ATTENTION!!!!

1- RESULTING FROM AN ERROR ON THE PART OF OUR MAILER WHEN MAILING THE FALL ISSUE OF POLIO PERSPECTIVES, SOME OF OUR MEMBERS DUES EXPIRATION DATES WERE INCORRECT ON THE MAILING LABELS. OUR RECORDS AND THE EXPIRATION DATES SHOWN ON THIS ISSUE ARE CORRECT.

2- DURING THE PAST 12 MONTHS, MAILINGS THAT WE HAVE SENT TO THE MEMBERS LISTED (ON PAGE 2) HAVE BEEN RETURNED TO US BY THE POST OFFICE AS "UNDELCIVERABLE." WE WOULD APPRECIATE ANY HELP OUR MEMBERSHIP IS ABLE TO PROVIDE IN REACHING THEM IN ORDER TO UPDATE OUR RECORDS. PLEASE CONTACT TIM BROWN (313)886-6081 OR LAURA BARBOUR AT (989)739-4065.

HAPPY NEW YEAR!!
MAY YOU ALWAYS HAVE LOVE TO SHARE,
HEALTH TO SPARE, AND
FRIENDS THAT CARE.

MPN BOARD MEETING
The Board of Directors Meeting begins promptly at Noon at
TONY M’S RESTAURANT
3420 S CREYTS RD
LANSING, MI 48917
March 17, 2012, May 19, 2012
CONSIDER ATTENDING ONE OF OUR MEETINGS.

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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
WE WOULD APPRECIATE ANY HELP OUR MEMBERSHIP IS ABLE TO PROVIDE IN REACHING THEM IN ORDER TO UPDATE OUR RECORDS. PLEASE CONTACT TIM BROWN AT (313)886-6081 - tpbrown@frontiernet.net OR LAURA BARBOUR AT (989)739-4065.
FROM THE CHAIR

When you read this hopefully you will not be walking through the ice and snow of another Michigan winter, but rather sitting safely in your home while others help you with your shopping.

Polio survivors are still needed for research. Dr. Claire Kalpakjian and her team from the University of Michigan were awarded a research grant by Post-Polio Health International to study people with post-polio and the effect of taking the dietary supplement glutathione. (See article on page 20.)

According to a newspaper article “More parents skip school shots for their kids.” When our children were small we made sure they had their polio shots along with the other vaccinations. As grandparents we need to encourage our children to vaccinate all our grandchildren.

It appears that the Mayor of New York City does not want any of us wheelchair/ scooter users to visit his city. He stated in an interview that it is not realistic to have wheelchair users on the streets hailing taxis. Out of more than 13,000 taxis cruising the streets of the Big Apple, only 231 are wheelchair accessible.

A suit was filed in January by United Spinal Association, the Taxis for All Campaign, Disabled in Action and the 504 Democratic Club, maintaining that the city is violating the Americans with Disabilities Act by failing to provide equal and accessible taxi service.

If you would like to respond to the mayor use the contact information below. Mayor Michael R. Bloomberg City Hall New York, NY 10007 PHONE 311 (or 212-NEW-YORK outside NYC) FAX (212) 312-0700 E-MAIL: http://www.nyc.gov/html/mail/html/mayor.html

Enclosed in this newsletter is the ballot for the Annual Michigan Polio Network Board of Directors Election. Please compete the ballot and mail promptly.

Thank you,
Bruce Sachs, Chairman

“Don’t make such thorough plans for rainy days that you don’t enjoy today’s sunshine.”
—John Mason
MY POLIO STORY
By Linda Wincenc Dobkin

My “polio story” is not unlike that of many others. I was 6 in the summer of 1953, about to enter into second grade, when, after a family camping trip at Allegany State Park, my whole family became ill with the polio virus. I was the only one of us to suffer any paralysis. Hospitalizations, rigorous and painful physical therapy, surgeries, learning to walk several times, missing school, and not being able to keep up with my peers are all part of my earliest memories. But I was able to put that all in my past as I reached my high school years, and then began living my “normal” life.

