Paula Lemieux has been a driving force and chairperson for the last two conferences. Nothing is an obstacle for Paula. When confronted with the DNR rules and regulations for the handicapped in a state public park, she addressed the concern with a state committee who changed the ruling and the way handicapped are treated in the parks. She even got the DNR to provide information on accessibility and recreational opportunities in the outdoors for the handicapped for our conference attendees. Congratulations Paula on receiving the Ruth Cornwell award!

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MPN Board of Directors Meetings
2011 Board of directors Meetings begin promptly at NOON at TONY M’S RESTAURANT
3420 S CREYTS RD
LANSING, MI 48917
November 19, 2011
Your board members are very interested in what you have to say. Consider attending one of our meetings.

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FROM THE CHAIR

Chairman, Bruce Sachs

Many of you attended the recent Post-Polio Conference and came away with useful information from both the presenters and the vendors. These conferences would not be possible without the help of many people. I especially would like to thank Conference Chairman Paula Lemieux, and assisting her were Laura Barbour, Tim & Ginny Brown, Dianne Dych-Sachs, Vera Hazel, Sharon & Rick Kugel, Arnie Lemieux, Bonnie & Dick Levitan, Dan Matakas, and Barbara Oniszczak.

Due to circumstances beyond his control our keynote speaker was unable to fly in from New York. A big thanks to Orthotist Tamera Treanore and Amigo dealer Scott Chappell for speaking on very short notice. We surveyed the attendees about the next conference and now would like to get statewide input. [See the related survey on page 19]

At the Annual meeting in May I outlined the State of the Network and divided it into 3 parts.

MEMBERSHIP-- Due to a great effort by the Membership Chairman and the Librarian we have increased our membership, but there are former members that have not renewed and there are survivors that don’t know about the Network. We all must make an effort to sign up former members and recruit new members.

LEADERSHIP-- Prepare for the future. Although we have a good group of Board members now, as Board members we must continue to look for the next leaders of the Network. Remember, most polio survivors are retired and may be looking for something to do. Also, Board members do not need to be polio survivors.

FUTURE of the NETWORK-- Where will we be in 5 years? None of us know where WE will be 5 years from now, but if we want the Network to continue we must put more effort into the first 2 parts of this report. The Network has 4 major assets, The Perspectives, the Library, the Web Site, and most important, the membership. We must continue to support these and also provide Conferences for our members. The Network has been in existence for over 25 years, we must continue to work on the next 25 years.

Presently we have openings on the Board of Directors. We meet in Lansing about 4 times a year from 12:00 to 2:00 at a restaurant and have lunch as part of the meeting. Board membership is open to both polio survivors and non polio people. Following are the Board requirements. The Directors of the Network shall hold office for a term of two years commencing with the first day of June following their election to office. A Membership election shall be held prior to the Annual Membership Meeting to fill all vacancies existing at that time. Premature vacancies may be filled by appointment by the Board of Directors for any period until the next election, at which time a Director shall be elected for the same tenure as the terminated Director held. If you are interested, we would like a short paragraph on your background and why you would like to serve on the Board, to be submit to me. If you would like to wait to make a decision, you are invited to attend any Board meeting as a guest.

We hope to see you at our next conference.

Bruce

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
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
c-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 Rapids 616-363-7625
Lynette Hooker Grand Rapids 616-455-5748
Email: lysue@inbox.com
Chuck Bond Rockford 616-866-1037

INFORMATION CONTACTS

MICHIGAN POLIO COLLECTION LIBRARY
% Laura Barbour
1156 Avon Manor Road
Rochester Hills, MI 48307-5415
Phone 989-739-4065

FRED MAYNARD, MD
UP Rehab Medicine Assoc PC
580 W College Ave, Marquette, MI 49855
Phone 906-225-3914
fmaynard@penmed.com

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

Autumn, 2011
Many thanks to all attendees at the MPN Conference who stopped at the Library table for a chat or to pick up some of our information about various aspects of Post-Polio Syndrome. It was, as always, a pleasure to match names with faces!

Thanks also to the man who won a copy of David M. Oshinsky's excellent POLIO: AN AMERICAN STORY at the Conference. He very kindly turned around and donated his prize to the Library!!

READER REVIEWS
One of the MPN Board Members read a new book entitled THE POLIO JOURNALS: LETTERS FROM MY MOTHER, by Anne K. Gross, Ph. D. In her review, Judy Pasich stated that "this book was quite enlightening as I seldom reflect on my having had polio, it is just a given. [The book] made me much more aware of the psychological effects of having a disability and how it affects family dynamics. It gave me insight as to how and why some things I feel stem from my polio. This book gave me many "aha" moments. I felt myself relating to the mother who had polio and [to] her mother and daughter. This book would benefit anyone, including the non-handicapped, as it tells how a feeling of being different and trying to fit in affects everyone, the one with a disability and their family and friends. The author also give examples of how and how not to deal with difficult situations. There is much to be learned from this book."

