rather than *at*, can be a way of expressing negative emotions while sustaining the common bond of friendship. I realize now that much of the humor of that ward from long ago was fueled by rage at fate and fear of the future. It was also the safest way to let assorted doctors, nurses, and therapists know when their ministrations were in some way wanting. It had a lot to do with getting us through those hard times as it does to this day.

Next time anticipate the coping mechanism of anticipation.

Margy Hull Ph.D. is a Psychologist who formerly worked in a community mental health center in Atlantic County,

What to Do With 3 1/2 Left Over Inches

Two peanuts walk into a bar. One was a salted.

A sandwich walks into a bar. The barman says, "Sorry, we don't serve food in here."

A mushroom walks into a bar. The barman says, "Sorry, we don't serve food in here." The mushroom asks, "Why not? I'm a fungi."

A dyslexic man walks into a bra.

Polio Biology

VIII - Post-Polio Pathogenesis

By Eddie Bollenbach M.S.

Editor's Note—This Series was originally written for and published in the Lincolnshire Post Polio Library. It is republished here by Eddie's kind permission. This is the eighth in the series

There are words we use to describe aspects of pathology, which means the study of disease. Often, when we look for a clue to unlock a mystery like Post-Polio Syndrome we neglect the words invented by epidemiologists and get confused about what we are truly seeking. Let me give you an example of what I'm getting at. Everyone with the debilitating and uncomfortable fatigue of Post-Polio Syndrome eventually asks the question: "what is **causing** this?" When they find out they have PPS they may obsess about the **cause**. When you talk to people they will tell you PPS is caused by the overwork of already over-burdened muscles. Or some may say it is caused by aging of a damaged neuromuscular system (this really doesn't tell us much --- muscles or nerves? --- how is the aging manifesting itself to **cause** [that word again] damage)? Some are beginning to say that PPS is **caused** by latent viral particles inside cells of the central nervous system.

Ever since the writings of Copernicus we, in the Western Hemisphere, have used reductionism in our thinking to the extent that we think problems must always have a single cause. So we say this, not that. And we seek until we find a single simple explanation.

Nothing but a single understandable cause, it seems, will relieve the nagging uncertainty about what is going on inside our bodies. I don't think things are this simple, especially inside the nervous system.

Let's get back to the words that epidemiologists use to clarify aspects of disease. First, there is the etiology of a disease. Etiology means cause. When we are asking what is the cause we are really asking for the etiology. The etiology could be very simple: "People who overuse muscles enervated by giant motor units (one nerve cell with multiple fibers) will over tax those nerves and the nerves will die". This is the most common idea for an etiology of PPS right now. Another epidemiologist's word, which is a bit more complex in its meaning, is pathogenesis. The pathogenesis of a disease is the mechanism, or steps which occur in the disease manifesting itself. This can be very complicated.

We have found, recently, that motor nerve cells infected with polio virus do not die the way we thought they did. We thought that if a neuron was infected with polio virus the virus multiplied inside the cell and lysed it. The infected cells were always killed in this lytic model. This is one reason why many medical doctors think that once an individual recovers from acute polio it is clear sailing for life. Now we know differently. Many infected cells did die because the cell itself, not the virus, proceeded through a series of programmed steps toward its own death and disintegration. This programmed cell death occurs after certain cell

structures have been damaged and appears to be an evolutionary adaptation that removes cells which have no chance of normal function. The process is called apoptosis. Many polio infected cells underwent apoptosis and not lysis. The significance of this is that many cells that were infected did not apoptose and consequently trapped viral particles inside. Pathogenic organisms that live inside cells have a neat adaptation. They evade the immune system by being safely tucked away where immune processes cannot remediate. Add to this the blood brain barrier and you have an ideally insulated hideaway. The blood brain barrier consists of extremely tight junctions between capillary cells nourishing the brain and spinal cord. Because of it many drugs can't even get into the brain and this has been a problem in medical intervention for tumors and other disorders of the central nervous system. But I digress.

