

POLIO

PERSPECTIVES

VOL 27 NO 3 FALL 2012

Promoting Understanding Though the Michigan Polio Network, Inc Since 1986

FRANK LEE, FOUNDER & FIRST EDITOR OF THE POLIO PERSPECTIVES NEWSLETTER & MPN LEGEND

Frank Lee passed away on September 21, 2012 with cherished friend, Connie Breitbeil, by his side. Frank leaves behind daughter Connie, granddaughter Gabrielle and grandson Jacob in Michigan as well as brothers, sisters and extended family in Kentucky & Tennessee. He happily left his c-pap, oxygen tanks, wardrobe of wheelchairs, and an army of pillows.



April 13,1943 - Sept. 21,2012

Frank came to the First Statewide Post Polio Conference in 1985 at the invitation of Charlene Bozarth. Back then, he alternated between crutches and a wheelchair. On his blog, frankieeeee.wordpress.com, Frank speaks of his

severe depression when his ability to maintain a successful career as a journalist disappeared as his body failed him. " I thought all hope of any hope for my life was gone. A career down the tubes... A body quickly following suit... But Janice and Charlene, then-president of MPN, pumped and punched and pounded and pled until I started breathing again. Very Slowly at first..." "We need a newsletter, boy; can you put one together for us?" Yes, he did. We needed a journalist; God sent us our own Hemingway. We have reaped the benefits ever since. Thank you, Frank Lee with all our hearts. *(more of Frank on page 2)*

POLIO PERSPECTIVES NEWSLETTER
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Frank Lee story continued...

Frank moved to Cincinnati in 1995. He and Connie B. made a name for themselves on the scrabble circuit; both are nationally ranked. Frank passionately followed the trail of blues festivals around the countryside. As traveling became limited, there was always Scrabble. "The Lunch Bunch," immortalized in Frank's blog, combined "Scrabble (copyright 'til you die)" and gastronomical adventures around Cincinnati; and most recently brought food and Scrabble to Frank & Connie's apartment.

Ever the chronicler of our life experiences, Frank's induction into "the elite of the Cincinnati Hospice program" inspired him to send "death letters" to old and new friends, relatives and others to try to tell folks why they've been special in his life. My husband, Roger, and I each received unique letters.

February 16, 2012 from Frank Lee: "Dear Roger, I'm on my way, looks like, my friend. They put me in hospice care two months ago. Once my lungs & my heart calmed down a bit, I hit upon the idea of these "death" letters. A kind of summing up and a final thank you..."

February 16, 2012 from Frank Lee: "Dear Janice, Once more down the track and again... Until we rest our weary bones and, perhaps, release our world-weary souls from their earthbound chains.

...Hospice: Don't know whether it will kill me with kindness & pain killer, but it certainly has spurred me to pack for the trip. ...The [polio] support group, in my opinion, saved me time and again. For awhile, my life was truly going down for the third time when I reached the doors of the church. Thank goodness..."



Janice Gross, Frank Lee, and Roger Gross

Roger & I enjoyed our visit with Frank late in February (see photo). His poetic letters brought him many visits from friends and family. Again from Frank's blog, "This hospice stuff throws a lot of sand in the cogs of life. ...people have decided it's time for you to go, for them to work on making you comfortable and sliding you out wrapped up in sailcloth into the deepest, darkest, unknown space."

MICHIGAN LOAN CLOSETS

Hello. My name is Janice Selden. I have put together a website, MichiganLoanClosets.us <<http://michiganloanclosets.us/>> , that lists home medical equipment loaning programs and ramp programs. These are all free or low-cost. This website is freely accessible to anyone without charge.

The loan closets that are listed lend home medical equipment such as wheelchairs, walkers, canes, crutches and hospital beds for those in need. They are especially beneficial for those with limited or no income.

These services are usually free or at a very minimal fee.

The website lists programs by county, which allows viewers to quickly find the programs they need. Each organization has been contacted to make sure the information is correct.

Today we have over 175 programs listed in this directory. We will continue to add more organizations and edit existing programs when necessary to keep the information current.

From the Lansing Area Support Group

FROM THE CHAIR

By *Bruce Sachs*



I read recently that the average age of polio survivors, in the United States, was about 62.

Having been associated with many polio survivors I have come to realize that age is not as important as what we do with our years. Many of us have been retired for a while and although we are not able to do everything we used to do, we have found replacements.

I have expanded the amount I read and through my work with polio survivors I have been able to travel and have met many strong, inspiring, and positive people. I'm not sure where we get the strength, maybe it is a byproduct of having polio, but it is present at meetings of polio survivors.

We all need to keep up our social contacts, whether it is at a support group meeting, a senior center, a card or book club, etc. we need to continue interacting with people. In my State of the Network comments I stated that our Polio Library is a great source of material on polio and there are many books about polio and the experience of having polio. We continue to add new books, so keeping checking

www.michiganpolionetwork.com

Many of you have participated in our post-polio conferences in the past.

We are planning a conference for Saturday

October 5, 2013. at the Genesys Conference and Banquet Center in Grand Blanc, MI. (the same location as our 2011 conference) time to mark your calendar. We will start the program at 9:30 and finish by 3:00.

We plan to have 3 speakers, lunch and vendors will be included.

Registration information will be available in the Spring.

The MPN Board of Directors has changed their Board meeting site to Bakers of Milford, Milford, MI.

We hope you have a great holiday season and stay safe. Spring will be here soon.

Bruce, Chairman of MPN

NEW BOARD MEETING SITE

The Michigan Polio Network, Inc will now be holding its Board of Directors meetings at:

Bakers Of Milford,

2025 S Milford Rd, Milford Twp, MI

The MPN invites anyone who is interested to attend our meetings.

Our next meeting will be on November 17, 2012.