Ginger Ford read a new book called A ROUGH ROAD by Patrick J. Bird. She commented that the book "illuminates nineteen months in his young life in the 40s when he contracted polio and was institutionalized in what he called a "Reconstruction Home." Full of sentiment and anecdotes, it stirred memories of my life when I too was hospitalized for surgeries and rehabilitation."

Bruce Sachs read FOUR BILLION DIMES by Victor Cohn. This book, published in 1955, is rather short and is actually a series of newspaper articles. Bruce commented that he thought they were well-written and covered an overview of the history of polio, with a great emphasis on FDR and the rise of the March of Dimes under the leadership of Basil O'Connor. The book also explores how the March of Dimes got involved in the search for a polio vaccine. In Bruce's opinion, FOUR BILLION DIMES would provide a good overview for someone just beginning to learn about polio.

Judy, Ginger and Bruce, thank you all for completing your book reviews, and letting us know your thoughts about these new and old books in our Library Collection.

OTHER NEW BOOKS
Besides the aforementioned and reviewed new books, there are two others for you to think about borrowing.

THE POLIO HOLE: THE STORY OF THE ILLNESS THAT CHANGED AMERICA comes to us from Shelley Fraser Mickle, who had polio six weeks after beginning first grade, when she fell "down the Polio Hole," which is how she thinks about the illness. According to a paragraph on the back of this volume, Ms. Mickle, "while dealing with braces, crutches, and the loss of muscles that will never come back, ...finds she is still very much who she always was. Only now she is more aware of the world’s miracles.

SOS(STOP ONLY SUGAR) DIET, was written by James A. Surrell, M.D. He maintains that most other diets are way too complicated, and that people can lose weight by following these simple rules: 1. Low sugar; 2. High fiber; 3. No more rules! This book was donated to us by an attendee at last year's Bay Cliff week. How kind!"

Until next issue of "Polio Perspectives," enjoy the change to autumn's colorful landscape, and take care.
Laura Barbour, MPN Librarian
POLIO STORY
By Sue Ann Price
My polio story starts at Perry High School on a Wednesday in October of 1953. I was 13 years old and my class was having a hayride that evening. I didn’t feel well all day, but I knew if I told my mother she wouldn’t let me go. So I kept quiet. Needless to say I didn’t have a very good time. I was unable to find a comfortable way to sit on the wagon, with my legs hanging over the edge, straight on and flat on the wagon, or on my knees. I just hurt. I continued to feel worse and stayed home from school on Thursday. I was unable to sleep Thursday night because of the pain. On Friday Dr Rozan in Lansing agreed to see me without an appointment. I remember sitting in the waiting room with my mother and sitting with my back very straight on the very edge of the chair seat and thinking if maybe I didn’t move and breathed very carefully the pain may not be so bad. Also waiting that day was a lady on her lunch break from work. When her name was called she gave me her appointment time, because she saw I was in so much pain. Dr. Rozan examined me and because of my reaction when he touched the back of my neck and I was unable to put my chin on my chest he told my mother I probably had polio.

I went with my mother to #.W. Sparrow Hospital Annex directly from the doctors office. The building is no longer there. It sat on a corner of Michigan Ave close to Flandor Shopping Center and across from a Chevrolet dealership. It was torn down when highway 127 was built. I was admitted and given a spinal tap to confirm Dr Rozan’s diagnosis. I remember the doctor that performed the spinal tap and the nurses that assisted as being very kind and patient, because I was scared. I followed the doctors instructions and curled up in a ball like a kitten and the procedure was soon finished. I was placed in isolation and the hot packs were started, which began to relieve the pain. It was in that room that I learned to spell Chevrolet. While lying in bed the only thing I could see out of my window was the word Chevrolet in big letters vertically on the smokestack of the dealership. I remained in isolation for a week and the only people allowed in my room were those that cared for me and applied those wonderful pain relieving hot packs. They would gently slap those pieces of wool against my legs until I said I could tolerate the heat. During the week I spent in isolation the things I missed most were kisses and hugs and the touch of the people I loved most—my family. When my family visited they had to stand in the hall and we looked at each other through a window. During that week my paternal grandmother and aunt returned from a vacation up north. My grandfather had passed away in the spring. My aunt snuck into my room when the staff wasn’t looking to show me the pictures she had taken on their trip. She held them up for me to see and we never touched. The day I was moved out of isolation I was given what I thought was a strange bath. I was washed by the staff first on one side of my body vertically from head to toe and then the other side. I was transferred to a huge ward. There were 16 to 20 patients in the room. I was told they were painting in the smaller rooms. It was great. I had had enough of being alone. I was given a pamphlet explaining physical therapy and the biggest lie on it was “it won’t hurt.” Apparently that was supposed to prevent us from being afraid the first time we went to therapy.

Therapy was hot packs, massage, stretching, muscles and moving limbs where they would not go on their own. At the end of the second week I was discharged to go home. My mother took me back to the hospital three times a week for therapy and that gradually decreased until it was no longer needed. During this phase I exercised at home on my own in a tub of hot water and on the floor twice a day. Every evening my Dad worked with me. I taught him how the therapist moved my legs to stretch the muscles.

