

POLIO PERSPECTIVES

Volume 26 No 1 Spring 2011

Promoting Understanding Through the Michigan Polio Network, Inc Since 1986

AGING WISELY WITH PPS

The Michigan Polio Network, Inc. will be holding an Educational Post-Polio Conference, "Aging Wisely With PPS" on August 20, 2011. It will be held at the Genesys Conference & Banquet Center in Grand Blanc, MI.

Presentations will be made by the following:

Professor Mike Kossove, Microbiologist Touro College, New York, New York

Ann Laidlaw, MD, Post-Polio Clinic University of Michigan

Mark Taylor, Orthotist, Post-Polio Clinic University of Michigan

Lawrence Walny, MD MS, Anesthesiologist Genesys Hospital, Grand Blanc, MI

Come join us at this educational conference. See the Registration Form on page 19.

"Wellness Retreat"

Doctor Maynard will again be leading a "Wellness Retreat" at Bay Cliff Health Camp located in Big Bay, Michigan, north of Marquette. Sept. 12-16, 2011. See info to apply in the form on page 3.

Polio Perspectives is the newsletter of the Michigan Polio Network, Inc. It is published four times a year. (January, April, July, and October)

Send articles, information, personal accounts to:
Vera Hazel, Editor of Polio Perspectives
15235 Ackerson Drive
Battle Creek, Michigan 49014

MPN NEW PIN FOR SALE

The Michigan Polio Network has created a pin to offer to the Membership.

The pin is the size of a quarter and cost \$3.00. If you wish to buy one they will be available at the Warren Post Polio Clinic or at our 2011 Conference "Aging Wisely With PPS" in Grand Blanc, MI.



Michigan Polio Network Inc Board of Directors Meetings

The MPN Board of Directors meet on the third Saturday of the month, 6 times a year. Members of the network may come and join us at Tony M's on Creyts Rd, Lansing, MI. The following dates are set: May 21, July 16, September will be internet email, November 19.

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FROM THE CHAIR



SPRING 2011

With Spring finally coming it looks like we can again get out and enjoy the fresh air without the fear of falling on the snow and ice.

Your first activity of the new year is to return the annual MPN Board of Directors ballot which was mailed to you several weeks ago.

As has been mentioned in previous articles the MPN has planned a one day conference for Saturday August 20, 2011.

It will be held at the Genesys Banquet & Conference Center in Grand Blanc, which is on the campus of Genesys Hospital, I 75 Holly Road Exit 108.

Registration details are in this issue of the Polio Perspectives (page 19) and on our web site [www.michiganpolionetwork.com] Plan to attend this educational conference. Doctor Maynard will again be leading a "Wellness Retreat" at Bay Cliff Health Camp located in Big Bay, Michigan, north of Marquette.

The retreat is scheduled for Monday September 12 - Friday September 16.

The MPN will again offer a scholarship that covers the registration fee for a polio survivor to attend the retreat. See details in this issue on the form on page 3.

As we begin our 26th year the Michigan Polio Network, continues to provide information to Michigan polio survivors through The Polio Perspectives, the MPN library, MPN web www.michiganpolionetwork.com and the local support groups.

If you do not belong or have not renewed your MPN membership, now is the time. See the application in this issue (page 18) and check the address label to see when your membership expires.

If you know a polio survivor, please give them information about the Network and how to make an appointment at the Post-Polio Clinic in Warren. (See page 14)

Post-Polio Health International www.post-polio.org has added a new feature to their web site called www.polioplace.org

Polio Place explores the past, the present, and helps to build a promising future for the world's polio survivors. The topics include People, History: artifacts, collections, Resources: books, web, multimedia, Medical articles, and Living with Polio.

This is a growing site and there are directions on how to contribute. Check it out. We are in the process of up dating the e-mail address list that appears in this issue. (See Survivors Sharing List on pages 16-18)

If your e-mail address has changed, please forward the new information to Vera Hazel, at: vlhazel38@comcast.net

Enjoy the Summer and we will see you at the conference in August.

Bruce

BAY CLIFF HEALTH CAMP POST-POLIO WELLNESS RETREAT SCHOLARSHIP CRITERIA

The Michigan Polio Network is offering one scholarship, to the Post-Polio Retreat being held at the Bay Cliff Health Camp in Big Bay, Mi September 12 - 17, 2011. This scholarship will cover the entire registration fee of \$250.00.

Applicants must:

1. Be a Michigan resident or have been a camper at Bay Cliff as a child
2. Be a polio survivor
3. Be independent in ADL [activities of daily living] or be accompanied by a caregiver. The caregiver is responsible for their own registration fee.
4. Arrange their own transportation to and from the Camp. There is no public transportation to the camp
5. Be a first time Retreat attendee
6. Be willingly to show proof of financial need
7. Be a member of the Michigan Polio Network

APPLICATIONS MUST BE RECEIVED BY AUGUST 22, 2011

INFORMATION ABOUT BAY CLIFF HEALTH CAMP.

The Camp is located about 30 miles West of Marquette on Lake Superior
The Camp continues to provides help for handicapped children in the summer
On site housing is wheelchair accessible and all meals are home cooked on site
A scooter or power chair is recommended for those with mobility issues

For more information visit their web site at www.baycliff.org

For an application to the Wellness Retreat contact:

Bay Cliff Health Camp, P.O. Box 310 Big Bay, Michigan 49808

(906)345-9314 THIS IS SEPARATE FROM THE SCHOLARSHIP APPLICATION

SCHOLARSHIP APPLICATION TO BAY CLIFF POST-POLIO WELLNESS RETREAT

NAME _____ M / F

ADDRESS _____ CITY _____

STATE _____ PHONE _____

E-MAIL _____

ATTENDING WITH CAREGIVER / SPOUSE YES / NO _____

SHORT STATEMENT WHY YOU NEED A SCHOLARSHIP TO ATTEND THE
REREAT _____

THIS APPLICATION MUST BE RETURNED BY AUGUST 22, 2011 TO:

**BARBARA ONISZCZAK, 332 WOODSIDE CT. APT.113, ROCHESTER HILLS, MI
48307 or DIANNE DYCH-SACHS, 1070 BALMORAL, MT. CLEMENS, MI 48043**

LETTERS

3-31-11

I have just successfully come through emergency open heart surgery. I am rarely sick, not even with a cold, and I was not aware that I had a heart problem. I was not aware despite the fact that I see a doctor every six months for general blood work and check-up.

I was on vacation and developed very mild sensations in the left side of my chest, but they were so fleeting and faint that I hardly noticed. However, at the end of two weeks, I knew something was going on and thought I would go to the doctor when I returned home in a day or two. I have scoliosis so thought it may be related to that problem as I did have some chest muscle issues a few years ago, and I needed physical therapy to correct it. Upon returning home, I still let things go a few more days but the symptoms grew stronger and I had trouble breathing. I went to the main St. John Hospital on Moross Road as it is closest to my home.