MICHIGAN POLIO NETWORK INC

Presents an

EDUCATIONAL POST-POLIO CONFERENCE

At the

GENESYS CONFERENCE & BANQUET CENTER

Grand Blanc, MI 48349

Saturday October 5, 2013

Conference hours 9:30am to 3:00pm

REGISTRATION INFORMATION WILL BE
AVAILABLE IN THE SPRING

HUMOR YOURSELF!

By Frank Lee

What we all need, especially the likes of us who are struggling to come to terms with polio's late effects, is a very generous dollop of belly laughs in our lives. That's the message from Lila Green, of Ann Arbor, a professional teacher of humor.

Her sense of humor is different from mine, but her advice is as sound as the dollar allegedly once was. Humor is something I've been doing for myself for several years. Everyday I look for some way to get a chuckle, and another, and yet another. A joke, a tease, a cartoon, a perverse reaction to an unintentional straight line someone has left suspended in midair. And somewhere along the way almost every day, regardless of how rotten the beginning was, I'm able to find the belly laugh, the delight I need to get jump started as a human being. My office wall is jam-packed with FAR SIDE cartoons, like the one where Mr monster is sitting at the dinner table talking to Ms. Monster as he's having his last cup of coffee. He looks at his watch. Then screeches with panic obviously growing in his voice, "Dang! It's almost six o'clock and I've got to be in Johnny Harrison's closet before dark!"

Lila Green says smiles and titters and laughs are good for us all. Doctors, hospitals, etc., could be improved by adding laughter to their treatment options. She suggests incorporating humor in all aspects of our lives. Fill bulletin boards with favorite cartoons. Change from force of habit to farce of habit. Look for funny movies. Look for things to smile at, to laugh at. I've found I can even, at times nowadays, laugh at myself.

Whatever its pathology, laughter works! If you haven't already, I strongly suggest you put it on your daily agenda. You could start off gradually to avoid traumatizing yourself if you've been bereft of this benefit before - say one good laugh a day for the first week, moving cautiously to two the second week and three the third. By the fourth week, you will have become sufficiently acclimated to allow for a dozen or more with no serious repercussions! *from Polio Perspectives Vol 5 No2 spring/summer 1990*



NOT JUST ANOTHER PIECE OF ADVICE!

By Frank Lee

Don't you wonder why, with all the sagacious advice we're getting on how to make our lives wonderful, we're not all happy, we can't stand ourselves? The theme recurred Friday night and Saturday at the annual meeting. Basically, it all boiled down to "more smile will make us feel better."

We cynics agree there are too many people in this advice-giving mode for the money with too little expertise and too little true concern for those of us who desperately need to raise ourselves by our emotional bootstraps. Sometimes we do find one who can offer keys to self-improvement, or in the case of Sean Hogan-Downey some insight, some gut-level truth for us to chew on and work with to help ourselves out of these hellholes of enduring misery. Some of the notes I jotted down during her discussion on Saturday morning:

Too many of us feel our bodies are dirty, that they should be covered, that they should not be touched and that we shouldn't talk about it.

Post-Polios have been told repeatedly, "Don't feel pain; don't talk about pain; work through pain." We Post-polios have suffered so much self-neglect that all we know is our impression of how we manage to ignore the pain and the exhaustion. Too many of us have tragically lost ourselves in that nonstop management of our impressions of ourselves. When someone asks us "How are you?" We almost never answer with truth but with, "Fine, how are you?"

Impression management.

In socialization our personality is something we do but don't talk about. It is time to change the tapes.

Continued next page...



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Another Piece of Advice *continued...*

Hogan-Downey says our self-image is the answer to the question of “Who are you?” which is the result of a lot of influences on our lives. It is the consensus response to multitudinous questions we must answer to ourselves about ourselves either as our own perceptions or as how we think others feel about us. Who am I allowed to be? Who can I fully be? What does society allow me to tell you about who I am.

One thing she said that caught my attention and which I am going to tape on the wall of my office is “When we refuse or spurn complements about ourselves offered by others, we are, in fact, insulting that person and writing off that person’s perceptions, telling him/her what she/he thinks is irrelevant.

Among the fallacies we allow to rule our lives is that self-worth is based on performance and when performance and/or pace is reduced, self-esteem is reduced. That self-image can be improved by restructuring our lives to mobilize our strength.

While most post-polios need to redesign our lifestyles, others around us may be ignorant or insensitive. Family members often go into denial when we make changes to adjust to our new situations because they don’t want to recognize our new limitations either; the pressure of that denial can force some of us back into unadaptive ways.

We should learn to recognize the difference between good days and bad days and adjust our lives accordingly. If it hasn’t risen above a “3” by noon, you’re not having a good day and you shouldn’t waste energy in a futile attempt to prove that it is!

Do you equate self-worth with what you do or with simply being?

The type A personality adapted by so many post-polios is absolutely a survival tool, but often things which help us survive during one period can be extremely damaging to us later in our lives.

Type A’s take downtime when they collapse. Type

B’s plan downtime. Type B’s plan a slower lifestyle. Type B’s think it’s okay to leave work unfinished at the end of the day.

You must BUCK society to get time for yourself. Type A’ism is a habit! Increase your awareness of yourself, your self-image. Change the way you talk to yourself. Give yourself some slack. Listen to how you speak to yourself. How often do you call yourself: “stupid”? “Idiot”? Get rid of that all-or-nothing thinking.

Reorder your time to give yourself time and energy for what’s truly important in your life.

If you have only a little energy and you spend it vacuuming, you’re nuts. Don’t spend all your energy on THINGS. Don’t ignore RELATIONSHIPS. Don’t worry ahead of time. People who worry are usually stuck in the past or the future and are not living the NOW.

But what about the family of a person with chronic illness? Members go through three stages: (1) they’re shattered “What are we going to lose?; (2) they’re disorganized; and (3) they become reorganized.