My first awareness of the late effects of polio came from an article that my mother saw in a Buffalo newspaper, sometime in the early-1980’s. According to the article, it was not known then if the polio virus had re-emerged in those previously infected, or if there was some other mechanism causing new symptoms of muscle weakness. I remember thinking how lucky I was not to be among those having new problems, and I got on with my “normal” life. Sometime in the early 1970’s I had noticed I was tripping more frequently, all of which I attributed to the fact that my smaller polio foot needed extra padding to fill up the left shoe, which left me with “no foot” in the toe of my shoe. I consulted an orthopedic surgeon at the time to find out if the surgeries I’d had as a child had somehow come “undone” over the years. His recommendation was to start wearing a brace again. This was the most ridiculous thing I’d ever heard—how could I need a brace after being without one for over 20 years? Stubbornly, I ignored his recommendations.

Fast-forward to the late ‘80’s when I first heard about the Greater Boston Post-Polio Information Association. I believe I had seen a small notice in the newspaper and called to inquire. I probably spoke to Elaine Burns, who invited me to an upcoming meeting in a church in Newton Center (which I now know was the Eliot Church). I was very reluctant to go, because I didn’t want to be with a lot of “crippled” people. You see, I wasn’t handicapped—I just happened to have polio in my medical history, but I was fine.

I’m sure, like a lot of people, not only was I denying that I could possibly have PPS, but I was scared. Polio was a part of my past, not my present. I’d been leading a very active and healthy life for a long time since my “polio days”, able to go to college and graduate school, hold several professional positions as a medical researcher, get married, have a child, and then go on to be the financial officer of a company founded by my husband and me. I was busy and active, morning to night, with family, business, and community volunteer work.

Eventually, I made it to a meeting and was surprised to see all these smiling faces. I guess I had expected to see sad, complaining, wheelchair-bound old people with severe disabilities. But everyone was so friendly and cheerful, in spite of their wheelchairs, canes, and crutches. I particularly remember how warm Elaine was when she greeted me. I felt as if I were among new friends.

So little was acknowledged about PPS by the medical community in the ‘80’s, and my HMO in particular seemed to turn a deaf ear when my symptoms of new weakness and increasing fatigue became too much for me to ignore. The answers I was looking for didn’t come from within my HMO, because PPS wasn’t a well-established diagnosis then, so I was shuttled to several specialists who tried to fit me into their diagnoses—fibromyalgia, chronic fatigue syndrome, obscure neuromuscular and psychosomatic problems. I was told to seek psychotherapy, lose weight, and get into shape with a rigorous physical exercise program—all things guaranteed to strengthen my muscles and make me feel better. Finally, my primary care MD did some research and referred me to the Post-Polio Clinic at Spaulding Rehab. Hospital in Boston. After their initial work-up, where I first became acquainted with Linda Wobeskya, I was given the diagnosis of PPS and told I had to wear a brace.

That long day of appointments and bad news was on my 44th birthday, 37 years after contracting

Continued next page...
Linda Dobkin Story continued...

polio, and 2 years after my mother had died. I remember thinking I was glad she wasn’t alive to know about my PPS, because she had always blamed herself for my contracting polio. The GBPPA became a lifeline for me. What I was experiencing physically and what all my previous medical visits hadn’t acknowledged as PPS was validated by the support I received from GBPPA members—all people who were dealing with problems similar to mine. It wasn’t possible that we were all imagining this! At meetings, all I wanted to do was read the newsletter, gather all the available literature, and find out as much as I could about PPS. I gradually started to think of those I met as my friends, not just a bunch of anonymous people whose only connection to me was having had polio. I became obsessed with checking out everyone’s braces and shoes. I had gone through a mourning period for my coveted footwear, no longer wearable with my brace, all filling up an enormous box in my bedroom—it took me over a year to get rid of those shoes.