I think I was more afraid of getting doctors who would not listen to me about polio issues than I was of whatever was wrong.

To complicate the matter, my doctor who I have been seeing for more than 10 years, and who understood polio issues, had just suddenly died, so I did not have a regular doctor to call. I just had to take my chances once I got there.

St. John is known to be a nationally rated top heart hospital, and that was a good thing because all the tests indicated I needed open heart surgery immediately. I was in that hospital ten years ago, and I want you to know that the difference between then and now regarding polio issues was night and day.

Ten years ago, during my hospital stay, I told the doctor in charge that I had Post-Polio Syndrome and he scoffed and replied "Who made up that diagnosis, you?" This time, the doctor in charge asked me right away, "What kind of polio did you have?" I was so shocked I could barely think of the answer. Then because of the polio, he brought in a neurologist and two cardiologists and a doctor that specialized in electrocardiology, and an anesthesiologist who knew about it. They all spent time with me prior to surgery. They



In Memory of Louise Swartz

Louise Swartz, age 76 died February 6, 2011. A life long resident of Utica, MI. Her memorial service was on Saturday, February 12, 2011 at Gramer Funeral home, Diener Chapel, Shelby Township.

She was a member of the Michigan Polio Network Board of Directors from 1992-2003.

We are very grateful for her contribution to the Michigan Polio Network.

were all respectful of what I had to say and they were interested. And most importantly, they were all aware of the special issues and I was told that the hospital recently offered an in-service training session regarding Post-Polio issues. It relieved my mind so much to know that I was in such capable hands.

The cardiac unit at St John was fabulous.....the doctors had a team that worked with them on the floor all day so I had immediate access if I had any concerns or questions.

No one would choose to go through open-heart surgery, but if you have to, this was an outstanding experience.

The following are the names of the doctors in charge and I believe some or all of them also operate at St. John Macomb....I only choose St. John main because it was close to my home and when I went there I still thought there was not much wrong with me. In addition I am a high-risk patient and St. John main is a trauma hospital and fully equipped.

The surgeon is Dr. S. Batra and he is in with Dr. F. Azoury....they were both wonderful and they can be reached at 313-343-7444 The cardiologists are Dr Ravi and Dr. Yamasaki 586-7754594

Anyone who needs additional information may call me Bonnie E. Levitan at 313-885-7855

Little bit of ingenuity gives polio survivor new horizons

By Karin Stanton | Hawaii 24/7 Contributing Editor

Jean Hartley likes to get out and do things. The 70-something former college teacher is not one to sit at home and crochet or do crossword puzzles. For Hartley, however, each excursion has to be carefully planned. From grocery shopping to covering the Ironman World Triathlon Championships as a freelance writer, she has to plot and prepare. Hartley is a polio survivor and lately finds it more difficult to walk more than a few dozen steps. She relies on two other modes of transportation – a red VW Bug and her shiny red Go-Go Ultra X electric scooter.

Recently, Hartley found a way to take full advantage of both four-wheeled vehicles. With a little help from a couple of local mechanics, the scooter now can be stored in the trunk of the shiny red VW, attached to a hydraulic lift and easily taken out so Hartley can zoom around shops and along Kailua-Kona's streets. "This island is not disability-friendly if you have a physical limitation. The geography of the island makes accessibility a big issue," she said. "I'm just an example of a person who solved my unique transportation needs. The application here is, if I can do it, others can also search for any options to being house-bound."

Hartley is used to asking "how many stairs?," "can I please have an aisle seat?" and "is there an elevator?"

"I'm good for walking maybe 30-40 feet," she said. "Even going to the movie theater, the movie I want to see is always in the theater furthest away from the entrance. By the time I get there, I'm just pooped."

Now, with her new scooter-in-a-bug invention, Hartley's world has opened up. "It's bought such great independence and freedom. It's really all about confidence" she said. "I can go to movies by myself. I can shop by myself. I can go to Kahaluu Beach Park by myself." Hartley really likes to use those words: "I can." "If you've been disabled a long time, it's so easy to get stuck in the negative," she said. "It can be such a huge shadow over everything you are and everything you do."

Even a manual wheelchair isn't the answer for people like Hartley, who want to be in the thick of the action wherever it is.

The Big Island presents a long list of barriers, including sand, lava rock, and uneven or nonexistent sidewalks. Many homes are two-story post-and-pier structures. And, of course, on an island made up of five volcanoes, everything is on a slant.

Surviving the polio that struck her down in childhood was just the first battle. Every day since has included some up-hill obstacle. Until now, Hartley has taken it as it comes, raised her children, taught her classes and shopped for her groceries.

All the while, she has fought off the muscle weakness, the pain and the energy loss each day metes out.

Traditional medicine has few answers for the 80 percent of adult polio survivors who experience these symptoms.

Hartley relies on physical therapy, massage, acupuncture, vitamins and supplements to keep herself fit.

Just being fit is not enough for Hartley. She created and maintains a Web site that connects disabled visitors with accessible sea, land and air activities along the Kona Coast.

Then she started looking at her own challenges.

She already had her beloved little VW Bug, which is not compatible with a manual wheelchair.

"That was not the answer for me. I had no one to push a wheelchair and I could not lift it into my car," she said.

With donations from the Kona Mauka Rotary Club and Hilo and Kona Adult Care, as well as private gifts, Hartley was able to purchase her scooter from Bannix Medical Supply.

A team of auto wizards worked to complete the conversion. Waimea Auto Center/Thunder Alley Auto installed the hitch and hydraulic lift on the back of the VW.

They were able to install the hitch and hydraulic lift to the back of the VW without having to make alterations to the car. They devised a way to safely, carefully and easily get the scooter into and out of the car at the touch of a remote control devise.

Ron Meyers at Big Island Upholstery and the team at European Auto put on some finishing touches and the scooter-in-a-bug was complete.

"Those guys were just fantastic," Hartley said. "They really made my dreams come true."

Within five months of the idea, Hartley and her wheels are good to go ... just about anywhere.

Check out Hartley's Web site at: www.disabledadventureshawaii.com



Jean Hartley guides her scooter into her car with the help of an automatic hydraulic lift. (Hawaii 24/7 photo by Karin Stanton)

LIBRARY CORNER

By Laura Barbour, Librarian
1156 Avon Manor Road
Rochester Hills, MI 48307-5415
Phone: 248-853-5465
denilaur@sbcglobal.net



Hello, and happy spring to you all (even if current weather may look a lot more wintry than you'd like)!