Some tools for coping:

- Family approach
- Get feedback on your perceptions
- Discuss
- Be flexible and tentative
- Develop thick skin “It’s okay to be angry.”
- Support systems
- Respite care
- Sense of humor helps

Set Realistic goals

Accept your limits

Unwind

Nurture yourself

Accomplish what is important to you

Let the candle burn at its own rate.

from Polio Perspectives Vol 5 No2 spring/summer 1990



Before Leaping To 10 Golds, Athlete Beat Polio

by Mike Pesca

Ray Ewry is an all-but-forgotten Olympic great from the early 1900s with a remarkable story. Before winning his 10th gold medal in 10 tries, Ewry accomplished something truly remarkable: He learned to walk again.

The debate over who is the greatest summer Olympian in U.S. history is relegated to a familiar list of names: Michael Phelps, Mark Spitz, Jim Thorpe, Carl Lewis, Jesse Owens, perhaps Jackie Joyner-Kersey. Then there's Ray Ewry, an all-but-forgotten Olympic great with a remarkable story. Ewry won his 10th gold medal in 10 tries by leaping, bounding and hopping to such heights and lengths that spectators were awed — but also dumbfounded— that a human being could perform such feats. In fact, the French dubbed him "L'Homme Grenouille," the "Frog Man." But before Ewry ever cleared that bar in Paris in 1900 and then again at three subsequent games, he accomplished something truly remarkable: He learned to walk again.

Beating The Odds

Ewry contracted polio as an 8-year-old in 1881. Thomas Carson, Ewry's grandson and biographer, says the disease overwhelmed the doctors of Lafayette, Ind. "He was stabbed numerous times around the knees with long pointed needles to get some kind of nerve response and, of course, when you have ascending paralysis, it just deadens the nerves from the ankles up to the hip," Carson says. "He had no feeling, so they thought he was going to be paralyzed for life." That was the thought. The truth is, but for the polio, Ewry might not have been an Olympian.

Ewry's therapist, only mentioned as "she" in the journals he kept, put her patient through a series of exercises to strengthen his legs. His 19th century rehabilitation was very similar to what today is known as plyometric training.

In 1889, Ray was a high school senior still using crutches. The following year, he was an engineering student at Purdue University who was setting records in the standing high jump and long jump, events that have fallen away from the world of track and field.

'Absolutely Phenomenal'

Ewry soon made his way east, where he became a member of the New York Athletic Club. "He was an appealing fellow, who was generous with his skills," according to a contemporaneous description of Ewry from the Athletic Club archives. "He was well thought of, but also viewed as a very, very special person. I'd say as our best." Ewry was so dominant at the standing long jump, high jump and triple jump that he was kind of boring, Carson says. "After everybody had done their very best, Ray would walk out and beat it by half a foot or more and walk away with a gold medal," he says. Just how impressive were his records? His best standing long jump was 11 feet, 4 7/8 inches.

Nick Winkelman, director of performance education at Athletes' Performance, takes the nation's top college football players and trains them for the NFL Combine. He says current players don't come close to Ewry. "Last year, we had Julio Jones just clear 11 feet, and that would be absolutely jaw-dropping. So to see anybody get into the high 10s — let alone break 11 feet — is absolutely phenomenal," Winkelman says.

More than 100 years ago, Ewry jumped farther than any modern NFL player has ever jumped. Higher too— no NFL player has ever recorded a vertical leap of 4 feet. Ewry jumped well over 5. "I can't fathom someone getting their hips, their center of mass, that high," Winkelman says. It's easy to imagine that today the letters E-W-R-Y would be stitched on the back on an NFL jersey.

A Legacy's Challenge

During the London Olympics in two months, you might hear Ewry's name come up ahead of the swimming. Phelps hopes to win his 10th individual gold medal, tying Ewry. There's a wrinkle there, though. Two of Ewry's golds were won in Athens in 1906, which the Olympic Committee doesn't officially recognize, even though most historians do. Also hindering Ewry's legacy is the fact that his events no longer exist. In fact, neither do his medals. They were stolen from the New York Athletic Club and have never surfaced.

But he's still there in the Olympic record books —

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Source: NPR ♦

COUGH ASSIST: THE MACHINE OF YOUR FUTURE?

By Rick Van Der Linden

Winter can be a dangerous time for those of us PPS folks with weak breathing muscles. There are many dangers out there, and even right here at home. As weak and tired muscles get even weaker with the cold weather we are even more susceptible to sick lungs. Breathing can become more difficult, and with it swallowing can be hazardous, making aspiration a real danger. Fluids or food in the lungs can result in pneumonia as tired muscles lose the ability to cough up foreign matter. And, of course, there are the flu and cold bugs. We avoid red-nosed people, coughing in our direction, sneezing and sniffing.

A common virus can be life threatening to us. If a bug or some pizza or saliva should slip down your pipes, a weak cough can result in pockets of fertile farmland for bacteria to grow deep in the lungs. Once the process starts, it's hard to stop without medical help. Antibiotics are the most common line of defense, but as we know, bacteria can become resistant over time, especially if treatment leaves a few strong survivors behind.

The best defense is to avoid the problem in the first place. Shunning sick people is always a good idea, but what can you do about aspiration? And what if you do get a bronchitis bug?

My usual method of coughing up goop (that's a technical term) is to throw myself over the back of a soft chair. This compresses the abdomen and chest while inverting my upper body so that the goop can go downhill. Works well when food or fluid has gone down the wrong pipe, not so good for bronchitis. For bronchitis you need to take an expectorant to loosen the phlegm, then get it out any way you can. But still, coughing is increasingly more difficult and painful.