There are other pathogens which elude immune attack by living inside cells. The tubercule bacillus is one of them. Now also, with polio, we have detected unquestionable signatures of the virus in a little more than half of those studied who have PPS but we find no virus in people who have had paralytic polio without late effects.[1] What are the role of these polio viruses in PPS? Are they etiological or are they a part of the pathogenesis of this disease? I think right now there is a consensus building that they may be a part of the pathogenesis of Post-Polio Syndrome.

What results in their release? It is

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Polio Biology VIII - Post-Polio Pathogenesis

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likely that cells are suddenly undergoing apoptosis many years after acute polio. Why? Overuse? Immune attack? Age? Each answer leads to a new question. And it seems we've arrived where we started, looking for causes. One thing is for sure: we will find many steps in the pathogenesis of PPS along the way toward understanding an etiology.

References.

1. J Neurol 1999 Jun;246 (6):472-6, Postpolio syndrome: poliovirus persistence is involved in the pathogenesis., Julien J, Leparc-Goffart I, Lina B, Fuchs F, Foray S, Janatova I, Aymard M, Koppecka H.

Editor's Note

I had planned on doing an article regarding Cold Intolerance after talking with Bill Eddy following an experience Bill had in the hospital. As I recall it, Bill had been taken on a gurney to the surgery suite where he had to wait for an extended period. He got very chilled and could not get warm again in spite of the fact that nurses brought him extra blankets.

This is what some polio survivors experience as cold intolerance. When I heard that Linda Wheeler Donahue had written this article I jumped at the chance to publish it in our newsletter. Thank you Linda for granting us permission to print these articles.

Cold Intolerance: Why is this a Problem for Many of Us?

By Linda Wheeler Donahue

Cold intolerance is one of the more bothersome physical discomforts associated with post-polio syndrome. Why do we feel cold more than people who did not have polio do? This may be a question you have wondered about. I would like to share what some leading polio authorities tell us about why we have the difficulty of cold intolerance. Then I would like to explore some practical suggestions to help you obviate this problem.

Fortunately, the major polio physicians and researchers are quite consistent in their appraisal of this issue. Let's take a look at what they have to say.

Dr. Julie K. Silver, Director of the International Rehabilitation Center for Polio in Framingham, Massachusetts, explains that polio survivors' sensitivity to cold is due to atrophied muscles that do not contract adequately, and are therefore unable to assist blood vessels in bringing warming blood to the extremities.

Dr. Richard R. Owen, Emeritus Medical Director of the Sister Kenney Institute, is one of the first experts to describe "polio feet"; in fact, he coined that phrase. People who had polio often have blue, red, or violet feet. Part of the explanation for our colorful tootsies is that the poliovirus not only attacked our motor neurons, resulting in paralysis of our muscles, but also

attacked sympathetic nervous system neurons within the spinal cord. When it did that, we lost our ability to control the blood flow into our veins and arteries. When our veins are unable to contract, they become too open. Blood then "pools" in the feet, giving the skin a bluish tint and causing puffy swelling. Our "polio feet" get colder than the feet of someone who did not have polio, since our sympathetic neurons are damaged.

At the time of the original infection, the poliovirus damaged the sympathetic nerves, explains Dr. Lauro S. Halstead, pre-eminent polio author and director of the post-polio program at National Rehabilitation Hospital in Washington, DC. These nerves were part of the autonomic nervous system and their damage caused malfunctioning of the sympathetic nerves.

Dr. Richard Bruno, clinical psychophysicologist, noticed that the skin on the affected arm of his first polio patient was cold to the touch. This suggested a problem of blood flow to the limb. As Dr. Bruno studied more patients, he discovered the same thing. He deduced that the size of the polio survivor's skin blood vessels could not be regulated properly because the poliovirus killed off the sympathetic neurons in the spinal cord. These are the ones responsible for making the muscles around blood vessels contract.

People who did not have polio may also experience coldness, but Dr. Silver explains that we polio survivors feel this unpleasant

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ant sensation even indoors in a warm room. This sets us apart from others. We are often cold even at room temperature because those peripheral nerves that supply the muscles surrounding our blood vessels were damaged when we contracted polio. These small muscles play a major role in warming the extremities.

What can we do to keep warm? Our polio experts all agree on this. The management of cold intolerance is largely symptomatic, that is, all we can do is treat the symptoms. There is no known cure.