We'll begin this quarter's "Corner" with a reader review of books from our collection. Barb Oniszcak read the following: **BREATH: A LIFETIME IN THE RHYTHM OF AN IRON LUNG** by Martha Mason, and **POLIO: A DOSE OF THE REFINER'S FIRE** by Jeane L. Currey

Dille. In Barb's opinion "these are books about two amazing women who spent their lives without an ability to 'look normal'. Both Martha Mason and Jeane Dille lived their lives serving others and never considered only their own comfort. Though I have never been in an iron lung, I so appreciate my life with polio and post-polio syndrome after reading their stories."

Please don't forget that these and many other polio-related books, videotapes, and DVDs are available from the MPN Library. Please let me know by phone(248-853-5465) or e-mail denilaur@sbcglobal.net if you wish to borrow the books mentioned here, in other issues of "Polio Perspectives," or in the website booklist.

If you find out about new books/'tapes/ DVDs and want to bring them to my attention so I can make a library purchase, please contact me as noted above.

Next issue, watch for reviews of any and all new library purchases. In the meantime, take care!

Laura Barbour, Librarian

POST-POLIO SYNDROME? WHAT ARE THE SYMPTOMS?

(PPS) is a condition that affects polio survivors years, an average of 30 to 40 years, after recovery from an initial acute attack of the poliomyelitis virus.

Common signs and symptoms include:

- Progressive muscle and joint weakness including skeletal deformities, such as scoliosis, and pain
- General fatigue and exhaustion with minimal activity
- Muscle atrophy
- Breathing or swallowing problems
- Sleep-related breathing disorders, such as sleep apnea
- Decreased tolerance of cold temperatures

In most people, post-polio syndrome tends to progress slowly, with new signs and symptoms followed by periods of stability. The severity of weakness and disability after recovery from poliomyelitis tends to predict who might be at higher risk of developing PPS. Individuals who had minimal symptoms from the original illness are more likely to experience only mild PPS symptoms. People originally hit hard by the poliovirus attack and who attained a greater recovery may experience a more severe case of PPS, with greater loss of muscle function and more severe fatigue.

According to estimates by the National Center for Health Statistics, more than 440,000 polio survivors in the United States may be at risk for post-polio syndrome. Researchers estimate that the condition affects 25% to as many as 60%, depending on how the disorder is defined and which study is quoted.

While polio is a contagious disease, PPS is not transmissible, one must be a polio survivor to contract PPS.

www.ninds.nih.gov/.../post_polio/detail_post_polio.htm -

[/www.medicinenet.com/post-polio_syndrome](http://www.medicinenet.com/post-polio_syndrome)

www.mayoclinic.com/health/post-poliosyndrome

Polio Place

<http://polioplac.org>

an internet repository for medical and practical information, historical records and artifacts, launched on January 30, the 129th anniversary of Franklin D. Roosevelt's birth.

Polio Place looks at the past - not only the history of the disease, but also the stories of its survivors. It examines the present from the perspective of people around the world who are living with polio and post-polio syndrome today.

Post-Polio Health International (PHI) developed Polio Place with the generous support of the Roosevelt Warm Springs Foundation.

PHI is committed to reaching out to polio survivors and their families, health professionals and policy-makers, particularly in countries where living independently and successfully as a polio survivor is not a priority.

PHI invites survivors and health professionals worldwide to explore this storehouse of information and let us know your needs, concerns and successes.

Here's how to participate: Polio survivors - Have you devised a unique way of doing something to increase your independence? Have you created a simple device to assist you? Can you write an essay on Living with Polio? Contact us.

Do you have a photograph, letter, newspaper article, etc., that tells your polio story? Please visit the Artifacts area of the website, and submit it.

Health Professionals and Researchers - Are there Medical Articles you would recommend or articles you judge to be classic, seminal, excellent overviews or longitudinal studies? Click on Contact and let us know.

Historians and Authors - Do you have suggestions for additional Collections of historical material or recommendations for additions to the People section? Have you written a book that should be included? Contact us.

Polio Place is a new additional website and an extension of our mission to enhance the lives and independence of polio survivors through education, advocacy, research and networking. Our other trusted sources of online post-polio.org and ventusers.org will continue.♦

“AGING WISELY WITH PPS” CONFERENCE SPEAKERS SATURDAY, AUGUST 20, 2011

(Keynote Speaker:) Professor Mike Kossove, Microbiology, School of Health Sciences. He will speak about the polio virus (the source, its replication within the human body and transmission, and how it destroyed motor nerves causing paralysis).

Dr. Ann Laidlaw, physiatrist and Mark Taylor, prosthetist & orthotist, both from U-M's Post-Polio Clinic, will speak on post-polio syndrome and treatment.

Ann Laidlaw, M.D., Clinical Assistant Professor at University of Michigan Health System. Physiatrist for the Post-Polio Clinic at U-M Health System:

Mark Taylor, MLS, CPO, Certified Prosthetist and Orthotist, Director of Clinical and Technical Services, Orthotist for Post-polio Clinic at U-M Health System, Polio Survivor and a member of PHI's Medical Advisory Committee and presenter at PHI's conference held in Warm Springs.

Registration Form to the conference is on page 19.

POLIO STORY

By Barbara Anne Oniszczak

Barbara Anne Oniszczak - Polio Survivor 1949 Age 2.5 Buffalo, NY

My experience with polio seems different from those who hailed from Michigan. After several days of fever, pain and fatigue I was taken to the Buffalo Children's Hospital for a spinal tap. The diagnosis showed I had polio but it was not in the "active" stage so I was told to be taken home. During the next few months I was given the following treatment as expressed by the hospital physician: keep her comfortable, don't allow stress and hope for the best.

My mom gave me regular stretching exercises to loosen up the tightness in my legs and my grandmother gave me daily warm baths. I wore orthopedic shoes most of my school life. They were the brown and white or black and white saddle shoes.

I was always scrutinized by my family to make sure that I had no relapse of fever, pain or fatigue and well into my teen years, pretty much what I said or wanted to do I did. I was allowed to "boss" my family around, they giving in to my every request and expectation. This kept me quiet and happy and very spoiled. (I don't think the doctors meant that the spoiling should last so long.)

I did not suffer many after effects of polio except a limp when I walked while fatigued and an atrophied right leg. While in high school my mother heard about a successful but experimental surgery that could help me control my limping. I had a tendon transfer in the right foot. The outcome was not favorable. March of Dimes would not pay for the surgery, which my family could not afford, because I was never officially diagnosed with polio. In my early twenties I had neuromas removed from my right foot and bracing was used for the first time. I wore a spring type brace that was permanently affixed to my right shoe but after many trials and adjustments, it was thrown away and I never wore braces after that initial trial run. (1972)

It was determined by my family at an early age that I should not partake in ballet, dance or any activity that consisted of longstanding, complete exhaustion, etc. I never did ballet, but I did dance and was notoriously famous for dancing the night away with any man who showed an interest and knowledge of dancing on any floor. Hence, my ability to glide to a waltz, cha-cha, rhomba, or "dancing with the stars" style ensued well into my late 30's. It was here that I first noticed that I was having difficulty walking off the dance floor after the music stopped. Was this the first signs of PPS?