Enter the Cough Assist machine. I could only find one manufacturer – Respironics. They make the Cough Assist CM 3000 (manually operated) and the CA 3000 (automatic). The manually operated

machine is apparently intended for use by adults, while the automatic version (which can also be operated manually) is more likely intended to be preset by a technician so that a child or limited person can use it. Basically, the machine functions by filling the lungs with positive air pressure by way of a tube and mask or mouthpiece. There is also a trache attachment available. Then, upon manually flipping a lever (or timed automatically) the machine quickly switches to a higher negative pressure (vacuum) while the user coughs. This is repeated 3 or 4 times. As you can imagine, it's just another mechanical aid for weak muscles, but it really works. For example: I recently went to the dentist. During a simple teeth-cleaning I aspirated saliva. Happens all the time. Obviously I couldn't jump up and throw myself over a chair and cough it out, so by the time I got home the fluid had gone deep into my lungs and I couldn't cough it out. I tried for days. A week went by and the cough was getting worse and worse. I had been trying to get a Cough Assist machine for months, and now I really needed it. In the meantime I was helping a fellow PPS person, Manny, work his way through the system to get a better bi-level ST. I told him of my difficulty getting a Cough Assist through my new Medicare/DME supplier. Manny had a Cough Assist, said he hadn't figured out how to use it yet, would I like to try it? A few days later Fed Ex dropped it off at my door. Within 2 days of receiving the machine, the 8-day cough that was threatening to become pneumonia was gone. Thanks, Manny.

In the two months since then, I've made progress in getting a machine of my own. I also learned that it keeps minor problems from becoming major. It's also handy for doing lung expansion exercises similar to, but better than, breath stacking with my bi-level ST. I don't want to ever be without a Cough Assist again. It may sit around most of the time and get in the way, but there's no doubt in my mind that it will prevent little problems from sending me to the hospital!

*CoughAssist Mechanical Insufflator-Exsufflator
Philips Respironics www.respironics.com/*

EATING CHOICES AFFECT AGING WELL WITH PPS

By Carol Prellberg

What you eat can help determine if you will be “aging well with PPS.” This was the message from Beth Young, MS, RD, as she explained the importance of good nutrition at the PNNJ annual conference on the late effects of polio. Ms Young is a registered dietician and nutrition consultant and is president of Princeton Health Systems, Inc. She explained that several symptoms of PPS, including fatigue, muscle weakness, and sleeping and swallowing problems, are related to nutrition and may be minimized with proper diet. Ms Young began by identifying the basics of a healthy balanced diet, giving information about carbohydrates, protein, fat, water, vitamins, and minerals, and explaining the role that each plays in good health. She said that carbohydrates found in milk, vegetables, fruit, and starches are the primary source of energy and should compose about 50% of the daily calorie intake. She added that the fiber found in many of these foods is very important and that a good diet includes about 25 grams of fiber per day. She cautioned, though, that foods containing refined sugars, such as candy, baked goods, soft drinks, and alcohol provide no nutritional value and should be limited.

Proteins may help muscle weakness of PPS.

Proteins, Ms Young explained, are the building blocks for tissues and cells and may help with the muscle weakness of PPS. She recommended that 15-20% of the calories in a healthy diet should come from proteins found in meat, dairy products, nuts, and beans, but cautioned against consuming too much protein, which can sap calcium from the body. She added that amino acid supplements do not get absorbed well so are not a good substitute for real food.

Ms. Young explained that fats, especially polyunsaturated fats found in plant sources, are important to polio survivors because they help cushion organs and the spinal cord, provide stored energy, and help with endocrine function. She said that fats

should make up about 25% of our daily calorie intake per day (or 56 grams of fat in a 2000 calorie diet), but that saturated and partially hydrogenated fats should be avoided because they are harmful to the circulatory system.

Weight management, Ms Young explained, starts with determining a goal weight based on height and frame size, and establishing an appropriate calorie range (goal weight x 11 for a person with little exercise who is trying to lose weight). She added, though, that it is important to be realistic about what really works for each individual's life style for the long run. She said that planning and journaling food intake, eating frequently (5-6 times a day), balanced meals, exercise, and drinking fluids (8 glasses of non-caffeine beverages) are the keys to weight management. Food choices should always be as close to natural as possible, and should be varied with lots of “color.”

In closing, Ms. Young explained that the measurement of success from good nutrition is that, even if your weight does not change, your health will improve.

For more information about good nutrition, go to the Dietetic Association at www.eatright.org. Reprinted from the Polio Network of New Jersey Newsletter, NJ, Winter 2010.

FAITH HEALING

THIS IS FAITH HEALING:

You go to a doctor whose name
you can't pronounce.

He gives you a prescription
you can't read.

You have it filled by a pharmacist
you don't know.

You take the medicine
you can barely swallow.

And you believe you will get better!

That, without question, is

FAITH!

*From the Fort Wayne Chapter of the
Allen Co Ostomy society*

FAMILY CAREGIVERS OF NORTHWEST MICHIGAN

February 2008 Tips and Topics

Emphasize the Positive in Care Giving

As caregivers, you sometimes encounter feelings of negativity. Your attitude and how you manage the stress in your life are the keys to coping with your role as a caregiver. Anger, self-doubt, guilt, and other negative feelings can overcome your ability to be an effective caregiver. De-stressing your emotions can help you focus on your multiple roles as caregiver, parent, or an employee. First you need to look at those negative feelings and find the reasons for your negative feelings.

Some questions to ask yourself are:

Are you more negative or more positive most of the time? What percentage of each would you consider yourself to be? Can you get in touch with some of your feelings of inadequacy, of inferiority and even fear itself, or fear of the unknown? These questions should help you take a good look at what is upsetting you and causing some of those negative feelings/emotions that are interfering in your daily life. Having realistic expectations, knowing your limitations and your loved one's strengths and limits, setting family and personal goals, exploring outside resources, and staying flexible are keys to successful care giving.

We all have the power to change ourselves. It is only a matter of looking at ourselves by examining our attitudes and desires. As long as we are aware of our own attitudes and are willing to change what we don't like, change can and will occur.