How do we treat the symptoms? There are a number of easy lifestyle adjustments you can make. One of the most important things you can do is to stay warm from the moment you wake up in the morning. Your body will be warm and snug at that time of the day. So hold on to your body heat with warm socks and layers of clothing. Three thin layers will keep you warmer than one thick layer.

Go to a camping store and purchase clothing made of polypropylene. Polypropylene is comprised of a thin plastic film woven into a soft fiber and is excellent at insulating your skin from the cold. Outdoorsmen have known of its warming properties for years. It is sold under various brand names such as Thinsulate and Gore-Tex.

Skiers and outdoor enthusiasts use a resourceful clothing technique called layering. This is an efficient way to stay warm and comfortable in cold weather by protecting and preserving your

core body temperature. One of the advantages of layering is that you can add or remove clothing to adjust to changing conditions.

Here is how layering works. The first layer is the thermal base layer. The fabrics used for this layer are generally stretch knits, often made of synthetic fibers. They are typically lightweight, machine washable, and fast drying. Special occasions sometimes present a warmth-dilemma for women. I recommend silk as a first layer. Silk is non-bulky with a luxurious feel and impressive thermal properties. It is light enough to be undetectable beneath blouses or slacks, yet insulating enough to provide that extra layer of warmth. With a thin silk layer worn as an undershirt, ladies will look trim even in evening clothes. Fancy dress situations no longer have to mean women are freezing!

The second layer is called the mid layer. This is a thicker, cozy layer that really locks warmth in next to your body. Fleece, in various thicknesses, is an excellent mid layer insulator. My favorites are Polarfleece 100 and Polarfleece 200. This space age fabric brings comforting warmth, softness, and lightness. The characteristics of warmth and lightweight are particularly important to polio survivors. We need warmth yet our bodies cannot tolerate dragging around excess weight in the form of heavy clothing. Polarfleece offers a dynamic warmth-to-weight ratio, compared to traditional fabrics. Its tiny springy fibers create multiple air cells to trap warmth inside. This feature provides excellent protection from the cold.

Since it does not retain moisture and facilitates evaporation, the fabric remains dry and comfortable. If there is no Polarfleece in your closet, I suggest you head out on a shopping trip. You can shop either in a brick and mortar building or in cyberspace. My suggestions of some good e-commerce sites follow.

The third layer is referred to as the shell layer. This layer must be breathable for the layering system to function. If it is not breathable, condensation will form causing chilling. The top layer, or shell, is often windproof and waterproof. It should be loose fitting to allow for movement. Polarfleece 300 as your third layer will keep you warm no matter what Mother Nature delivers.

It is wise to even layer your socks. Sock liners made of polypropylene are superior heat retainers. They are designed to be worn as a base layer under athletic socks. You may want to try battery operated heated socks. I did not have luck with them as they had uncomfortable seams and hot spots, but they may work for you.

Remember, your entire body must be insulated in order to stay warm, especially in bitterly cold weather. So do not neglect your neck region. Wear a turtleneck style top to warm that area. In addition, do include a hat, mittens or gloves, warm socks, and a scarf when you venture out of doors.

At the GINI Conference in June of 2000, I purchased a fantastic product from one of the many

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Cold Intolerance: Why is this a Problem for Many of Us?

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vendors there. These were grain-filled, heat-activated booties. You place them in the microwave for 3 minutes, then put them on and savor the rejuvenating deep heat for over 20 minutes of warmth. I have since seen these in various home health mail order catalogs.

Many of us PPSers spend most of our time indoors, but we still have trouble staying warm. I suggest that throughout the day you take several breaks from your daily activities. Sit in your favorite chair or recliner with your feet elevated as high as possible. I have an old twin size electric heating blanket draped on my recliner ready to warm me up like nothing else. If you do not need that large a covering, try using a warm heating pad and a cozy lap blanket as you rest and enjoy the feeling of your extremities warming up to a comfortable temperature. When your muscles are warm, you not only feel better, but you also move and function with more ease and efficiency.