I am the mother of two boys and married to the most wonderful caregiver of 31 years. Ron saw no limits to my living a full life until post polio set in, in 1996. It was as if the rug had been pulled out from under me. My life whirled, spiraled downward and I was no longer "in control" any longer.

When fatigue, pain and weakness wrote my life, I spent a lot of time with physicians who could not even conger up any reasonable explanation for my physical changes. A psychiatrist concluded that I had "post polio syndrome" and assured me that I could control my life and that mentally I needed a shift change in what I believed was important in my life.

It took me years of research as the Michigan Polio Network librarian and hours of talking to other polio survivors to know that what was going on in my body was also going on in others who had thought they had conquered a horrific disease in their early years.

I am most grateful to the staff, and especially Dr. Fred Maynard, at the Bay Cliff Wellness Week for showing me that I face a devastating disease that is within my body. They have given me tools to overcome the emotional and physical challenges and have assured me that I can be well. I broke the circle of pain, emotional upset, chronic phases, fatigue and suffering.

I was able to engage the resource of a great hypnotherapist Dr. Charles Kinney. Through his sessions I have re-centered myself and concentrated on issues that allow me to cope and live with my post polio symptoms. My life is not my PPS. My life is what I make it.

I trust the support group system which I established in Northeastern Michigan and the Southeast Michigan group of which I am now a participant. I recreate with those in "my boat" and explain my situation with those who are not "in my boat".

I am especially grateful to my husband and family who have been supportive and have cried with me in my new life adventure as a polio survivor. I know that I have to exercise regularly and maintain bodily strength when I can.

I have found new ways to occupy my time. Work still seems like something I would like to have done until I reached 65 but I have so many more options to choose from to occupy my time. I attend conferences and seminars where I can to learn new and upcoming things in the treatment of PPS. I value each new person I meet and I know that I am a better person because of those I meet along the way who are also on my journey.♦♦♦

MY STORY

By Sue Bannan-Engel

During the Polio epidemic of 1949, I became a victim of this dreadful disease. It happened when I was only 10 months old. When I reached for my baby bottle, I fell and knocked my front tooth up into my gum. That was the beginning of this horrible nightmare ... From that day on, I was ill with flu-like symptoms.

After 3 days of being ill, my mother took me to the doctor. He suspected Polio as the bug had undoubtedly entered through the tooth opening in my mouth. A spinal tap was performed in the hospital. I was placed into isolation and developed breathing problems which proved to be Bulbar Polio. The doctor immediately put me in a respirator in preference to an iron lung because I was so young. It became more difficult for me to breath, therefore the doctor didn't give my mother much hope for my survival. After three days the crisis was over. Then my body was sore to touch. After more testing, the dreadful results revealed the fact that I had become paralyzed.

I was then transferred to County Hospital. My mother moved into the hospital with me as there were not enough nurses to care for the large number of Polio sufferers. My brother and sister had to go live with my grand parents during this time.

After 16 days, I was released from the hospital. My mom had been taught how to exercise my arms and legs and did so 4 times a day. My mother took me to therapy at the hospital 3 times a week for two years. The Crippled Children Foundation encouraged my mother to transfer me to a special hospital, but my mother refused. She wasn't going to send me away to an institution. As I look back at the situation, I realize what a valiant, loving caring mother I had.

When I was two years old, I was fitted with a brace on both legs and on my back. I had to learn how to walk as I never learned as a baby. To assist in learning to walk, my dad built a parallel bar to put in the living room.

The March of Dimes helped tremendously with the hospital bills and the brace that I needed. In fact, the March of Dimes wanted me to be the poster girl for the foundation. After 12 years of being the poster girl, I asked them to replace me with someone else that was younger.

Gradually, I began to walk with crutches and a walker. Dr. Kickham was my doctor. He suggested

several surgeries which included transplanting muscles and bones from various parts of my body to help where I had weak muscles. Another surgery was to stop the growth in one leg so the other leg would catch up the 2 inches that were shorter. To correct my ankle from rolling, surgery was performed to place a plate in my ankle. A cast was put on my leg. The nurses failed to elevate my foot and my ankle swelled so bad that I screamed in pain. They called the doctor and he removed the cast and replaced it with another. He mentioned to my mother that gangrene could have set in if this wasn't taken care of immediately.

Shoulder surgery was also done to fuse my shoulder so I would have more strength in my lower arms. This meant wearing a cast from my shoulder to my waist for 6 weeks. When the cast was removed, my arm couldn't turn the way it was supposed to.

After 2 months of therapy, I went through another surgery which meant breaking my shoulder and realigning it. That meant another 6 weeks in a cast. Several more operations were performed. I was determined to make the doctor's comment of being in a wheelchair by the time I was 12 years old wouldn't happen. My mother and I were determined that this would never happen.

I was also told that I couldn't ever have children. I proved them wrong on that also. I carried and delivered three sons with no difficulty at all.

I am a very independent person. I do anything I set my mind to, it might be done in a different way then the average person. However with the help and strength of our loving God, I can do just about everything. I am a very religious person.

During the years, I have been a Sunday School teacher, in the church choir and helped out with the Christian day school. Every night I pray to God that he helps me through another day. He has never failed me.

For the past 25 years, I have worked full time. For several years I worked for several Orthopedic surgeons. Now, I enjoy working in the office of Saginaw Senior Care Nursing Home. I am a very compassionate person with the elderly.

At the present time, I am facing post-polio issues. Gaining weight has caused me to tire easily when I walk, but I hold my head up high and keep hanging in there trusting in the Lord to continue to take care of me.

Continued next page...

Sue Bannan-Engel Story *continued...*

I will be eternally grateful to my mother for being the wind beneath my wings, giving me the strength to persevere.

As I look back, I remember how upset I got when children would stare at me. Now, it doesn't bother me as much. When people stare I tell them right away that I had Polio before a vaccine was available.

I have been married twice and both men did not consider my disability a problem. I was accepted for what I was inside, not any disability.

The End ♦♦

BEWARE VESICARE!

By Dr. Richard Bruno

January 10, 2011 at 1:41pm on Facebook.

BEWARE VESICARE! No polio survivor -- no one with breathing problems -- should take Vesicare.

A polio survivor was given Vesicare on November 18th. Four days later she was too exhausted to leave the house. The next day, all she did was sleep. By Wednesday, she was unable to stay awake. When she was awakened she stared into space, unable to understand or respond to questions. Even more frightening, her ability to breathe was compromised and she was placed on a ventilator.