Listed below are some tips to help you keep a positive outlook about care giving include:

- First off family members need to realize that care giving is not a one-person job. It requires teamwork, whether that assistance comes from other family members or from volunteers, friends, or paid help. You need to make this need known to the best the situation presents itself.

- Take ownership of your role as a caregiver. "I am a caregiver. It's a tough job, but I can do it." Find time to pursue the things that are truly important to you.
- Pace yourself, this is a marathon, not a sprint.
- Enlist community resources, such as local meal site programs or financial assistance from county or state programs. Know what your community has to offer regarding housing options, community programs, volunteer services, support groups, and respite care.
- Listen to your body and respond. When it needs food, exercise, rest or medical attention, make sure to give it what it needs.
- Find a local Caregiver Support Group and communicate with other caregivers. They'll understand what you're going through and offer comfort and help. You can also use the illness to open doors to new friends and relationships. This can happen from talking to other people who have faced the same problems.
- Get enough rest and sleep.

Final Thoughts

Successful caregivers have a positive attitude toward care giving. Successful caregivers emphasize the positive parts of care giving. For example, some successful caregivers see their work as helping someone they love and care deeply about. Others see care giving spiritually-"I think this is part of God's plan for me." Others feel that care giving has enriched their lives. Others see it as a challenge and want to do the best job they can.

Take care of yourself!

MY POLIO STORY

By Bernice Brooks

I contracted polio in 1931 when I was just three years old. I was outside playing with my sister, when I started feeling sick. I went inside and told my mom about it then I went to lay down, soon after that my leg started to feel odd as best I can remember. I was only three so I barely remember it. I got worse as time went on so my parents took me to an osteopathic doctor. What he did made it worse because he didn't know what it was.

A week or so went by and I kept getting worse. Until one night I was so bad my mother said four people held me on a sheet lifted off the bed because I was in so much pain. She said my stomach was rolling and it looks like a washboard.

My dad took off in the middle of the night in his old model T Ford and drove to St. Louis Missouri. We lived in Risco, Missouri about 175 miles from St. Louis. He brought back a doctor that he was told about that could help me. When they got to the house the doctor had a huge needle that he gave me a shot with and I kept it for a long time in the box it came in which was about 6 inches long. Then a few minutes after the shot the pain subsided and they let me back down on the bed. The doctor said if he would have been another hour I would have been dead.

After that, my folks had a big washtub full of hot water, and they would bathe my legs in it. In a few days I was taken to the Shriners Hospital in St. Louis for treatments. I can't remember how long I was there but when I came home it was quite a while until I could walk again. From the age of three years until I was almost 8 years old my spine was deforming into almost a perfect S shape. I walked way leaned over. That was when Roosevelt was president, I loved him. He started the March of Dimes, which helped me greatly because my folks couldn't afford the treatments I needed so badly. Someone told my folks about the March of Dimes so when my folks contacted them they came out immediately.

The decision was made for me to go to Ann Arbor

University Hospital, I didn't know then when I left that I was headed to the torture chambers but I was. I was only eight years old when my folks had to leave me there alone. Back then the doctors and nurses were so different then they are today. They were very professional and cold not like they are today where they call you "honey" and say "I'm so sorry you hurt" and "sweetheart let me explain this to you, there was no compassion. They took me to the basement of the hospital and hung me up by my neck, my toes were barely touching the floor, then they started wrapping hot wraps around my whole body from my neck to over my hips. They did not explain anything to me and I was so scared. I did not know what was happening. I was put into a full body cast then I was put on a frame and taken to my bed. The frame was set about a foot above the bed, they turned me on my stomach and there was a round hole for my face to fit through. I could see nothing but the bed, and I was crying with tears dropping on the bed. I could not understand what was happening to me. I was left that way until my cast dried.

I was there for three years; in a body cast until my spine was straight, then all my surgeries came one after another. I had a spinal fusion at the age of 12. They removed the marrow from the big bone in my leg and pasted it all along my spine to hold it in place. There was so much pain I thought I was going to die and that's the only time my mom could come by my bedside. She would just hold me and cry.

I think that was so stupid of the doctors and nurses to think polio was still contagious, I had slept with my sister all those years and she never got it. It was so hard just seeing my mom and dad only once a week and looking through a glass at me.

When I finally could come home I was the happiest person in the world. I came home in a back brace, one full-length leg brace and a half leg brace on my good leg. I wore them about six months, and one hot summer day the braces were so hot I took them all off and learned to walk with one crutch. I did it very well. I had a full teenager's life with gobs of

Continued on next page...

Bernice Brooks Polio Story continued...

boyfriends. I learned how to have a contagious personality to overcompensate for my disability. I hate the word disabled; I never wanted to look that way. I would never wear the ugly shoes I didn't care if they were comfortable or not just so they were cute. I'm sure there are many of you out there that can identify with that: -)

I was married and had a baby that I was not supposed to have, the doctor said I would be in bed the last two months, but not so. I took care of a two-story home and an old man, that we lived with, and my husband. Canned an enormous amount of food that year packed my own suitcase and walked to the car the day I delivered. Not one day in bed. I had a 7 1/2 pound girl that has been the joy of my life. We have had a ministry in singing gospel music for about 50 years; we even recorded two albums together. Then when my daughter Debbie was 10 years old she was so lonely she wanted a brother or sister. We had a God planned opportunity to adopt a baby girl right from the hospital, her name is Starla and she has been a joy to our family. Starla was an angel sent from heaven into our home and she brought us much happiness. Debbie and I had a chance to go to the holy land as guest singers and we got to sing in the garden of Gethsemane, a highlight of my life.

Through it all God's been good to me but later in my life my husband died of cancer and I was single for seven years. I started a Christian dating service; it was lots of fun and had I helped put many couples together that created lots of happy marriages. Through my own dating service I met my second husband, and we had 27 wonderful years together, he passed away four years ago.