With my denials and reluctance behind me, I started looking forward to meetings. I was eager to hear all the speakers and attend all planned events. I got involved in an early support group, which met at New England Rehab. in Framingham. I joined a PPS support group run by Sally Johnson at Spaulding in Framingham. Eventually, I expressed to Elaine my desire to become more involved in the GBPPA, and was asked to join the Board in 1998. Of course, with the friendships and acquaintances also comes a bit of sadness. The same people I would greet at early meetings often became more disabled or eventually stopped coming altogether. Sadly, I have gotten to know too many who have since passed away, like Ada Rosten, Marie Vienneau Iliff, Barbara Johnson, Barbara Whaley, and Pat Prell, my “polio sisters” whom I will miss dearly. And there are also the lucky ones we miss, like Jim Dougan, who escaped the New England winters and moved to Florida.

I must say that the one person who has always inspired me the most was, and still is, Elaine Burns. She represents to me the heart and soul of this organization. If she hadn’t reached out to me at a time when I was most vulnerable, I would still be sitting at home feeling sorry for myself. I am very proud to have been a part of this vital and valuable organization of wonderful friends. My years on the Board and this past year as President have been more meaningful than many items listed on my resume.

Thank you all for being there to support me.

A TRIP DOWN POLIO LANE

By Thomas (Thom) Matheson

I suppose that I’m to be considered one of the younger set when it comes to PPS. I contracted it in 1953 and as a 3 year old, my memory is quite selective. I suppose that is a good thing all in all. I don’t really remember the hot packs, the spinal taps, or the tubs and such. I remember feeling sick and having my mother telling me later on, “She had a feeling”. Most of the treatments are a blur, and the time spent in the iron lung came and went, as my first real memory of my childhood really doesn’t include Polio. I can’t tell you if that is just blocked out or if in fact I just don’t recall any of it. Looking back on it all, I guess that is the former rather than the later because most kids have memories long before age six and that is where mine really start.

My day started and ended doing exercises with my Mom, lifting those darn weights that my Dad made at his shop. Lifting 6oz. bars over my head with my right arm was a major deal back then. Tying my shoes was part of my graduation from physical therapy. Throughout the entire 3 year period I thought of it as more of a, I got sick and now I’m better. I suspect that my folks just chose to keep the details from me. I don’t know. With both my folks passed on, and my siblings and their age differences so small, their memories are limited as well. Oddly I have seen pictures taken the night before I became ill, showing my twin (yes I have one), with a neighbor child eating spaghetti from a