Vesicare was stopped on November 24th. The next day, Thanksgiving, she was still unable to stay awake on her own but, when prompted, did try to eat. She discovered that her stomach and intestines had shut down.

Unfortunately, Vesicare has an extremely long halflife. It would take her body anywhere from 10 to 14 days for Vesicare to clear out. During those days, although she mostly slept, she became progressively more aware and mentally sharp when awakened, but she could only eat very small amounts.

On the 15th day after Vesicare care was stopped, she awoke. She was able to stay awake on her own and was her usual intelligent and funny self, albeit easily tired. Today, one month after waking from her Vesicare-induced stupor, she is eating nor-

mally, still requires the ventilator at night and at times throughout the day when her diaphragm is unable to push enough carbon dioxide out of her lungs. She will need the ventilator for the rest of her life.

WHAT ARE THE MORALS OF THIS STORY?

FIRST, no polio survivor -- no one with breathing problems -- should take Vesicare.

Vesicare not only turns off the bladder, but also turns off the stomach and intestines and enters the brain. Vesicare is known to block activity brain areas damaged by the original polio infection, the brain activating system. In fact, the FDA has recently required Vesicare's manufacturer to add "somnolence" to Vesicare's list of side effects. (Somnolence? How about a coma?)

Vesicare is also known to block brain diaphragm stimulating neurons. I am concerned that Vesicare will very likely have the same effect in other polio survivors, especially those who originally had bulbar polio or any polio survivors who have breathing problems, such as central sleep apnea. What's more, I am also worried that individuals who have both difficulty breathing and bladder problems, and might be prescribed Vesicare -- those with muscular dystrophy, multiple sclerosis, traumatic brain injury -- might have a similar reaction. **SECOND, polio survivors can have difficulty blowing off carbon dioxide and should not be given oxygen without having their carbon dioxide monitored, since oxygen levels can be normal while carbon dioxide can become dangerously high. THIRD, a polio survivor should never take a drug that is anti-cholinergic or that enters the brain without your doctor researching the side effects. The coma you prevent will be your own.♦♦**

*Never Think Hard about the PAST,
It brings Tears...
Don't Think more about the FUTURE,
It brings Fears..
Live this Moment with a Smile,
It Brings Cheers.!!!*

Can Polio Be Eradicated?

A Skeptic Now Thinks So

By Donald G. McNeil Jr.

Two weeks ago, at the end of an interview about whether polio really can be eradicated, Bill Gates muttered aloud to an aide escorting the interviewer: "I've got to get my D. A. Henderson response down better." By that he meant that as long as he was committing his fortune and prestige to the battle against polio — as he did that day in an announcement at the former Manhattan home of Franklin D. Roosevelt — he would need a stronger riposte to journalists quoting Dr. Henderson's powerful arguments that the virus is just too elusive to subdue. In a world of quotable medical experts, why does it matter what one particular expert thinks? Because, for better or worse, the mantle has been wrapped around the venerable 82-year-old Donald A. Henderson that he is "The Man Who Wiped Out Smallpox." (In truth, the smallpox fight — the only successful one so far against a human illness — had many generals. One is Dr. William H. Foege, 74, a former director of the Centers for Disease Control who is now a senior adviser to the Bill and Melinda Gates Foundation and who fervently believes that polio can be eradicated. But over the years, Dr. Henderson has patiently explained his doubts, in persuasive detail, to many medical journalists calling him with questions about any disease eradication effort.) What neither Mr. Gates nor the reporter interviewing him knew was that Dr. Henderson had changed his mind two days before. "I see as much greatly augmented the probability that we can stop wild polio virus," he said Wednesday in a follow-up interview — the opposite conclusion to the one he had given to the same reporter on Jan. 26, five days before the Gates interview. "I apologize," he added. "It's not my wont to turn on a dime like this. I don't think I've done anything like this before." What changed his mind, he said, was a conversation with Dr. Ciro de Quadros on Jan. 29. Dr. de Quadros, a former director of the Pan American Health Organization, has his own mantle: "The Man Who Found the

Last Case of Smallpox in Ethiopia and Chased Polio and Measles Out of the Western Hemisphere." While nothing has changed about the virus or the vaccine, several things Dr. de Quadros told him were persuasive, he said. "I was unaware of how committed Gates is," he said. "He's saying polio is his No. 1 priority." Also, he said, he was impressed with the new nine-member monitoring board being set up to advise the World Health Organization. Polio has been driven down by 99 percent since 1985, but the last decade has been frustrating, with repeated outbreaks in countries where the virus had been eliminated. "There's been too little dissent in the last 10 years," he said of the approach used by the W. H. O. and its partners, much of which depended on endless new rounds of fundraising. "Now the thinking and the muscle have changed," he said. Also, Gates Foundation money will allow more experimentation with the oral vaccine used in poor countries. In theory, he said, the live virus in it can be weakened enough to prevent the one-in-two-million chance that it will mutate into a form that can paralyze, a problem known as vaccine-derived polio. (While one in two million sounds infinitesimal, it is not when 134 million children are vaccinated in one day, as happened in India in 1998.) And it may be possible to make a vaccine that needs no refrigeration. Vaccine going bad in the tropical sun is a major problem for rural vaccination teams. Also, he added, Dr. de Quadros himself taking a role will change the field. "I watched him perform in Ethiopia," said Dr. Henderson, who recruited Dr. de Quadros into the smallpox campaign. "The obstacles were unbelievable — the emperor assassinated, two revolutionary groups fighting, nine of his own teams kidnapped, even a helicopter captured and held for ransom. He kept the teams in the field — and that helicopter pilot went out and vaccinated all the rebels." Asked about Dr. Henderson's change of mind, Mr. Gates said on Monday, "He's right, and I'm looking forward to sitting down with him in the next month and getting his advice on this thing." -*The New York Times February 16, 2011*

POLIO TALES

by Jerry hazel

Onset of my Polio

I was 7 years old, and it was a beautiful sunny September Sunday morning when I woke up. My neck hurt a little bit and was stiff when I went out to get the Sunday morning paper. We were in the process of peeling off the wallpaper of our living room and it was in a disaster area to say the least. I sat down in the only chair available and it faced our big east bay window. The sun was streaming through the window as I attempted to read the paper. I loved Red Ryder and Little Beaver, which was a comic strip in our Sunday paper. My neck was so stiff by then. I had to hold up the paper to read it. The sun was coming through the window so strong that I could not read the paper well and got a little upset. Mom got up and made breakfast and asked me why I was so quiet, and I told her I didn't feel good. In mid-afternoon I felt bad and was so weak that I laid down on the couch and never got up again for many months. Our family doctor was called and diagnosed Polio. As I recall, he did this almost immediately.