I'm single again, I'm in hospice but I keep getting better instead of worse. God's not through with me yet, I'm 84 and Debbie and I still sing but not as often. We also had a jail ministry for 20 years or more every Sunday we were there. I've had a very full and happy life and I always tried to do everything I did better than the ordinary person to

prove I was just as good and could do as much as anyone else. I'm sure you can identify with that also. Ha!

About 12 or more years ago I started into post polio syndrome. I started having trouble with my shoulders so painful after all those years on one crutch, wore out my shoulders and I had to go to two crutches. The pain became so bad with no relief that I went to an Ortho Dr. and he suggested that I have shoulder replacements, OH wow what a difference it has made, I am now pain free it has been wonderful. But my legs have gotten weaker and I am now in an amigo scooter all the time. But I can do almost everything in it. I had a beautiful apartment built on to Debbie's house and I live there, it is all handicapped accessible, but I don't like to tell anyone that, they might think I was handicapped! © All I need now is the man to drive my beautiful car and put my amigo in and out of the trunk and we could go places and have fun. I'm into fun and romance! To old? You should never be too old for romance.

This is not nearly all of my life, I've had a car accident and broke my bad leg all to pieces took a year to recover, then I fell down the basement steps and broke my leg again, I was laid up six months or more, have broken my ankle and my wrist different times then my leg again when I ran off the curb in Frankenmuth in my amigo at a car show. I don't know how much longer I have, but I want to thank God for bringing me this far, and I know he'll be there when it's time for me to crossover. What a day that will be, a whole new body and everything works! I'll never stop running and dancing! Like the song says: " I can only imagine what that day will be!"

God bless,

Bernice Brooks

PS Since I first wrote this I have been discharged from Hospice so I'm ready to hit the road again. If anyone would like to have a friend I'd love to hear from you. My number is 810- 656-2637.



LIBRARY CORNER

*Michigan Polio Collection Library
c/o Laura Barbour, Librarian
1156 Avon manor road
Rochester Hills, MI 48307-5415*



Autumn 2012(already)

Dear Readers,

Greetings to you all as summer eases into fall, the trees start to change, I finally get into the garden (I'm sorry, but it was just too darn hot out there during most of the summer!), and add still more zeroes on my paper calendar, where I keep track of whether or not it rained in our little bit of Michigan (chances are, it didn't). My apologies to those of you who might be enjoying a rainy season, but right here, it's been pretty dry.

Since living in Australia when I married my husband, Denis, 'way back in 1982, during one of the worst drought years up to that time, I've paid attention to rainfall...and there hasn't been enough, not in our backyard, at any rate. Maybe the change of seasons will bring a change of weather? Since my last column, I purchased a few new books for the MPN Library Collection, and will now tell you a bit about each of them.

THE MASTER'S MUSE is a novel written by Varley O'Connor, daughter of Don Varley, late Founder and President of the Network. I quote from the book jacket, which states: "[This book] is an evocative imagining of the deep yet complicated love" between Tanaquil Le Clercq, ballerina and, from 1956, polio survivor, and George Balanchine, her husband and the man many considered the "Shakespeare of dance." Ms. O'Connor uses the form of the novel to tell the story of their life together, both before and after poliomyelitis steals Le Clercq's ability to dance or even to walk. At approximately 250 pages in length, this novel/biography may be of interest to many of you. For those of us who are caregivers, Rosalyn Carter's book **HELPING YOURSELF HELP OTHERS** may provide some guidance. Written with Susan K. Golant, this book is a result of a survey done by the Rosalyn Carter Institute (Georgia Southwestern College, Americus, GA), to determine the needs of those in that area who pro-

vide care for chronically ill or disabled relatives or friends. Chapter titles indicate that helping caregivers remained the goal of this project.

Appendices containing lists of helpful organizations, resources, and books add to the amount of knowledge made available to readers.

At less than 300 pages in length, this book appears to be filled with information, and not just for those living close to Americus, GA.

TRAVELING WITHOUT A SPARE: A SURVIVOR'S GUIDE TO NAVIGATING THE POST-POLIO JOURNEY was written by Wenzel A. Leff, M.D. On the back of this book, I found this description, which I quote: "Decades after recovering from polio, many aging Americans are grappling with an emergence of new pain, weakness, and fatigue. This unforeseen symphony of symptoms is a central fact of many polio survivors' lives. [Dr. Leff] explains how polio's initial attack depleted the body's neuromuscular reserves, so that when former polio patients begin to lose cells to the natural process of aging, they find they are truly 'traveling without a spare'" Sound familiar??

A man named Michael B, who lives, I think, in the United Kingdom, is a polio survivor. His slightly-over 40 page-long self-published autobiography tells his story, at least up until 2011. In a rather humorous way, Mr. B. tells of falling out a window when he was a child living with his family in Yemen (his father was in the RAF). Unfortunately, there was an outbreak of polio in the hospital in which he was treated, and the resulting effects of that "broken leg" have remained with him all his life. He hopes that his readers will "see that there is a life to be led...[maybe] not the life you wished for....but it is still a life."

If you would like a "short read," somewhat like the interesting Polio Stories you've found published in our very own newsletter, ask to borrow **BE THE BEST YOU CAN BE: POLIO MY CONSTANT COMPANION** by Michael B.

Our final new book is in honor of this Olympic year, and it is the biography called **WILMA RUDOLPH, OLYMPIC RUNNER** by Jo Harper. From the "Childhood of Famous Americans" series published by Aladdin Paperbacks, this 2004 publication tells the life story of Wilma Rudolph, black woman athlete...and polio survivor. You may know a child who is interested in 20th

Continued next page...