Continued next page...
bowl with the same spoon, sharing bites. Neither of the boys became ill. I can’t imagine the fear that my mother and the neighbor’s mother felt when I came down with polio. The rest of my childhood was rather normal, as normal goes. I don’t remember ever talking about polio with my family. The subject just never came up. If I didn’t know that I had a handicap, then, well one just didn’t exist. By then the vaccine was well used and the word polio just sort of vanished from everyone’s lips. By the time I was 10 and entering the 4th grade we had moved to another town, and I was just one of the new kids who happened to have a twin to create a bit of an oddity. I was not treated any differently by teachers or kids, I just did my schoolwork and life went on. I know that this was the time where I realized how competitive I was. Wining was not just a word, but a way of life. Credit my father for that. As a successful football player, both in high school, college and professionally, I am sure that competitiveness was next to an additional chromosome for us. Mom was the arts side, dad was the “win baby” side. I now know why I didn’t know about my disease. Even if I did know about what really happened, I doubt that I would have been allowed to really bring it up and discuss it. I think my folks wanted to make sure that it wasn’t ever used as a crutch in my adult life to come. More “win baby”. Even after my first surgery at age 18, I didn’t really understand what the heck was going on. I had a foot that turned in, and it finally started to hurt when I walked. I was told what caused it, and the surgery was to correct it and make it straighter. Imagine my happiness. Someone would finally make my foot straight. I just said lets go. I imagined running faster, hitting baseballs better, not being thrown out so often. Man I was ready to go. That one operation changed the entire rest of my life. Eleven more operations later and I still have more pain in my foot then I had when it was “crooked”. All through my life the one constant thought that I take back from my childhood was the all-important “win baby”. I choose to not let “it” win. I still played ball, I learned the even better game, golf and took life head on. It taught me to not quit, or if I found a wall I couldn’t climb over, I found a way around it, and still won. I don’t think I am much different than most PPS victims. We all seem to be the “just win baby” types. I hate using an “A” type personality profiling because there are too many caring wonderful people out there that feel as I do without, that kill instinct. I prefer to just say “just win”. Then about 3 years ago I started developing all the symptoms that most PPS victims start having. Mine was low back pain and breathing issues. Nothing that I didn’t mark off to lack of being in shape and all the other usual maladies that is associated with getting older. I still had a fair jump shot, I could hold my own on a golf course, my garden was pretty good and my lawn was not embarrassing. When I had my back “go out”, and finally had x-rays and saw the shape of my spine did I realize what was going on. It was the most devastating day in many long years. I had already beaten that disease, and was told that it could not come back. Whose idea was this? Let me just say that taking a nap was always a rare privilege not a daily necessity. I can’t remember feeling so angry ever in my life. This was not ever going to happen again, especially when I can’t ever win. Oh sure I can slow things down. I have learned to breath with different muscles, and once again I can put on my own deodorant with both arms, but the rest, well, the rest is learning to cope. Learning to cope? They don’t know us too well do they? I want my 57 year honeymoon back; I don’t want to just cope. I wish that I could tell you that I am involved, and have learned to adjust my life to live to the fullest within my boundaries, but the fact of the matter is, I am still angry. I want the magic pill, I want a cure, I want, well, I don’t know what I want really. I am realistic enough to understand that there are few researchers out there trying to solve this problem. After all, in about 20 or so years PPS will also pretty much disappear as we victims pass on. At 61, I’m one of the younger members of our fraternity. Not too much grant money out there for a self-defeating disease. But I can tell you one thing that polio or PPS cannot take from me, “Just win baby”. I will find a way. I can only say to you all, get mad. Get Mad and fight back. We are the only ones that can really help us. Collectively, I am sure that no one is better equipped for the job then us. I appreciate you taking the time to read thee ramblings and hope that in some small way it touches you as many of your stories have touched me. ♦

All the Best, Thom
Sixth Post-Polio Wellness Retreat at Bay Cliff Health Camp

I had the opportunity to participate in and present at the sixth Post-Polio Wellness Retreat at Bay Cliff Health Camp, Big Bay, Michigan, thanks to Program Director Christy Osborn and with encouragement from Dr. Fred Maynard and Sunny Roller.

The comments below are those of presenter William Waring, MD, Milwaukee, Wisconsin, read by Camp Director Tim Bennett, at the closing session. Dr. Waring and his wife Mary, left the retreat midweek due to the death of Mary's mother. His email is an excellent statement about the benefits of a wellness retreat. This retreat was different in that Bay Cliff invited others to come and learn how to organize a retreat, thus explaining Dr. Waring's reference to Canada. -Joan L. Headley

Mr. Doctor Bill and Miss Mary's last day statement: I hope our Canadian friends have been able to learn about the special things that occur in the Bay Cliff Post- Polio retreats. If you used your eyes and ears and opened up your hearts you have learned that this retreat is more than information and small groups.

Distilling this experience to its most basic level is addressing the fact that people with polio were never warned or taught how to age with their disabilities. Since chronic physical disabilities began as a new phenomenon in the 20th century, our medical, rehabilitative, and social services are also trying to learn how best to address the challenges of aging with disabilities.