Many of us suffer with the uncomfortable sensation of feeling cold. The foremost polio physicians offer a clear explanation for why this happens. The good news is that we can make lifestyle changes to remediate this troubling post-polio problem.

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Some Online Resources For Warm Clothing

By Linda Wheeler Donahue

Perhaps you would like to purchase some warm performance clothing but it may be too difficult to get out to a mall. If you have Internet access, a solution to consider is web commerce. Below is a list of some fine online merchants where you will find good insulating clothing. This merchandise is geared to climbing, mountaineering, and other outdoor sports, with features and fabrics ready to meet the harshest of winter mountain conditions. ***How perfect for polio survivors!***

L. L. Bean	http://www.llbean.com/
Campmor	http://www.campmor.com/
Diabetic and Comfort Socks	http://www.
Eastern Mountain Sports	https://www.ems.com/
Lands End	http://www.landsend.com/cd/
Outdoor Clothing Online	http://outdoorclothingonline.com/
Outdoor Recreation	http://www.outrec.com/
Recreational Equipment, Inc.	http://www.rei.com/
Sierra Trading Post	http://www.sierratradingpost.com/
Sock Company	http://www.sockcompany.com/
Winter Silks	http://www.wintersilks.com/

Cold Intolerance Polio Survivors Share First Person Accounts

By Linda Wheeler Donahue

I asked my post-polio friends how they deal with cold intolerance. Here are the responses from twenty-nine polio survivors sharing their favorite solutions and secrets.

I use electric heating pads over my knees and at my back when sleeping in bed or sitting in my recliner. If I get chilled, it takes me many hours to warm up again.

Hot baths work for me. After my bath, I put on warm hunter's socks and jump into bed.

I use several layers of flannel blankets and wear long-sleeved pajamas and heavy socks to bed. My side of the bed also has an electric throw.

In winter I wear long-sleeved, lightweight undershirts called "Cuddleduds" under long-sleeved knit shirts. When it is particularly cold, I add Cuddleduds long johns.

An electric warming mattress pad heats up my bed much better than an electric blanket. Having the heat source underneath, works best for me.

I have blue/purple feet much of the time. My polio leg gets cold from the knee down to the foot, while my other leg is warm.

Electric heating pads are scat-

tered all around my house. So wherever I am, I can warm myself up. My hands, neck, and knees give me the most problem with being cold. Applying the hot heating pad to the cold spot for a short time is the most workable and effective for me.

My body heats more rapidly in hot weather; and cools more rapidly in cold weather.

Small Polarfleece mini-blankets are very helpful. All the major discount stores sell them for about \$10.00. I bought several and even color coordinated them with my rooms, so they fit in with my décor while keeping me warm.

I wear dancers' leg warmers. Because they are loosely knit, they do not restrict my circulation. I sew the ends of the warmers shut to create long socks and I wear them all night in bed. The only way I can get warmed up and stay that way is to use electric powered heat. I use an electric throw and a small portable electric space heater directed right at my feet.

Hot paraffin wax works for me. I dip my foot into the wax and it feels absolutely wonderful.

My Sunbeam heated throw, model # 71460, 20% polyester - 80% acrylic, is my best friend.

When it is really cold and snowy, my feet, legs, and hands suffer. I then have trouble with function of my hands and legs and I experience a steady cramping feeling.

Hot showers work for me. I also use herb filled packs on my feet and hands. These are pads filled

with rice and various herbs. You toss them in the microwave to heat up.

I get cold all-over, but it is much worse from my knees down.

My home is filled with large bath towels, small throws, and knitted ponchos on all the furniture. I use these to toss over my knees and legs.

We use a down-filled comforter. Since I cannot tolerate any weight on my feet, the down comforter keeps me warm while being lightweight.

In the past few years, my feet and hands get cold even at room temperature. My daily routine is to bathe in the morning, after which my body is warm for hours. When this effect wears off, my left leg and the rest of my body gradually cool down.

I wear knit leg warmers on top of my jeans.

Since I don't want to turn the furnace up too high, I find that using a rice bag really helps. It is made of cotton material, sewn into a square shape, and filled with rice through an open corner, and then sealed up. After three minutes in the microwave, the bag stays heated for up to 30 minutes of soothing warmth.