I feel I was very lucky because within three days I

Continued next page...
Polio Story continued...

became sick, got an immediate diagnoses and treatment began. I was the only one I know of to contract polio in 1953. My family was very supportive and encouraging. My Father did not accept any financial help from the March of Dimes. He made regular payments to hospital to cover what was not paid by insurance. He felt there might be another family that needed those funds more than we did. In my sophomore year of high school I dated a boy who had a very mild form of polio. So because of this my doctor gave me the Salk Polio vaccine. Theory being that there was a very slight chance I could have polio again and if I did it would probably be a worse form. Later I was also given the Sabin vaccine.

I graduated from high school, married, had three children, attended Lansing Community College School of Practical Nursing and worked for 37 years.

When I was 45 years old my post polio symptoms started, not knowing at the time what was wrong. All of sudden I couldn’t lift a block of salt for the water softener that I had moved only a short time before. I made an appointment with my physician and after an examination he said, “something is wrong and I don’t know what it is.” Before I left the exam room he called and made an appointment for me with a neurologist. After an examination and testing the neurologist made the diagnosis of post-polio syndrome. The weakness has been focused in my right arm and hand and has gradually worsened through the years. In the past year I feel my right leg has started to weaken. If I walk any great distance without rest my right leg begins to feel “rubbery”. I’ve also noticed increased feeling of fatigue, weakness and coordination in my right arm and hand. When I had polio it was mainly my right side that was affected and mostly my right leg. After my diagnosis of post polio I was told to conserve my energy. When possible sit rather than stand, don’t over use my right arm by reaching or doing something that requires raising my arm over my head. Just take it easy, get lots of rest and don’t get overly tired.

One day a few years after my diagnosis I felt very energetic and decided to rearrange my living room furniture by myself like I used to do, knowing somewhere in the back of my mind that I probably shouldn’t. But I was home alone so I pushed, pulled and wiggled everything into new positions until I got to the television. It was a console T.V. and I had moved it to the center of the room when I started, but when I tried to push, pull or wiggle it into place — I couldn’t budge it. I immediately knew I had done something I shouldn’t. When you lose any strength, you never get it back. So in the years since I’ve tried to do better and listen to my body to conserve what strength and energy I have left.☺

Thank you
Conference Donors
March of Dimes Foundation Michigan Chapter,
Relax The Back Store,
Guardian Medical Monitoring,
Carroll Baker-Flint,
Mark Sobeck-Rochester Hills,
Susan Taylor,
Ernestine Pixley

PAULA receives the Ruth Cornwell Award
My life as a Polio survivor
By A. Lesa Quade

My story begins in 1959 on a farm in Arkansas where I lived with my grandmother. I was 6.5 years of age. It was a very hot summer night as summers go in Arkansas. I remember having to use the bathroom and when I got out of bed to go I fell and couldn't get back up. The next morning my grandmother took me to the doctor, I guess he was a general practitioner, but he couldn't figure out what was wrong. So this was the beginning of my life as a Polio survivor and many tests to figure out why I couldn't walk.

No one else in the family had Polio so there were no warning symptoms. No one suspected Polio because the vaccine was readily available. But because it was administered by needle I was not allowed to take it. My grandmother did not like the idea of poking holes in such a young child. I agree. I was deathly afraid of needles. Later in years it was administered by sugar cubes. I never could figure out why I had to take it after the fact, but so be it.

I was eventually sent to the Children's Hospital in Little Rock, AR. I suppose it was the best of the hospitals at that time. Remember, I was only 6.5 years old and didn't know what was going on. I was admitted to the hospital and the journey of many tests began. One of the most memorable tests given to me was the spinal tap. As a young child that had to be the longest needle I had ever seen. It was scary and painful. I remember the blood curdling scream that I let out when they poked me in the back. I heard my mother scream as she ran toward me down the hall and the staff had to get her under control. She was not allowed in my room until later. In reading other stories I see one thing we all have in common and that is the dreaded spinal tap. As a young child that had to be the longest needle I had ever seen. It was scary and painful. I remember the blood curdling scream that I let out when they poked me in the back. I heard my mother scream as she ran toward me down the hall and the staff had to get her under control. She was not allowed in my room until later. In reading other stories I see one thing we all have in common and that is the dreaded spinal tap. Some people were put into the fetal position when it was administered but I remember lying flat on my stomach. Either way it was very painful.

When I was admitted, I was placed in a ward with all girls each with different disabilities. I don't remember how long I was there I just know it seemed like a lifetime and I felt alone. My family had to get a ride to visit me so there weren't many visits. After awhile the long stay got easier and easier. I had fun with the staff, one nurse's aide in particular use to always check on me and she would play music and we danced and had a lot of fun. Everybody danced with Ms. Deloris. When it was time to go home, I didn't want to go; I felt like this was home. I wore board shoes at one time and I couldn't get out of bed at all; and I had to sleep in them too. Board shoes were high top shoes that had a metal bar screwed to the soles to keep my feet straight. I wonder how many sheets were torn because of those shoes. I remember the many surgeries and cast that go along with them. I hated when it was time to cut the cast off, kind of scary. One time I got cut by the saw, just a knick but it was scary enough to make me never want another cast. My last cast at age 13 years was a monster of a cast. It went from my waist to my feet with a cutout in the middle to allow me to use the bathroom. It had a bar in the middle to hold my legs open; I guess it helped to keep my hip straight because that was my last surgery done on my right hip.