**ANN ARBOR
POST POLIO CONNECTION
ACTIVITY UPDATE**

June 19, 2012 Pizza party at Liina's house. Sunny and I had sent out a survey to members asking how the group would like to proceed regarding our meeting schedule and content. It was decided that we would meet 3 times per year between April and mid November. One meeting we would have a discussion of issues and concerns members would like to discuss. We have great resources among ourselves and want to take advantage of these ideas. We had a discussion of some of these issues at the meeting. The group also viewed the home modifications I had done last year.

August 21st, We met at Paesano's Restaurant in Ann Arbor. We had a great lunch and then Sandra Loyer spoke maintaining a positive attitude while coping with changes we are all experiencing whether through aging or post polio issues. She also encouraged us to share the different strategies we all use to cope with our challenges. Sandra worked as a social worker at University Hospital for many years. She has also led discussions at Bay Cliff Camp.

November 6th is the date scheduled for our next meeting at the Olive Garden. This will be a social get together.

Library Corner *continued...*

Century American history, one who might like to read about this pioneer in athletics, women's rights, civil rights, and recovering from polio, the disease which effected one of the legs Rudolph used to win three gold medals at the Rome Olympic Games in 1960.

Please remember that you can contact me at my home phone(248-853-5465) or via the Internet (denilaur@sbcglobal.net) if you wish to borrow a book, or if you want to suggest the purchase of one you've heard about.

Happy reading! Enjoy the fall season, and take care until next issue of "Polio Perspectives"!!

Laura Barbour, Librarian

**LANSING AREA
POST-POLIO SUPPORT GROUP**

In October, the Lansing Area Post-Polio Support Group decided to move our meeting time to daylight hours, beginning with the December 2012 holiday gathering. Note that the November meeting will still begin at 7pm Here's the updated schedule:

7 - 8:30PM, WEDNESDAY NOVEMBER 7, 2012 - Cheris Grasse, a physical therapist, will discuss physical therapy and post polio issues. She is one of two physical therapists at Sparrow Out-patient Rehabilitation who have quite a bit of experience working with people affected by polio and post-polio.

1:30 - 3PM, MONDAY DECEMBER 10, 2012 - Holiday Gathering if the weather is good: Bring favorite Christmas cookies or other holiday finger food to share. Enjoy visiting with folks you haven't seen for awhile. If weather is treacherous and travel is "unsafe", stay home! The December meeting will be cancelled if travel is treacherous, but we cannot arrange to notify you.

JANUARY, FEBRUARY, MARCH — no winter meetings due to unreliable weather and travel. 1:30 - 3PM, MONDAY APRIL 8, 2013 - we plan to resume regular meetings with a time of sharing and supporting each other, updating "what's been happening" in our lives.

We are a shrinking group. Our attendance has been dropping as our members become less able to attend – and we miss key members who have passed away. If you are interested in attending but just haven't done so recently, now is the time. Some of us began attending regularly after retiring from demanding jobs. Others come looking for ideas about living with the effects of post-polio. We offer empathy and support, sharing ideas on living with post-polio. Some of these ideas can be life-saving – or at least life-enhancing.

Best wishes,

Margaret Nielsen

home phone: 517 336 5921

cell phone: 517 881 6956

SUPPORT GROUPS AND CONTACTS

ANN ARBOR (PPSG)

To obtain information of meeting call:

Liina Paasuke (734) 332-1715

Sunny Roller (734) 971-1335

CLIO AREA POLIO SURVIVORS SUPPORTGROUP

The New Clio Area Polio Support Group is held at the Clio Area Senior Center

2136 W. Vienna Rd. Clio, MI 48420

On the third Friday each month at 9:00-10:30am.

Facilitator is Dennis Hoose.

To join our group call (810) 687-7260

HARTFORD, MICHIGAN - PPSG

Jeannie Wessendorf

Support group meetings at Hartford Federated Church, Hartford Michigan for meeting times please call Jeannie at 269-621-2059 or email jeanniew@provide.net

LANSING AREA SUPPORT GROUP

Meet April thru December

Margaret Nielsen Williams (517) 336-5921

nielsenwilliams@yahoo.com

MID-MICHIGAN (PPSG)

Jean Iutzi, Harrison, MI (989) 539-3781

Group info. 1-800-999-3199

Meeting twice a year. June and Nov.

SOUTHEAST MICHIGAN (PPSG)

Bonnie Levitan (313) 885-7855

co-facilitated by Bruce Sachs (586) 465-3104

Dianne Dych-Sachs (586) 465-3104

Bobbi Stevens (248) 549-2149

Meets 4th Sat. of the month
March thru October 10am-Noon

THUMB AREA PP SUPPORT GROUP

Rita Wall (989) 673-3678

Blue Water Center for Independent Living

1184 Cleaver Rd Suite 1000

Caro, MI

Meets last Tuesday of each month 2:30pm

WEST MICHIGAN PPSG

Scheduled Meetings:

April, June, Sept, Nov

Linda Walthom Grand Rapid (616) 363-7625

Lynette Hooker Grand Rapids (616) 455-5748

Email: linsue@inbox.com

Chuck Bond Rockford (616) 866-1037

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info@post-polio.org

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www.post-polio.org

"MENTAL HEALTH ISSUES AND POST POLIO PATIENTS"

*By Susan Bowden LMSW, presenting at the
Lansing Area Post-Polio Support Group,
August 1, 2012*

1. Post polio patients are survivors. Therefore, they already have a very strong psyche and can take pride in what they have overcome. In fact, they could be more mentally healthy than the average citizen.

2. That being said, there are features of post polio syndrome that can promote emotional distress. These include:

A. Fibromyalgia (more frequent in post polio patients; depression is a side effect of this disease).

B. Chronic pain from the fibromyalgia and osteoarthritis that also are a feature of post polio syndrome. Depression lowers the serotonin level in the body; so does chronic pain.