"PEST HOUSE"

Most of you probably don't even know what a "pest house" is. A "pest house" back in history, was an old house of some sort, usually on the edge of town, where anyone with a contagious disease was banished. Our pest house was not that severe. It was quite a nice facility adjacent to our local hospital. While in the "pest house", my parents were not allowed to have any contact with me. The way that they visited me was to bring a stepladder and they would climb up the step ladder and talk to me through the open window. For some reason or other, I would not eat. They asked my Mom what to feed me, and they were dumbfounded when she told them spinach. So they got me spinach and I wouldn't eat it. So they asked Mom what was wrong. She tried some of the spinach they had fixed for me and found that there was sand in it, and I hated sand in my food. They had gone through the trouble of getting fresh spinach and cooking it for me in an effort to get me to eat something--and it failed! They felt extremely bad. Mom told them to get cans of spinach from the stores and feed it to me. The upshot of it was, I ate an incredible amount of spinach for a couple of weeks and survived. One of the very bad parts of being in

the "pest house" was that all of my toys that they had allowed me to have had to be destroyed. I raised a severe ruckus, as I had a Gene Autry cowboy doll. My aunt had made a number of clothes for the doll and I didn't want to give them up. My folks made a deal with them. My doll and its clothes had to be hung in the sun for a week, because they felt this would kill the virus. I still have the doll and most of the clothes that my aunt had made for it! While in the "pest house", the paralysis came on viciously! I was completely paralyzed and unable to do virtually anything. It was very, very hard on my Dad particularly as I was a big strong kid and able to compete in sports with kids much older than myself. In later years, Mom told me that when Dad saw that I was paralyzed, it was the only time she had ever seen him cry!

After approximately a month, I was released to a regular hospital for treatment.

TREATMENT

The first treatment that I had that I can recall is also the last one I can recall. They placed me in a "Hubbard" tank which I always called a "parboiling!!" tank. If you are not familiar with a Hubbard " tank, they place you in very hot water and they add steam until you are parboiled and you come out looking like a 10lb lobster. They took me out and placed me on a workout table. They took my right leg and raised it up and I screamed in agony and that is the last I remember of my therapy. The next 3 years are largely blotted out of my mind, which is a blessing. I do, however, remember some of the very nice things that occurred in this 3-year span, but none of the therapy.

The first thing I really remember after this period was going home for Christmas in 1941, about 4 months after the onset of Polio. When I went into the hospital, we had a 1930 Packard and in the interim Dad had bought a 1936 Packard with huge suicide doors on it. I was strapped to a Stryker frame as part of my treatment. They picked me up and put me in the big Packard through its monster doors so that the Stryker frame laid on the top of the back seat and the top of the front seat, and took me home!!!

Back in the hospital, the therapy continued and obviously I got better because I was given a wheelchair to scoot around with. This was LIBERATION! It was the old style wheelchair with big front wheels and small caster wheels on the back.

Continued next page...

POLIO TALES *continued...*

As part of my treatment, I was in a real confining "airplane" brace for my right arm. Obviously, I could not use my right arm to make the wheelchair go, so I used my right foot on the spokes of the right wheel and got very good at making the wheelchair go. We had some rather nice races, as I was in a children's ward. A couple of things happened as a result of using my right foot on the spokes.

One time I poked, my foot in too far and it got stuck and spun me around a couple of times because we were racing and one of the nuns was trying to catch us. Needless to say, with me spinning in circles, I got caught. Another funny thing that happened was a portion of the reception area hallway was carpeted while we were there. Being 7 years old, I didn't understand static electricity. The tires on the wheelchairs were hard rubber, and I came tearing down the hallway after a race and was very thirsty. I rolled my wheelchair up to the drinking fountain and reached to turn it on and got a violent electric shock and talked about it to myself. The friend that I was racing was right behind me and wanted a drink too, and asked me why I jumped and I just said, "I hurt", and got out of the way. He went to the drinking fountain and got the same vicious shock. Now you must understand, he was a little older and a little more versatile with language than I was. He discussed it with me as he was trying to catch me, which started a new race!!! Several times as a result of these races we "wall adjusted" our wheelchairs and gouged some pretty good sized holes in the plaster.

While in the hospital, I had a series of appendicitis patients except for one young fellow with a broken leg. He was in his mid-teens with a great sense of humor and a real nice guy. He had a friend of his bring in a live goldfish. He called for the bedpan and when the nurse left, he put the goldfish in the bedpan. He hit the call button for the nurse, and when she went to empty the bedpan, there was a world-class scream from the bathroom. I don't remember if there was any punishment meted out, but we sure enjoyed the episode. The only other thing I remember about the treatment was trying to learn to walk late one night with no one around. Apparently I did not want people to see me unable to walk so I took it upon myself to try to learn to walk with no one around. I can remember standing beside the bed and trying to walk, only to crash

into the floor with my airplane brace jamming into my ribs. Then I had to use the brace to hook to the bed and pull myself back up and try again. I only remember this one night, so I don't actually know how much of this I really did, but this incident is very vivid in my mind because it hurt so bad when I fell.

SWIMMING

At that time, swimming was the best physical therapy that we could have to help us rebuild our muscular system. I swam so many miles and so often, I nearly grew gills and to this day I do not like to swim. As result of all this swimming I got very good and by the time I turned 16 was one of the best in the area.

Unfortunately, I never got much faster while the rest of the boys kept right on getting faster so I quit and went on to other things. I now only go the beach for "bird watching, and this activity made, the whole trip worthwhile.

UNIVERSITY OF MICHIGAN

In 1942, I was sent to the University of Michigan for an experimental operation of a tendon transplant. To the best of my knowledge, this surgery had not been successfully done up to this point. It is also my understanding that my tendon transplant was the first successful one. They took a tendon from my left foot between my small toe and ankle and wove it into my right hand and thumb, which gave me the "opposable thumb" that I did not have in my right hand. This gave me my functioning hand back!!

For years after this surgery, at every Polio clinic or hospital I went to, all that had to be done was a cry sent up, "Here's a tendon transplant", and doctors and nurses would gather around to see how well it functioned. I can still remember how great it was to be able to use my hand again as a hand instead of just a hook to pull things to me. It has degenerated again through Post-Polio problems so that I have lost most of what I regained through the surgery.

One of the very interesting things while I was at U of M Hospital was laying in my bed and watching the Planetarium work. The door would open up and then the Planetarium would turn to whatever they wished to view. For an 8-year-old, this was quite an interesting thing to watch, especially when I didn't have much else to look forward to at that time. As a result of this I became somewhat

Continued next page...

Polio Tales *continued...*

interested in astronomy and eventually took it as an interest course in college.