My physical therapy treatments mostly consisted of getting into a huge tank of hot water, lying on a board on my back with whirlpool like bubbles everywhere. I suppose that would have been a spa day back then. The nurse's aide would take me out and they would massage and stretch my leg muscles and flex my feet. My leg muscles began to atrophy so that's why the stretching. I don't know how long it took for my legs to change shapes, one smaller than the other, but that's what happened and they became very weak so I had braces that went from my waist to my feet on one side and the left side had a half brace from the knee down. I loved my high top shoes until I got a chance to wear low quarter saddle shoes. They were brown and white and a little more feminine than the high tops.

When I left home not walking to go to the hospital, I remember telling my grandmother that when I come back I will be walking again. It took a long time but when I came back, I was walking with the Continued next page...
My life continued...

help of crutches and braces. Those braces did not stop me from doing much because I broke them on numerous occasions by climbing trees with my uncle and many cousins. I was such a Tomboy back then. I loved playing cowboys and Indians and then I'd play with my sea grass and bottle dolls, and cook food from our many fruit trees that spread across our property. Some things I never could do were ride a bike, roller skate or wear pumps. I could wear platforms though. I guess that was a type of salvation.

When I entered grade school in the first grade things went fine, I suppose, I don't remember much from 1st to 3rd grade. I have memories starting in the 4th grade with Mrs. Freeman. That was the year JFK was assassinated. I remember teachers crying, kids crying, I don't know that we even knew what we were crying about. I think it was just because everybody else was crying. Elementary school was when I really started to notice how the kids treated me differently, not in a good way. By high school it was pure hell. Ridicule and humiliation was a daily event. I walked with a limp so they tended to mock how I walk and call me names like gimp, kryptonite, Polio girl and many more. The good thing that helped me get through school was that I was smart enough that I became a tutor of sorts to some of the other kids. I made the Honor Roll a few times and that was impressive even though there were many more students that made it than me. But I saw my name on the board and that was good enough for me. The teacher noticed it and suggested that I help some of the other kids ... and I did. Just so happen some of the kids that made fun of me were my pupils. I liked it and things started to turn around with the kids. But as friends go, I always got the ones no one else wanted. We were sort of like nerds or something. Not cool to hang around with a person with a handicap. Will it rub off on them? I think they thought so. So with people around me like that made me very self conscious of how my legs look and how I walk because who wants to be known only for their limp instead of as a good person or a smart person? Most of the guys didn't give me the time of day. First boyfriend at 16, first fiancée at 18, didn't get married until 27. What a big gap. Only went to one dance in elementary school, one dance in high school, one football game in high school but never a Prom or anything fancy like that. People are cruel as kids and they continue to be cruel as adults. There is still so much intolerance.

Over the years I have worked with and have known several people with Polio. Vocational Rehab got me a job at Goodwill Industries as Secretary to the Director of Operations; first experience of working with a person with Polio that was confined to a wheel chair. I wanted to go into the military but couldn't pass the physical test due to Polio. Since then I have successfully worked and retired after 21 years of employment. I have been retired almost three years and since retiring my motto is "do everything I never did before". So some of the things I'm doing now or have done since retiring is took my first cruise ... to Alaska, join the Red Hat Society, host a weekly internet radio show at www.flinttalkradio.com. The Flaminpit Show, volunteer with a domestic violence group called Patricia's Promise, volunteer with a senior group called RSVP, involved with the community in numerous events, trying to write my autobiography and finish my Bachelor's Degree in Business Administration. You can "Friend" me on Facebook to watch my progress. So that's my story and I'm sticking to it! ☺

A truly happy person is one who can enjoy the scenery on a detour.
MEMORIES OF POLIO

By Connie (Langlois) Perry

It was July 16th 1951, I was 16 years old. I was at Iler Beach outside of Harrow Ont. when I fell ill. I was at a cottage and the week before I was taking care of my 5 year old cousin who came down with polio. I cried all week and wondered if the two of us had gotten into something that could cause us both to come down with polio.

That day I was taken by ambulance to Windsor’s Metropolitan Hospital’s contagious disease wing, I can still remember my dad helping to carry me up the stairs to my room and then could not come back into the hospital. In order to visit with anyone, they had to stand under my window two stories down and we would try to converse yelling at one another.

The pain for the first month was terrible and the only relief was the hot packs which I remember having at least 3 times a day. They would roll one of the old type washing machines into the room and ring out these woolen clothes to wrap my body in. After a month I was transferred to the regular part of the hospital and received therapy. The Red Cross would come three times a week to exercise me, but I was not able to sit up. I was flat on my back for the six months I was there. I can remember asking my Doctor at one point if I would ever walk again. His response as he was walking out of my room was “some do and some don’t”. (I was going to show him a thing or two.)