My left foot turns bluish when it gets cold. An hour after my warm bath, I can feel my left foot starting to cool. It is a very strange feeling because my right foot feels a bit too warm and the left gets ice cold.

I wear socks to bed and place an afghan over my lower legs. In

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Cold Intolerance Polio Survivors Share First Person Accounts

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extremely cold weather, I also use an electric blanket.

Velour blankets (brand name is Vellux) are great. They are lightweight and very warm and cuddly.

I purchased several Sunbeam heated throws at Wal-Mart for \$15.00 on clearance. Previously I used a twin size electric blanket but it was too large to use sitting in a chair.



The throws are a perfect size of 50" x 60". I take these throws on car trips and even to the hospital when I go.

Cold has troubled me all of my life. When my right hand gets too cold, it becomes weak and hard to straighten out my fingers.

Sheet blankets as both the bottom sheet and the top sheet keep me warm. They are not as shockingly cold as regular sheets.

I always have cold legs! I wear leggings under my slacks almost all year long. If I can keep my knees warm, I feel better.

Many a night I have actually wished there was a nurse here to wrap my legs in those smelly, steamy, hot packs again.

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GINI Is Not GINI Anymore—Now It's Post-Polio Health International (PHI)

By Larry Kohout

I've written about GINI in the past. I think it is the finest publisher of information on polio and post-polio syndrome in existence today. They should be. They are a fully-funded, professional organization. They didn't start out as GINI either, but as International Iron Lung Polio Assistance, Inc. GINI has had a number of other names and is now known as PHI. "We decided to focus on the future – knowing that our founder, Ginni Laurie, would have agreed." said Fredrick M. Maynard, M D, Board President.

While the majority of the people it serves are polio survivors, PHI has served, and will continue to serve, the needs of all ventilator users through its affiliate, International Ventilator Users Network. "The Board undertook a strategic planning process to determine how our organization could more effectively meet the needs of the people we serve." said Maynard. In the process, they took into consideration survey feedback from subscribers, website visitors, sponsors, donors, and healthcare professionals.

The result is a refocused and re-named organization along with their newsletters. *Post-Polio Health* replaces *Polio Network News*, *Ventilator Assisted Living* replaces *IVUN News*, and future issues will be expanded with new formats and carrying more news. *Rehabilitation Gazette* will be

discontinued with the appropriate cross-disability information being put into the other newsletters.

GINI newsletters have been a tremendous source of information to myself and my colleagues editing other PPS newsletters around the globe. PHI recognizes this relationship and is seeking to enhance it by identifying and developing additional organizations and individuals with compatible goals and philosophies to further their mission. What is the mission? "To enhance the lives and independence of polio survivors and home mechanical ventilator users by promoting education, networking, and advocacy among these individuals and healthcare providers."

How do you become a member of PHI? Send your name, complete address, phone number, and email address (if applicable) to Post-Polio Health International, 4207 Lindell Blvd., #110, St. Louis, MO. 63108-2915 U.S.A. or FAX to 314 534-5070.

Membership forms are available upon request. The following is a brief highlight of membership levels. Supporter - \$15 – Website access, Subscriber - \$25 – above plus either quarterly newsletter, Subscriber Plus - \$45 – both quarterly newsletters, Contributor - \$75 – all of the above plus *Post-Polio Directory* and *Resource Directory for Ventilator Assisted Living* + discounts on special publications and sponsored meetings, Sustainer - \$125 – all of the above plus one complimentary subscriber gift-membership for a designated person who has expressed financial need to PHI.

First AGM Now History

By Larry Kohout

As one member of the Executive Committee, I am proud to say that we have succeeded in putting together the first Annual General Meeting (AGM) of the PPASS MN membership. Was it a rousing success? That's not for me to say. However, I can say that I heard some pretty positive feedback. Our By Laws require an annual meeting of the membership. This is a time for you, the membership, to get a good look at what the leadership is doing with your organization, elect new officers, and say your peace about where you want to see the organization head in the future.