You heard the "F" word many times this week, that being the word FAMILY! Being isolated in this lovely environment has helped us act like a FAMILY without the distractions of television, bars, or shopping. The simplicity of kids' camp traditions also brought us together - tasks like eating our meals, requiring all sing or lip sync grace, passing the food and cleaning up when we are done eating. We learn as much as we think of ourselves as being independent, we are also interdependent. Like any family, our family members have a lot of things in common yet we are all individuals. We learn that individual challenges may include fear, anxiety, pain, confusion, anger and sadness. Like a big family, the wiser and more experience members can show others how to be assertive, ask questions and advocate for themselves and others.

Concurrently, participants can practice these new skills with the retreat faculty in group meetings and informally. The recreational activities, even the simple traditional camp ones, give our family the chance to try new things, give each other pats on the back, practice healthy new techniques and prove you are never too old to reinvent yourself.

We also want to acknowledge our Bay Cliff family, Mr. Tim, Miss Christy, Miss Karen, Mr. Ken, Mr. Adrian, Mr. Levy, the other Bay Cliff staff and all of the volunteer faculty. The success of these retreats is due to many priceless items like creativity, compassion and insight.

BAY CLIFF GETS IT!

Disability is just not going to camp, rehab or therapy but it is life long process and they have established a commitment to this construct. The all volunteer faculty deserve special praise - unlike a typical conference where speakers deliver their presentation, give out handouts and leave, our faculty spend time with the participants in formal and informal settings, get to know the participants and are willing to answers questions whenever they arise.

We would also like to say good bye to our post-polio family. It was nice to see old faces and some new faces - come to think about it, we are all pretty much old faces! Like any big family we don't always get along with everyone all of the time, but a beautiful outcome of these retreats is that the information sharing, caring, support and help after the retreats ends. We hope you all stay healthy, active and happy. Remember "We are all just walking each other home." Thank you for all of caring and kindness concerning the loss of Mary's mother. God bless you all and your work until we see you again.

-Bill and Mary Waring

PHI Membership Memo #17 10/03/11
MPN 2011 Conference

By Paula Lemieux

In the previous Perspectives our Chairman Bruce Sachs did an excellent job of summarizing our conference. He also thanked those folks who worked on presenting it. As conference chairman I would also like to thank them (& Bruce, too) for doing such a fine job. It’s a joy to work with this group. And, of course, another thank you to our presenters and vendors. If you have suggestions for future conferences, please complete the Conference Survey included in the previous Perspectives. We’d really like to hear from you.

At the conference, I was delightedly surprised to be co-receiver of the Ruth Cornwell Memorial Award. I served on the Board with Ruth in the 80’s. She was very dedicated to the MPN and set high standards. It’s terrific to have an Award in her honor…. & to receive it is… WOW! It was mentioned that I addressed the DNR about an issue affecting handicappers. Thank you to Roger Gross and Bonnie Levitan for accompanying me to the DNR’s Accessibility Advisory Committee (AAC) meeting. We courteously & professionally explained the repercussions of the DNR policy on scooters in the state parks. There was quite a bit of discussion and on a return visit I learned that several policies were indeed altered after our input. The Committee is comprised of representatives from a number of associations for people with disabilities. Their goal is to make the outdoors more accessible (refer to the DNR’s website for more AAC info.) I thanked them for the accessibility improvements I’ve seen/used over our years of camping in the state parks. They appreciated the pat on the back, too. Besides letting people know what’s WRONG, it’s also good to let them know what’s RIGHT! Thank you for the recognition. ☺

After the 2011 Conference

After the 2011 MPN Conference we headed to the Post-Polio Wellness Retreat at Bay Cliff Health Camp. We haven’t been able to go for a few years and found it’s still MAGICAL. We camped at the near-by campground. This year there was a waiting list for the retreat which was truly painful on both sides. In attendance there were both familiar and new faces. New folks came to experience the Bay Cliff spirit and to learn how to present a P-P Wellness Retreat in their own states or country (Canada). There is more on Bay Cliff & the Wellness Retreat in another article. Again Bay Cliff was outstanding.