When they finally said I could be discharged, I was fitted with a back brace and long leg brace and sent home. I continued going to the Red Cross for therapy and eventually started back to school. In those days you could buy polio insurance, so I was fortunate that my parents had done so and was able to go to Warm Spring Georgia for three months as the insurance would pay my air fare and my stay there. I traveled alone and it was my first time flying and had to stay at a hotel in town for the first night before I was accepted as a patient. That was a great experience having water therapy in the healing water that also helped President Roosevelt.

I was married in 1955 moved to Ferndale, Mi and had three children. I was able to get around quite well by that time with no braces. I believe it was around 1985 that I started having trouble again with weakness and was back in the leg brace for at least part of the day. Now I can’t walk without the brace and have to use a walker when I don’t have it on. I spend a lot of my time going to therapy as my neck and shoulders are giving me trouble, it takes its toll on your arms and shoulders pushing yourself up all the time. I just had a botox injection in my neck so hoping that will help with the pain and stiffness. Seems like there’s a lot of maintenance anymore to stay as fit as I can.

I still live in Michigan in the summer and have a pool to exercise in as I’m living in a condo. I spend my winters in Florida and use a scooter to get to the pool. I feel very fortunate to be able to get away from the cold winters in Michigan and enjoy the Florida sunshine. Have many friends there and besides the many social hours, play lots of bridge.

Enjoy the visits from my children and grandchildren and treasure the time I’m able to spend with them. I am blessed!!!!! ☺

THE MPN WEB SITE

www.michiganpolionetwork.com

Visit the Michigan Polio Network’s very informative web site. You will find information about our Library, our Newsletter Polio Perspectives, our Conferences, and many helpful articles and how you can join the network.
Fatigue and Brain Brownout

By Richard Louis Bruno, PhD

Fatigue and “brain blowout” - difficulty focusing attention and word finding associated with fatigue - are the most commonly reported, most disabling and, unfortunately, the least believed of all Post-Polio Sequelae. The biggest problem is that there is no medical test to prove that you have fatigue. Research that we began in 1993 on the post polio brain has documented damage done by the original polio-virus infection and prevents survivors from activating their brains and thereby causes fatigue and brain brownout. There are three new studies that support our findings.

A summary of the first study begins with a sentence that warms my heart: “While individuals with post-polio syndrome do not have diminished mental function when they are well rested, their mental function declines considerably after even moderate mental fatigue.” Researchers at the U.S. Uniformed Services University of the Health Sciences asked 65-year-old polio survivors to complete computerized neuropsychological tests of attention, thinking or memory once, and then again one hour later. The so-called “practice effect” typically improves scores the second time anyone takes neuropsychological tests. However, more than 40 percent of polio survivors had a decrease in performance on the second administration of seven of the eight computerized tests, while 50 percent did more poorly on at least three tests. Subjects didn’t make more mistakes the second time; they were just much slower performing the tests after being fatigued by taking the first set of tests. Slower performance on neuropsychological tests is exactly what our studies found. Polio survivors reporting severe daily fatigue required 23 percent to 67 percent more time to complete tasks requiring attention than did polio survivors with no or mild fatigue.

Why has our neuropsychological research and this new study found brain brownout to be related to fatigue in polio survivors? In our other studies, we used magnetic resonance imaging to look inside the brains of polio survivors. We found small individual or multiple “whitespots,” (technically called hyper intense signal) in the brain activating system of 55 percent of polio survivors reporting moderate or higher daily fatigue, and no spots in those with mild or no fatigue. The more white spots, the more severe were polio survivors’ fatigue, problems with memory, thinking clearly, staying awake, mind wandering, attention and concentration. Recently, researchers at Duke University published a study using both regular MRI, which we used, and a new, more sensitive imaging technique called DTI to look at white spots in the brains of individuals 60 and older without polio or any neurological disease. The study found that visible white spots on regular MRI may be just the tip of the iceberg, since DTI found that damage to the brain under the white spots was larger than the spots themselves. What’s more, the researchers concluded that those with white spots in one part of the brain may have invisible damage in brain areas where spots have not yet become visible on regular MRI, and that this damage may be preventing brain neurons from talking with each other. This could explain why 45 percent of polio survivors with significant fatigue had no visible spots on regular MRI. When it comes to seeing damage on MRI to polio survivors’ brain activating system, apparently little spots mean a lot. So, there actually is physical evidence that poliovirus damage is related to brain brownout in fatigued survivors. But listen to this: Mayo Clinic researchers studied a virus in the same family as the poliovirus - the virus that causes the common cold. They infected some mice with cold virus and not others. Both groups had their memory tested by completing a maze. Virus-infected mice made more errors and couldn’t figure out where they were going. Sound familiar? The mice that made the most errors had greater damage to their brains. The study concluded that even the cold virus could cause “at least some degree of neurologic deficit” in humans. If having a cold can cause brain damage, how can so many doctors still say that the poliovirus, a known killer of brain neurons, couldn’t possibly cause polio survivors to have brain brownout and fatigue? Time for doctors to read a medical journal or two and start seeing the spots.