It is also an opportunity to hear from some of the leading names in the community of PPS medical professionals. This year we were very fortunate to have Dr. Richard Owen, Emeritus Director of the Sister Kenney Institute, to present the keynote address. We will have to strive hard to keep up this level of talent at future events.

Likewise, the AGM is an opportunity to meet polio survivors from around the state. Will the AGM always be held in the Twin Cities? No! Chapters from around the state will be given an opportunity to host the AGM, and that will give us all an opportunity to see the locales of all the various chapters.

This first AGM came together with some haste. There were a number of reasons for that. The primary reason was that we did-

n't really have a state organization until after July. The Executive Committee spent much of the early part of the year identifying existing support groups around the state and then finding out whether or not they would like to join PPASS MN. This required that we make several trips to meet with these groups.

Once we met with the groups and they decided that they wanted to be part of our efforts, we had to merge their membership roles with what we already had. Then, according to the By Laws, we had to send out membership forms.

When the By Laws were originated we wanted to make certain that everyone who wanted to be a member of the organization could be – without regard to their financial circumstances. Therefore, we decided that to be a member you would need to sign a form once a year.

Note

If you have not signed a membership form in 2003, you will not be getting a form for 2004. Your name will also be dropped from our lists at the end of this year and you will no longer receive any information from PPASS MN.

By the time that all of that had been completed, we had very little time to pull together the AGM. As a matter of fact, we were still processing membership forms at the same time we were processing registration forms for the AGM. Unfortunately, with so little time to publicize the AGM, we did not end up with a sufficient number of members to reach a quorum. Next year,

which will include elections for Chair and Vice Chair, we will have to have a quorum or we'll have to adjourn the meeting. This means that we'll need to have 50% of the membership – either in person or through their signed proxy – in order to conduct the meeting.

We are learning. We now have a functioning Advisory Committee to help with these details. The Advisory Committee is made up of one delegate from each chapter and functions to facilitate communication between the chapters and the Board of Directors. Further, the committee assists the Board in accomplishing the organizations programs. Their first project was the revision of the By Laws of the organization. These changes were presented at the AGM.

What else happened between Dr. Owen's talk and the changes to the By Laws? Well, our chair, Jane St. Onge, introduced the Board of Directors, the members of Advisory Committee, and the leaders of the various chapters. She then presented the Chair's report in which she discussed the two committees put together by the Board of Directors. The Fund Raising Committee and the Outreach Committee. While fund raising is straightforward and understandable, the Outreach Committee needs some explanation. This is the committee that identified and contacted the existing groups around the state. They will continue to work on identifying new areas where groups can be started.

Through the Outreach commit-

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First AGM Now History

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tee, we are creating a leadership-training program whose purpose will be to aid volunteers in organizing new chapters. The leaders, who were at the AGM, agreed to work with this committee in developing the material and benchmarking the program before we take it to the new leaders.

Following St. Onge, Treasure Dick Baumer delivered the Treasurer's report in which he gave us a summary of the Background, Fiscal Operation, Report Period, Balance Sheet, Sources of Revenue, Major Expenditures, Fundraising, and a Discussion of Capital Equipment. He then took questions about the organization's books. Baumer also asked for volunteers to serve on the Audit Committee at year's end. At the time of his report (9-18-03), there was a balance of \$2,158.83 in the treasury.

I have failed to mention that the festivities began with a lunch prepared by Brine's Market in Stillwater and we'd like to thank the Brine's for their generous discount. AGM participants were also provided with a booklet containing the PPASS MN Purpose Statement, Philosophy Statement, Mission Statement and a program of the day's activities. It also contained the text of the Chair's report, a PPASS MN history by historian Margy Hull, an Outreach Committee report, the Treasure's report, and the Secretary's report. This booklet was provided, free of charge, by Kinko's of Edina,

who also does our newsletter printing throughout the year.

I would also be remiss if I did not point out the spectacular facilities of the First Lutheran Church of White Bear Lake. We all owe a special thanks to our Chair and her husband for providing this totally accessible facility.

The Board of Directors is planning a review of the AGM at their November meeting, but we would also like to hear from you. Were you there? What did you like? What didn't you like? If you weren't there, was there something we could have done about that? Please let us know your thoughts. Both snail mail and email addresses are on the back cover of the newsletter. Now it is on to AGM 2004!