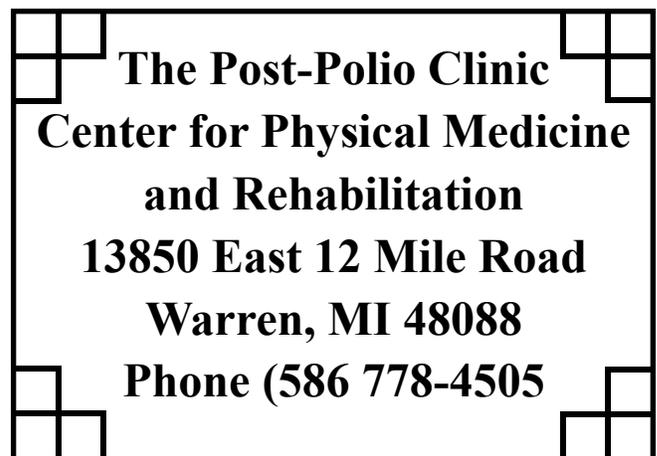
SCHOOL DAYS

As a result of Polio, I missed almost my entire second grade. It was stipulated by the teachers that if I could learn long division before I went into third grade, I could continue with my class. I spent nearly all summer and most of September learning long division. It was successful, as I was able to continue with my class.

One of the most vicious parts of my Polio that I can remember was the beatings that I got on a fairly regular basis from three kids in my grade school classes of 5th and 6th grade. We did not have much money back then, as the expenses involved in my Polio were a severe strain on our family finances. As a result of this, I wore many clothes that were from the Salvation Army and hand-me-downs from many different places. I had to wear stocking caps instead of the bomber helmets that many of the youngsters were wearing at that time emulating the heroes of the Air Force. These guys would say "well, let's find the crip and beat him up." One of things that they did regularly was take my stocking cap, fill it with snow, beat up on me, throw me down in the snow and wash my face with the snow. Dad, as a result of the World War II, was working a horrible amount of hours in the war effort, so was almost never home and he did not see me come home all beat up like mom did. One day he was home when I came home from school all beat up. He asked Mom "What 's going on here?" She explained the situation to him and he said, "Well, I guess you'll have to learn to fight." Dad had been a professional boxer and wrestler when he was young and had always taught us that fighting was not a good solution. He had a radical change of heart and proceeded to teach me to fight. He was a good teacher and I was a good student and learned to fight very well. The next part of the story my sister related to me, as I do not remember this at all. I came home from school beat up worse than I had ever been beat up, but I had a smile on my face. As Mom was helping me clean up, the telephone rang. It was a call from the hospital, as one of the boys was in the hospital with a badly broken nose. Telephone rang again, and it was another irate mother whose boy had some teeth missing. Another phone call about another boy that was having severe problems as a result of a beating he got after

school. The story I got was that I had gotten each one of these boys by themselves where they could not gang up on me and beat them up severely. Some days later, the police and juvenile authorities came to the house with the idea that I should be in a reform school because I was so vicious to beat up three kids this way. An older man from down the block heard the ruckus and came to see what was happening as we lived in a small town and most people were wont to do. He told the police what the boys had been doing for quite some time, and said he would testify in court as to what led up to this problem. The authorities left, and there was nothing more said about it. But the great thing about it was that I never had any more beatings (Interesting that I never had any fights of any kind in the rest of my school years apparently as a result of the severe beatings I gave these kids.)

It really is interesting that I don't remember beating up on those boys or anything connected to the episode ♦♦♦



SUPPORT GROUPS & INFORMATION CONTACTS

ANN ARBOR (PPSG)

Liina Paasuke (734)332-1715
Sunny Roller (734)971-1335
Meetings 3rd Tues. of August and December.

CLIO AREA POLIO SURVIVORS SUPPORT GROUP

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 of each month at 10:00am and lasts an hour. 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

Bill Messeroll (517)641-6398
Meet 1st Wed of Month (except July & January)

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

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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

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Linda Walthom Grand Rapids 616-363-7625
Lynette Hooker Grand Rapids 616-455-5748
Email: linsue@inbox.com
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INFORMATION CONTACTS

MICHIGAN POLIO COLLECTION LIBRARY

% Laura Barbour
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Phone 989-739-4065

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UP Rehab Medicine Assoc PC
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Post-Polio Health International (PHI)

4207 Lindell Blvd #110,
Saint Louis, Missouri 63108
FAX (314)534-5070 Phone (314)534-0475
info@post-polio.org www.post-polio.org

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

LAURELHAY@SBCGLOBAL.NET - Laurel
Escanaba, MI
BTOleksa@aol.com - Bernie
Rochester Hills, MI
vallen2@comcast.net-Velma
Muskegon, MI
hnjutzi2@ejourney.com- Jean
Harrison, MI
grossjjr@voyager.net - Janice
Lansing, MI
rick_kugel@hotmail.com - Rick
Rochester Hills, MI
sharon_kugel@hotmail.com - Sharon
Rochester Hills, MI
gramma44@hotmail.com - Linda
Farwell, MI
jpasich@sbcglobal.net - Judy
Ann Arbor, MI
vandar@sbcglobal.net- Darlene
Middleville, MI
pigger_38@yahoo.com - Bonnie
Grosse Pointe, MI
Patsyenne@aol.com - Pat
Allen Park, MI
PhyllisPanozzo@comcast.net. -Phyllis
Niles, MI
ronmagnuson@comcast.net - Ron
Warren, MI
rileyjlb@comcast.net - Judy
Dearborn Heights, MI
Cairnview@comcast.net - Ean
Dearborn Heights, MI
j.booth@comcast.net -John C. Boot
Grand Rapids, MI
lindagrimsley@sbcglobal.net Linda
Jackson, MI

ineer9298@wowway.com - Lawrence
Sterling Heights, MI
vhenry330@wowway.net - Virginia Henry
St. Clair Shores, MI
wwmessenger@aol.com - William
Lansing, MI
JPO6295@aol.com - John
Kalamazoo, MI
mleveemiller@frontier.com - Marilyn
St. Johns, MI
Tmartin458 - Theron
Battle Creek, MI
leberghoef@sbcglobal.net -Leonard
Jenison, MI
v1ctorious@sbcglobal.net - Vicki
Waterford, MI
GLacagoo@aol.com - Laura
Fraser, MI
LindaLRobb@aol.com - Linda
Kalamazoo, MI
jodell@netonecom.net - Jim
Marion, MI
besachs@sbcglobal.net- Bruce
Livonia, MI
BarbBasirico@cs.com - Barbara
Macomb, MI
turtles@voyager.net - Sue (TurtleLady)
Monroe, MI
maryk1660@aol.com - Mary
Muskegon, MI
Anniefred2001@yahoo.com - Pat
Okemos, MI
sithast@voyager.net - Sandra
Hastings, MI
bstevens1975@yahoo.com - Bobbi
Royal Oak, MI
KRBWAY@aol.com - Ken
Hart, MI
sharonf@btc-bci.com - Sharon
Lakeland, FL
fabo48@hotmail.com -Fran
South Haven, MI
LLBUTLER149@MSN.COM -Linda Butler
Quincy, MI
thadandshei@juno.com - Ted
Dearborn Heights MI
fradlefraser@aol.com - Lorraine
Auburn Hills MI
Fraser, MI
Continued next page...