Richard Bruno PhD is chairperson of the International Post Polio Task Force and director of The Post Polio Institute and International Center for Post Polio Education and Research at Englewood Hospital and Medical Center; postpolioinfo@aol.com
WE’RE STILL HERE!

Improving Accessibility in Places of Worship

Has it been more and more difficult for you to attend activities in your church, synagogue or place of worship? PHI encourages its Members to let their places of worship know that WE’RE STILL HERE! and that we can help make more facilities accessible for all people with disabilities. Are you unsure of the attributes of an accessible facility? Start with the following checklist.

Parking: --Accessible parking spaces clearly marked with an upright sign with the universal accessibility symbol. Van Accessible with 8-foot wide aisle – at least one for parking lots of 400 spaces or less. Car Accessible with 5-foot wide aisle 1 for each 25 spaces up to 100

Entrance: --At least 36 inches wide via ground level, a ramp (maximum incline of 1:12), or an elevator or lift (certified) from a smooth, level accessible path from an accessible parking space.

Interior hallways: --Level or have an incline of no more than 1:12 with a barrier-free width of at least 48 inches. At least one section of coat racks low enough to be accessible. Carpets and rugs 1/2-inch thick or less. Lever type door handles.

Restrooms: --At least one rest room stall and sink accessible to users of wheelchairs within the standard facilities for each gender or a family/single user restroom (highly recommended). Accessible family/single user restrooms meet the following criteria:

Entrance doors at least 32 inches wide that swing into the hallway and have lever door handles. Wall mounted grab bars 33-36 inches high next to and at the back of the commode. The toilet seat 17-19 inches high. Automatic doors wherever possible and easy-to-open manual doors.

Worship Area: --Seating provided (preferably scattered site cutouts), allowing a wheelchair user can sit beside family members. The platform and podium accessible to persons with mobility problems.

Classrooms: --At least one classroom accessible to wheelchair users.

Fellowship/Gathering Area: --Accessible to wheelchair users.

We realize that many places of worship were built with no thought of their accessibility, but as a handicapped person we can suggest improvements by being the instigators in your local area. Share the check list with a friend and together observe your place of worship. If it “passes,” find out who should be complimented. If it doesn’t, find more interested friends and begin to make your place of worship more accessible.

Information from: post-polio.org

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THANK YOU

A special thank you goes to the following groups who donated materials to be used at the conference and were dispensed to the conference attendees:

State Representative Tom McMillin of the 45th District for the booklet "Citizen’s Guide to State Government;"

Dream Products, Inc. for their catalog featuring products for daily living;

State of Michigan for the state transportation maps and information about the Michigan Assistive Technology Loan Fund;

“AGING WISELY WITH PPS”  
2011 CONFERENCE PRESENTATIONS

Ann Laidlaw, MD, Post-Polio Clinic University of Michigan  
"PPS, What We are Seeing and What We are Doing"

Dr Ann Laidlaw presented the history of polio. Suggested that the estimates of the number of polio survivors in Michigan and the United States is low. She demonstrated the need to have a proper diagnosis made by a physician knowledgeable in polio and post-polio syndrome. That this diagnosis is one of exclusion where no medical, orthopedic or neurological issues can explain the fatigue, weakness and muscle pain associated with patient symptoms. Dr. Laidlaw stated that there is no specific treatment of cure for PPS and reminded us to conserve energy.

Mark Taylor, MLS, CPO, FAAOP Post-Polio Clinic U of M  
“New Material, New Technology, New Challenges”

As a polio survivor, Mark Taylor knows first hand what is involved in bracing, wearing a brace and the challenges of a good fitting for the brace to be worn and a complement to the wearer. Orthotic challenges for the orthotist include but are not limited to a leg length discrepancy, fused bones and joints, and stressed joints.

A successful fit includes the control of non-wasted motions that can cause joint stress and will the brace create a new risk or do damage of harm to the limb and person using the orthotics.

Bracing must have all of the following components by both the patient and orthotist: commitment, communication, patience, taking small steps until the brace slowly feels comfortable, have follow up visits to make modifications and more communication.
Dr. Walny has noticed that polio survivors have a sensitivity to depolarizing drugs due to weak muscles. At times, polio survivors may experience central and/or peripheral fatigue after anesthesia. Depolarizing drugs should not be used on polio survivors due to a possible increase in potassium concentrations which can result in heart problems. NO SUCCINYL CHOLINE SHOULD BE USED IN POLIO PATIENTS. Muscles are already compromised and this further depolarizes muscles. Regional or local anesthetics should be used when possible to avoid gastro-intestinal complications. Muscular weakness and where they are weak should be considered in all patients when given anesthesia. Many questions were answered by Dr. Walny from the audience on the safety of today’s anesthesia. Dr. Walny reiterated that today the best and safest drugs are being used when surgeries are performed.

Tamara spent her time discussing the care and maintenance of braces. This fun-filled presentation not only instructed those present with the proper care and maintenance of braces, be they plastic or carbon fibers, leather or metal, but Tamara was able to show and tell the common practices she has seen at the clinic when a polio survivor tries to fix and repair broken and cracked devices.