Two of the new faces were Bill & Barb Gratzke from FL. Barb is a polio survivor and Bill is the President of the Handicapped Travel Club www.handicappedtravelclub.com Although the club is for all handicapped forms of travel, they focus on RVs. Bill & Barb travel a lot in their motor home which has a wheelchair lift cut right into the side. We were invited to attend the Club’s annual rally. It was held in Wisconsin the following week & not too far from my sister’s where/when we were visiting. We went on the day when the Rally campers were available to explain/demonstrate accessibility adaptations to their RVs. Good information.

From there we headed to the Keewenaw to RV R&R on the shores of Lake Superior. More new friends. We did get blown around a bit in an 18 hour mega windstorm off Lake Superior. More on that follows.

We returned to Bay Cliff for the Pioneer Workbee which was held at the end of the week that would have been the Post Polio Wellness Update (Reunion). There are a number of groups that help out Bay Cliff on workbees (clean-up/fix-up/painting projects.) The biggest workbee is the Telephone Pioneers’. There are 60 or so folks who return spring & fall to help out. And WORK they do – painting, cleaning, washing windows, decorating, sewing etc., and this year a LOT of fallen trees removal. Remember that windstorm? It hit Bay Cliff hard. Fortunately no one was hurt and there was no building damage. When they passed around the mike for introductions, I told them about the Retreat; that Bay Cliff has programs in addition to the summer children’s therapy camp. I thanked them for us. Mr. Tim did a fine job of describing post-polio for them. Did I keep up with the Pioneers? Not even close. Would I return? Sure. Did I mention that my husband was right in there painting?? Way to go!!

Paula Lemieux
Hello and Happy New Year to you all! I hope that you enjoyed a good holiday season and that this winter isn't being too difficult for any of us. As I'm beginning to write this in early December, with the snowy season barely getting underway, I know that, by the time you actually read this, you may have snow up to your ears. If that's the case, I can only say that my wish was well-meant!

It's been rather quiet in the library lately and I, quite honestly, haven't ordered any new books to write about. I shall try to do better in the new year, although I do have to rely on the authors and publishers just a little bit! If you hear about/read any good books on the subject of polio/post-polio and you think that they might be good additions to our collection, please share your idea with me at 248-853-5465(home) or denilaur@sbcglobal.net.

None of our book borrowers gave permission to have their reader comments published in this issue, so I'm unable to let you know what each reader thought about his or her book choices. Those of you who have borrowed books in the past know that readers are encouraged to provide us with comments about what they read. Yes, sort of like a book report, but not REALLY!! Anyway, permission to publish your comments is also requested. A "yes" might mean that you'll see your words in print; a "no" means, obviously, the opposite. So in this issue, I have no reader comments, but that certainly hasn't stopped me from being "Ms. Verbose of 2012," has it?? My high school English teacher's ghost just tapped me on the shoulder, reminding me that in many cases, the less written, the better!!

Now, when I write that it's been "quiet in the library lately" that doesn't mean I'm not working. In fact, the job description for MPN Librarian is rather long, involving not only "bookish pursuits," which is my term, but all sorts of other things. This quarter, I've made many copies of material having to do with polio, helped our Treasurer prepare the mailing of membership-renewal reminders, been the mail drop for those renewals which were sent back, listed all of the info contained in those envelopes for Tim Brown and mailed it all to him, and mailed various things to various members. After I finish this column (yes, boys and girls, the end IS in sight!), I'll go and do battle with an un-named computer program which doesn't think I should be able to single space whenever I want to do so, as I endeavor to complete the MPN Board of Directors' election ballot which you will find elsewhere in this newsletter. I think that one of my New Year's resolutions should be to take a class on how to convince that un-named thing that what I learned in high school typing still makes sense to me (and I'm disappointed that we don't see eye-to-eye on the subject)!

Enough said. Have a safe, healthy winter season. Let's hope that spring comes as early as autumn left late! Take care.