Metro Transit Options

By Larry Kohout

When leaving the West Metro Support Group meeting in October, I was blown away – not by the wind – but by the fact that fellow member Lois McIntyre was being tied down in the back of a cab. Well, let me say that again. McIntyre's wheelchair was being tied down in the back of a cab.

What's the deal? McIntyre had tried to arrange transport on Metro Mobility, and while they were able to get her to the meeting, they could not find her a ride back home. That meant, she was informed, that she could arrange her own transport and Metro Mobility would reimburse her – up to \$22.

She didn't know where to start. She was aware of the fantastic disability transportation options available in Las Vegas (that quiet grandmotherly appearance apparently hides things), but she didn't know anything existed here. Neither did I.

It turns out that there are four cab companies that can handle people in wheelchairs or scooters: Airport Taxi (952-928-0000), Rainbow Taxi Chair Cabs (612-332-1615), Town Taxi (612-331-8294), Yellow Cab (612-824-4000). McIntyre called around and ended up with Airport Taxi. Since all the drivers are independent contractors, I got a card from this driver – Darlette Knox (612-203-7276) – whose card reads "Airport Platinum Service."

McIntyre would agree with that. Knox asked her for a route recommendation from the Edina Library to her West St. Paul home. She reported that the ride was pleasant and followed the most efficient route, and she was escorted inside her building at the end of the trip.

What about the cost? The cost is exactly the same as the cost of any cab ride. So, what was the cost? The one-way ride was \$33.00 or \$11.00 after the Metro Mobility rebate. McIntyre figures that after all the free rides she has gotten because of late Metro Mobility rides, this was pretty much a wash. It was also on time, very comfortable, and very courteous.

So there are alternatives – but first you must get Metro Mobility to deny you a ride and if you are lucky enough to live within a \$22.00 cab ride – it's free.

Polio Particles

By Mary Westbrook

Editors Note: this article is reprinted with permission from POST—POLIO NETWORK (NSW) INC. and the author. *Polio particles is compiled by Mary Westbrook as items in the press or professional journals catcher her eye. Mary's series is now been syndicated around the world as other post-polio newsletter editors picked up on the interesting items Mary includes. Mary can be reached at: MTWestbrook@bigpond.com*

New Australian memorials to Sister Kenny

Two memorials honoring Sister Kenny marked the 50th anniversary of her death in November 2002. The University of Southern Queensland announced the establishment of the Sister Elizabeth Kenny Professorial Chair of Rural and Remote Health and the appointment of the inaugural holder of the Chair, Professor De-

sley Hegney. In Nobby (where Kenny is buried) a mural was unveiled at the Kenny memorial museum which was opened in 1997. The glass mural shows Kenny holding the hands of two children (showing no signs of disability) as they face the sunrise. At the same time a miniature model of the Sylvia stretcher was placed on view in the museum. Kenny made the original stretcher from a door to transport a young Nobby girl to hospital following a farm accident. A restored brass bed from Kenny's house was donated to the museum and four palm trees were planted; one by Kenny's adopted daughter.

Penalty for speeding wheelchairs

Valley College in Los Angeles has imposed a campus speed limit of 4 miles per hour on wheelchairs. People caught speeding may be

expelled. No wheelchair collisions have been reported at the college but the vice-president of administration pushed for the policy after seeing a wheelchair user going *very fast*. *'It's like a bad joke,' said 56 year old Lynn Eiler, 'We figured they've got to be kidding that we might be a danger to somebody. In fact we have to watch out for everybody else' (New Mobility, January 2003).*The Center for Individual Freedom (www.cfif.org) discusses the situation in its column, Jester's Courtroom. *We're curious to see how Valley College administrators plan to enforce this new 'safety' measure. Will student fees be used install radar cameras? Better yet, Jester's Courtroom readers stay tuned as some trial lawyer somewhere has got to be scheming up an argument to slap on Valley College—maybe the tried and true Americans with Disability Act.*

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Disclaimer—

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PPASS Times

Newsletter of the Post Polio Awareness
& Support Society of Minnesota

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