Common household glue, duct tape, screws and other materials not supplied by a certified orthotist should never be used on braces. Legs and bodies and arms are not as stable when home remedies are used to repair braces. When the Velcro wears out and no longer sticks together, take your brace in to have new velcro put on.

Tamara is a board member, vendor for our conference and an interesting speaker who filled in on the last minute request when Dr. Mike Kossove was unable to attend the conference.
The vendors who were at the conference in August 20, 2011 are listed here. Please refer to these Vendors for future reference, as they are all reliable companies who offer you good service, quality products at fair prices.
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 vhazel38@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

Patsyanne@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.boothe@comcast.net -John C. Boot
Grand Rapids, MI

lindagrimseys@sbcglobal.net Linda
Jackson, MI

ineer9298@wowway.com - Lawrence
Sterling Heights, MI

vhenry330@wowway.net - Virginia Henry
St. Clair Shores, MI

wwmesseroll@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

BarBasilrico@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 - Saundra
Hastings, MI

bstevens1975@yahoo.com - Bobbi
Royal Oak, MI

sharonf@bte-bci.com - Sharon
South Haven, MI

Continued next page...
POLIO SURVIVORS SHARING continued...

fabo48@hotmail.com - Fran
Quincy, MI

LLBUTLER149@MSN.COM - Linda Butler
Dearborn Heights, MI

thadandshei@juno.com - Ted
Auburn Hills, MI

fradlefraser@aol.com - Lorraine
Fraser, MI

jmc65@ncats.net - Michael
Fremont, MI

mrsrogers@chartermi.net - Sharon
Fenton, MI

boborsarah@juno.com - Bob
Clarkson, MI

virginiafinkbeiner@yahoo.com - Virginia
North Branch, MI

itopor@aol.com - Iris
Farmington Hills, MI

jackofwb@juno.com - Jack
W. Bloomfield, MI

jeanniew@provide.net - Jeannie
Hartford, MI

r1obin@localnet.com
Clare MI

dmrydzon@aol.com - Debbie
Chelsea MI

abufflogal@yahoo.com - Barbara
Rochester Hills, MI

dausterberry@sbcglobal.net - Doris
Farmington Hills, MI

AlanLoisS@aol.com - Alan
Plymouth, MI

gdr1237@hotmail.com - Gordon
Decatur, MI

JoanMcCarthy@sbcglobal.net - Joan
Grand Haven, MI

jackofwb@juno.com - Jack
W. Bloomfield, MI

denny@power-net.net - Dennis
Chesaning, MI

cndchurch@lakeshore.net (summer)
cndchurch@gls3c.com (winter) - Charles
Pentwater, MI

gpjay@toast.net - Pat
Six Lakes, MI

jhuck@att.net - Jerry
Selby Twp, MI

jandj316@aol.com - Jennifer
Livonia, MI

winim@att.net - Wini
Livonia, MI

rconnectus45@yahoo.com - Richard
Manistee, MI

PRISCSMTH@aol.com - PAT
Livonia, MI

Kathi644D@aol.com - Kathe
Shelby Township, MI

suzee5@juno.com - Ellen
Ortonville MI

kwoodbeck@att.net - Kaye
Redford, MI

ruthkos12@yahoo.com - Ruth
Rockford, MI

ehbucsek46@yahoo.com - Elizabeth
Romeo, MI

RLloreJ@aol.com - Ramón
South Haven, MI

tryry@comcast.net - Mary C Riley
Waterford, MI

steve@vear.com - Stephen
Hillsdale, MI

hrkolde@comcast.net - Rowena
Bloomfield Hills, MI

johnandsue6563@yahoo.com - John
Evart, MI

tpbrown@frontiernet.net - Tim
Grosse Pointe Woods, MI

kkopro9885@aol.com—Karen Koprolces
White Cloud, MI

woodsfamily@alldial.net - Alan Woods,
West Olive, MI

jwanchik@comcast.net - Joe Wanchik
Harper woods, MI

ajlsguik@att.net - Linda/ Al
Fremont, MI

nandurston@comcast.net—Nancy Durston
Ann Arbor, MI

Continued next page...
POLIO SURVIVORS SHARING continued...

mperry248@aol.com - Connie Perry
ljcot@aol.com - Larry
Aeriba@aol.com - Arlene Riba
markt@umich.edu - Mark Taylor
kram@charter.net - Karen Rambadt
susanvrm@clear.net.nz - Susan Kerr
cheryl_obannion@hotmail.com - Cheryl
dworthy@usamedia.tv - Douglas
lkfrisco@msn.com - Lee
daao@home.com - Anne
decopainter1998@yahoo.com - Jeannie
eddyc7@peoplepc.com - Edward
PPSBIB7@aol.com - Bonnie
Ellaroy@aol.com - Ellie
bashley1@cfl.rr.com - Burnett
KRBWAY@aol.com - Ken
kmerrill@cfl.rr.com - Chuck
deniswahl@comcast.net - Dennis
JSGrady@aol.com - Jerry
beckie44@juno.com - Beckie
ppsgen@aol.com - Dr Richard Bruno
professormike2@aol.com Mike
jjscg123@adelphia.net - Jane
JohnandKeriG@yahoo.com - Keri
wctubandt@aol.com - Walter
Bobuschi@msn.com - Ursula