POLIO SURVIVORS SHARING *continued...*

jmc65@ncats.net - Michael	Fremont MI	suzee5@juno.com -Ellen	Ortonville,MI
mrsrogers@chartermi.net - Sharon	Fenton, MI	kwoodbeck@att.net -Kaye	Redford , MI
boborsarah@juno.com - Bob	Clarkson, MI	ruthkos12@yahoo.com Ruth	Rockford, MI
virginiafinkbeiner@yahoo.com - Virginia	North Branch, MI	ehbucsek46@yahoo.com Elizabeth	Romeo, MI
itopor@aol.com - Iris	Farmington Hills, MI	RLloreJ@aol.com -Ramón	South Haven, MI
jackofwb@juno.com - Jack	W. Bloomfield, MI	tryry@comcast.net -Mary C Riley	Waterford, MI
jeanniew@provide.net - Jeannie	Hartford, MI	steve@vear.com -Stephen	Hillsdale, MI
r1obin@localnet.com	Clare MI	hrkolde@comcast.net - Rowena	Bloomfield Hills, MI
dmrydzon@aol.com - Debbie	Chelsea MI	cheryl_obannion@hotmail.com - Cheryl	Phoenix, AZ
abufflogal@yahoo.com- Barbara	Rochester Hills, MI	dworthy@usamedia.tv- Douglas	Grass Valley, CA
dausterberry@sbcglobal.net- Doris	Farmington Hills, MI	lkfrisco@msn.com - Lee	Santa Maria, CA
AlanLoisS@aol.com - Alan	Plymouth, MI	daaog@home.com - Anne	Southern California
gdr1237@hotmail.com - Gordon	Decatur, MI	decopainter1998@yahoo.com - Jeannie	Roseville, CA
JoanMcCarthy@sbcglobal.net - Joan	Grand Haven, MI	eddyc7@peoplepc.com - Edward	American Canyon, CA
jackofwb@juno.com - Jack	W. Bloomfield, MI	PPSBIB7@aol.com - Bonnie	Half Moon Bay, CA
denny@power-net.net - Dennis	Chesaning, MI	Ellaroy@aol.com - Ellie	Colorado Springs CO
cndchurch@lakeshore.net (summer)	Pentwater, MI	johnandsue6563@yahoo.com - John	Evart, MI
cndchurch@gl3c.com (winter) - Charles	Six Lakes, MI	tpbrown@frontiernet.net - Tim	Grosse Pointe Woods, MI
gpjay@toast.net - Pat	Selby Twp, MI	jjscg123@adelphia.net - Jane	Chickasaw, Ohio
jhuck@att.net - Jerry	Livonia, MI	bashley1@cfl.rr.com - Burnett	Bushnell, FL
jandj316@aol.com - Jennifer	Livonia, MI	cmerrill@cfl.rr.com - Chuck	St. Cloud , FL
winim@att.net -Wini	Manistee, MI	deniswahl@comcast.net - Dennis	Sanibel Island, FL
rconnectus45@yahoo.com - Richard	Livonia, MI	kkopro9885@aol.com—Karen Koproces	White Cloud, MI
PRISCSMTH@aol.com - PAT	Shelby Township, MI	JSGrady@aol.com - Jerry	Fort Wayne, IN

Continued next page...

POLIO SURVIVORS SHARING *continued...*

- beckie44@juno.com - Beckie
Indianapolis, IN
- JohnandKeriG@yahoo.com - Keri
TENN
- wctubandt@aol.com - Walter
Woodinville, WA
- Bobuschi@msn.com -Ursula
Olympia, WA
- ppseng@aol.com - Dr Richard Bruno
Englewood, NJ
- susanvrm@clear.net.nz - Susan Kerr
New Zealand
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7569 Harrison
Westland, MI 48185
(734) 422-5659

SECRETARY

Dianne L. Dych-Sachs ps2011
1070 Balmoral
Mt Clemens, MI 48043
(586)465-3104 dldych@wowway.com

ASSISTANT SECRETARY

Judy Pasich ps2011
617 Revena Place
Ann Arbor, MI 48103-3639
(734) 623-1252 jpasich@sbcglobal.net

TREASURER

Timothy P Brown ps2012
1530 Fairholme
Grosse Pointe Woods, MI 48236
(313) 886-6081
tpbrown@frontiernet.net

ASSISTANT TREASURER

Richard Kugel 2012
2715 Plymouth
Shelby Twp, MI 48316
(586)786-1029 Rick_kugel@hotmail.com

LIBRARIAN

Laura Barbour ps2011
1156 Avon Manor Road
Rochester Hills, MI 48307-5415
989-739-4065 denilaur@sbcglobal.net

Ginny Brown 2011
1530 Fairholme
Grosse Pointe Woods, MI 48236
(313) 886-6081
tpbrown@frontiernet.net

Susan Burton 2011
40547 Firwood
Plymouth, MI 48170
(734) 765-8384
Lucyandbailysmom@aol.com

Carl Fenner ps2012
1146 Kettering St
Burton, MI 48509-2368
(810) 742-2709

POLIO PERSPECTIVES

EDITOR, Vera Hazel 2011
15235 Ackerson Dr
Battle Creek, MI 49014
(269) 964-8184 vlhazel38@comcast.net

Jeremy Jaworski 2012
21553 Indian St.
Southfield, MI 48033
(248) 350-8948
jjorthotist@yahoo.com

Bonnie E Levitan ps2011
311Lothrop Rd
Grosse Pointe, MI 48236
(313) 885-7855
Pigger_38@yahoo.com

Paula Lemieux ps2012
21295 Whitlock
Farmington Hills, MI 48336
(248) 474-1817
Plemu@sbcglobal.net

William Messeroll ps2011
13350 Chandler Rd.
Bath, M 48808
(517) 641-6398 wvmesseroll@aol.com

Michigan Polio Network, Inc
1156 Avon Manor Road
Rochester Hills, MI 48307-5415

Pam Spinella 2011
23304 Beverly
St Clair Shores, MI 48082
(586) 294-3135
plspinella@sbcglobal.net

Tamara L Treanore 2012
13850 E 12 Mile Suite 2-13
Warren, MI 48088
(586) 541-1040
tltreanore@yahoo.com

William Thiedeman 2011
6537 Ostrum Rd.
Belding, MI 48809
(616) 794-9738
uscgill@pathwaynet.com

MPN WEB SITE

[http://
www.michiganpolionetwork.com/](http://www.michiganpolionetwork.com/)

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