C. Fatigue! That can be depressing.

3. What can be helpful if you are experiencing depression:

A. Get support. Educate your family and friends and co-workers about post polio disease and how it can affect you.

B. Join a support group.

C. Stay informed on the latest research on post polio syndrome; be a part of a study.

D. See your doctor for medication that can help. An anti-depressant such as Cymbalta also helps with chronic pain.

E. Make sure you go to a doctor who understands post polio syndrome.

F. Seek help from a mental health professional if you find yourself overwhelmed.

4. Remember that the hardest part for you is now over with. You overcame polio and you understand now what post polio disease is. The period of experiencing unknown pain and symptoms is over for you now because you are educated already. With knowledge comes the power to move on and survive.

5. Recommended reading:

A. The Mayo Clinic Newsletter

B. Arthritis Today

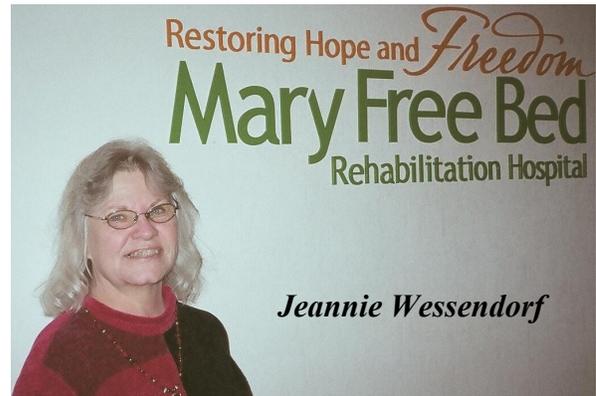
6. Don't forget to try new types of therapies that can make yourself more physically comfortable. Better equipment is becoming available all the time that can make your life easier. Seek out a physical or massage therapist who has experience with post polio disease when you feel worse. Light massage and warm packs work better than vigorous exercise.

Prepared by Susan Bowden LMSW, with Professional Psychological and Rehabilitation Services, 302 South Waverly, Suite One, Lansing MI 48917, Phone (517) 321-5900

JEANNIE WESSENDORF POLIO STORY

I was born March 23, 1945 just one day after my father went off to WW II as a Marine. I had two older brothers and we lived in St Joseph in south-western Michigan. I was told my father didn't see me till I was 6 months old. Life went on pretty normal and we moved to Meadowbrook Road Benton Harbor when dad came back from the war. In a few years we moved to County Line Rd. Hartford, Michigan to a place on the Paw Paw River . By then there were two more children in the Wessendorf family; another boy and the youngest was a girl. So I am the middle child in a family of five children.

When I was 14 we all got a shot for polio at the doctor's office. All seven of us had the shot that day. A couple of weeks later I became very sick and was admitted to the hospital. This was in January of 1960. I was diagnosed with influenza and not responding to any treatment. I did get better and went back to school but noticed much trouble in climbing stairs. Our two story school had a long flight of stairs to climb to get to my classes. The railing was only on one side. I remember pulling my self up that side against the flow of those coming down. I had much weakness in my left side. Later it was noticed the left side was not growing and there was at least one inch difference in the length of my legs; the left being shorter. I kept telling my mom my legs hurt so bad and she would say it's growing pains. Well I got better and the year went by. After high school I worked for a company in Hartford as office girl and earned enough to go to airline school in Minneapolis. I was hired by TWA Chicago. Some years later, came back to Michigan and worked for AAA Benton Harbor. I married twice and divorced twice and had three daughters and one son. I was working at a bank as teller at that time and was noticing my legs getting very tired in the afternoons. It got worse with much pain arms and legs and much weakness in my limbs. That was December 1985 and the cold seemed to make it all worse. In April 1986 I was diagnosed with post polio syndrome. I was glad to know what it was but really worried about the out come. I went to California to be with my brother, a Navy Chaplain, later that year. Before I could move there it was the first Persian



Gulf uprising and my brother was chaplain chosen to be with the five U. S. ships sent there. So I stayed with cousins. After a couple years I came back to the Hartford, Michigan area. I was feeling pretty alone and decided I wanted to talk with others who had post-polio syndrome. I went to my pastor at my church and talked with him. He thought it was a really great idea and arranged for me to have meetings at our church. I put out flyers and posted on local bulletin boards. I put announcements in local papers about a post-polio support group. There was good attendance and we all brought something for our pot luck meal. I was surprised to see many people from my hometown and even some classmates of mine that I didn't even know had polio.



*In foreground Mr John Overley and wife Halene
In background Mr. Ray Llorens and wife Merna
At Post-polio Support Group potluck.*

We are planning another pot luck meeting in the fall. We are helping each other and I was surprised to see that most of all it has helped me to help others. We are survivors and I guess I am a double survivor because of the cancer too. I am still here and will keep on keeping on as long as God has something for me to do. ☺

POLIO SURVIVORS SHARING

This is a one-on-one e-mail list so you can mail only to the selected name; an e-mail list of Polio Survivors who wish to communicate with other Polio Survivors and discuss your concerns, ideas, fun, jokes, as well as sharing information of what is happening to each other. I would like your permission to add you on this list. Please email to vlhazel38@comcast.net to get on the list! Also include your city and state.

Happy Sharing!! ☺ Vera Hazel, Editor

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"Your renewal check should be sent along with the completed Membership Form found in this issue."

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Two Post-Polio Clinics in the Southeast Michigan Area

St. John Post-Polio Clinic
Center for Physical Medicine &
Rehabilitation, P.C.

13850 Twelve mile Road
Warren, MI 48088

Phone: 586-778-4505

Fax: 586-552-4878

University of Michigan
Post-Polio Clinic

Eisenhower Park West

2850 South Industrial Highway Suite 400

Ann Arbor, MI 48104-0758

Phone: 734-936-7175

Fax: 734-975-4726

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