Laura Barbour
Librarian, Michigan Polio Network, Inc.
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
Meets 4th Sat. of the month
March thru October 10am-Noon

THUMB AREA PP SUPPORT GROUP
Rita Wall (989) 673-3678
Blue Water Center for Independent Living
1184 Cleaver Rd Suite 1000
Caro, MI
Meets last Tuesday of each month 2:30pm

WEST MICHIGAN PPSG
Scheduled Meetings:
April, June, Sept, Nov
Linda Walthom Grand Rapid (616) 363-7625
Lynette Hooker Grand Rapids (616) 455-5748
Email: lysue@inbox.com
Chuck Bond Rockford (616) 866-1037

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FAX (314)534-5070 Phone (314) 534-0475
info@post-polio.org www.post-polio.org
TIMOTHY P BROWN is a survivor of paralytic polio since 1953. He retired in 2008 after a career spanning forty years working for three companies in executive financial management positions. Tim has been a member of the Michigan Polio Network for many years, and, since having been elected to the MPN board of directors in 2010, has served as Treasurer and Membership Chairman. Tim would be pleased to continue to contribute his efforts to the MPN as a member of its board of directors.

VIRGINIA BROWN (Ginny) has recently retired after a 40 year career in elementary education with a specialty in Reading Recovery. Ginny has served on the MPN board for the past two years. Ginny is the spouse of Timothy Brown, who currently serves as the MPN Treasurer and, along with him, is very active in network activities. She also serves on the board of the Grosse Pointe Garden Center.

CARL FENNER contracted polio in 1952 at the age of 14. Carl has been involved in many voluntary endeavors, most of all at the Disability Network in Flint, Michigan. He is involved in housing for the disabled and transportation for disabled. Carl has been on the Michigan Polio Network Board of Directors since 1992.

RICHARD KUGEL Served on MPN board from 1993 to 2006, as Treasurer from 1994 to 2002. He is currently Assistant Treasurer of the network. Retired from General Motors Audit Staff in 1998, currently working as a consultant for Bartech at General Motors. Is currently living in Shelby Twp. with wife Sharon. They have six grandchildren. Rick did not have Polio.

RICHARD (RICK) SCHWENDENMANN. I am married to my wonderful wife, Gwen, of 26 years and have one daughter Heather. I have been a member of the Post Polio Network for about five years. I retired from United Airlines in 2005 after 28 years with the company in many different roles. One of the last was helping to establish our Aero Medical desk which was responsible for helping our disabled passengers with their travel. Prior to that I held my first job as clerk/office manager of a Standard Oil, (remember them?), fuel oil terminal in Livonia, Michigan. I have an Associates Degree in Accounting and Data Processing from Schoolcraft College.
CANDIDATES FOR MPN BOARD OF DIRECTORS 2 YR TERM 2012-14

PAULA LEMIEUX is a Polio survivor, Grandmother and a Retired Nurse. She was on the Board in the 1980's and is now on the board since rejoining in 2008. Paula was the Chairperson of our last 2 MPN Conferences. Paula is a Recipient of the 2011 Ruth Cornwell Award for advocating for the disabled.

BRUCE E SACHS I have served on The Michigan Polio Network Board, since 2003, and have been a polio survivor since 1940. I was a public elementary school teacher for 42 years and have a masters degree in Educational Leadership. Presently I am Chairperson of the Michigan Polio Network, Co-facilitator of The Southeast Michigan Post Polio Support Group, a MPN representative on the Chronic Illness Coalition and a greeter at the St. John Post Polio Clinic in Warren. Since being elected to the Board, I have attended International Post-Polio Conferences in St Louis, MO, Miami, FL, and Warm Springs, GA. I also have participated in the annual Bay Cliff Health Camp’s Wellness Retreats in Big Bay, MI. I believe with my background and my interest in Post-Polio I would be a positive influence as a member of the Board of Directors of the Michigan Polio Network.

TAMARA L TREANORE I have been an orthotist for over 20 years and still find the field fascinating and my patients more so. Working to understand and address the challenges of the polio population has been one of the best parts of my job over the last 4 years that I have spent in the Polio Clinic. I believe that my role as an orthotist as well as my involvement in the Clinic provides me with unique perspectives that lend themselves well to the Michigan Polio Network Board of Directors.