Give me a sense of humor. Lord, Give me the grace to see a joke, to get some humor out of life, and pass it on to other folk

MICHIGAN POLIO NETWORK, INC
FINANCIAL RESULTS
FROM RECENTLY COMPLETED FISCAL YEAR

MICHIGAN POLIO NETWORK, INC. SOURCES OF FUNDS
FOR FISCAL YEAR 6/01/2010 TO 5/31/2011

MICHIGAN POLIO NETWORK, INC. USES OF FUNDS
FOR FISCAL YEAR 6/01/2010 TO 5/31/2011
Request to all membership

"Please check the mailing label on the back of this Polio Perspectives for the expiration date of your membership"

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

Please direct all MPN MEMBERSHIP and ADDRESS CHANGES to one of the following Board Members:

Tim Brown at 313-886-6081
(tpbrown@frontiernet.net)

or

Laura Barbour at 248-853-5465
(denilaur@sbcglobal.net)

---

**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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**MICHIGAN POLIO NETWORK, INC. MEMBERSHIP FORM**

The Michigan Polio Network, Inc. is a tax exempt non-profit organization with 501 (c) (3) status. Your contribution is tax deductible as allowed by law. Membership includes our newsletter Polio Perspectives. To join it is not necessary to be a resident of Michigan or be a Polio Survivor.

**PRINT:**

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Are you a Polio survivor? ( ) Yes ( ) No

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I wish to make a contribution to support the work of the Michigan Polio Network, Inc.

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Make check payable to:

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AND mail to:

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1156 Avon Manor Rd

Rochester Hills, MI 48307-5415
CONFERENCE 2013

Although we just completed a Post-Polio Educational Conference we are now looking for input to help with planning our 2013 conference. If you attended the conference and completed an evaluation form you do not need to respond to this survey.

Please, return this survey to me at:
Bruce E. Sachs,
1070 Balmoral,
Mt Clemens, MI 48043 or besachs@sbcglobal.net

CONFERENCE SURVEY

What month in 2013 would you like the next conference to be held?
______________________________________________________________

How far would you be willing to drive to attend a conference
______________________________________________________________

What topics should be presented?________________________________
______________________________________________________
______________________________________________________

Would you be interested in attending shorter conference [10:00-2:00 including lunch] with 1-2 speakers. Yes____ No____

Would you be interested in attending shorter conference [9:00-2:00 including lunch] with 2-3 speakers. Yes____ No____

Name and address of a handicapped accessible conference site in your area:
___________________________________________________________________
___________________________________________________________________
MICHIGAN POLIO NETWORK
Board of Directors 2012-2013

CHAIRMAN
Bruce E. Sachs   ps2012
1070 Balmoral St.
Mt. Clemens, MI 48043
(586) 465-3104
besachs@sbcglobal.net

FIRST VICE CHAIR
Barbara Oniszczak   ps2013
332 Woodside Court Apt 113
Rochester Hills, MI 48307
(248) 260-7195   abufflogal@yahoo.com

SECOND VICE CHAIR
Daniel A. Matakas   ps2013
7569 Harrison
Westland, MI 48185
(734) 422-5659

SECRETARY
Dianne L. Dych-Sachs   ps2013
1070 Balmoral
Mt Clemens, MI 48043
(586)465-3104    dldych@wowway.com

ASSISTANT SECRETARY
Ginny Brown   2012
1530 Fairholme
Grosse Pointe Woods, MI 48236
(313) 886-6081   tpbrown@frontiernet.net

TREASURER
Timothy P Brown   ps2012
1530 Fairholme
Grosse Pointe Woods, MI 48236
(313) 886-6081

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

LIBRARIAN
Laura Barbour   ps2013
1156 Avon Manor Road
Rochester Hills, MI 48307-5415
989-739-4065   denilaur@sbcglobal.net

Susan Burton   2013
40547 Firwood
Plymouth, MI 48170
(734) 765-8384
Lucyandbailysmom@aol.com

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

POLO PERSPECTIVES
EDITOR, Vera Hazel  2013
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
tjorthotist@yahoo.com

Bonnie E Levitan   ps2013
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

Judy Pasich   ps2013
617 Revena Place
Ann Arbor, MI 48103-3639
(734) 623-1252   jpasich@sbcglobal.net

Pam Spinella   2013
23304 Beverly
St Clair Shores, MI 48082
(586) 294-3135   pspinella@sbcglobal.net

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

William Thiedeman   2013
6537 Ostrum Rd.
Belding, MI 48809
(616) 794-9738
uscgbill@pathwaynet.com

BOARD MEMBER EMERITUS
William Messeroll PS
13350 Chandler Rd
Bath, MI 48808
(517) 641-6398

MPN WEB SITE
http://
www.michiganpolionetwork.com/

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