MICHAEL W. R. (MIKE) DAVIS of Royal Oak, Michigan, had just turned 13 in the summer of 1944 when he was struck down in Kentucky's second largest polio epidemic—-from which he has a partially paralyzed left arm, luckier than some polio survivors, not as lucky as others. His business card says "Author-Journalist-Historian" and his 12th published book, a photographic history of Chevrolet, is under contract for release in July. In his 54 years in Michigan, he has been a journalist; corporate public relations and marketing executive; executive director of the Detroit Historical Society, and has served previously on several local and national boards. Presently, he is a long-standing trustee of the National Automotive History Collection at the Detroit Public Library.
MICHIGAN POLIO NETWORK, INC., BOARD OF DIRECTORS OFFICIAL ELECTION BALLOT TWO YEAR TERM 2012-14

You may vote for a total of twelve (12) persons, including any write-in which you may add below the ballot. Please provide the required information for any write-in candidates, as well as a brief biography stating your/his/her intentions and interest. Place this on a separate sheet of paper and place it inside the ballot envelope (you will need to tape the sides of the fold-up envelope).

The 21st ANNUAL MEETING of the Michigan Polio Network, Inc., will be held on Saturday, May 19, 2012 at Tony M's Restaurant in Lansing, MI at 12:00 P.M. We encourage all interested in the future of the Network to attend.

THIS YEAR’S NOMINEES ARE AS FOLLOWS:

Timothy Brown (PS)*  __________ Yes
Ginny Brown*  __________ Yes
Michael W. R. Davis (PS)  __________ Yes
Carl Fenner (PS)*  __________ Yes
Rick Kugel*  __________ Yes
Paula Lemieux (PS)*  __________ Yes
Bruce Sachs (PS)*  __________ Yes
Rick Schwendenmann (PS)  __________ Yes
Tamara L. Treanore*  __________ Yes

*=Incumbent  (PS)=Polio Survivor

WRITE-IN CANDIDATES (PLEASE PROVIDE STREET & E-MAIL ADDRESS, AS WELL AS ABOVE-MENTIONED BIOGRAPHICAL INFORMATION ON A SEPARATE SHEET OF PAPER AND SEND ALONG WITH YOUR BALLOT):

1. NAME __________________________________________________________ (PS?)Y/N
2. NAME __________________________________________________________ (PS?)Y/N
3. NAME __________________________________________________________ (PS?)Y/N

Please mark your ballot and remove this page from your copy of “Polio Perspectives.” Turn the page over, write your return address in the appropriate place, fold the page in thirds according to the lines, tape the newly-made “envelope” closed, put a stamp in the upper right corner, and mail the ballot. It must be postmarked no later than March 31, 2012 in order to be counted.
From:

MICHIGAN POLIO NETWORK
% BARBARA ONISZCZAK
332 WOODSIDE COURT APT 113
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HENRY HOLLAND, MD
WRITES ABOUT BULBAR AND SPINAL POLIO

Bulbar polio involved the brain stem where the centers for the cranial nerves are located. The cranial nerves involve smell (olfactory), vision (optic), three cranial nerves that control the various muscles that control eyeball movements, the trigeminal nerve and facial nerve which innervate cheeks, tears, gums, and muscles of the face, etc., the auditory nerve which provides hearing, the glossopharyngeal nerve which controls, in part, swallowing and, functions in the throat, another cranial nerve which controls tongue movement and taste, and one that actually sends signals to the heart, intestines, respiratory (lungs), and the accessory nerve that controls upper neck movement. Thus bulbar polio could affect any or all of these functions.

Death from bulbar usually occurred from damage to the cranial nerve sending the signal to breathe to the lungs. This nerve stimulates our breathing during sleep. An iron lung, invented around 1926, could keep victims alive with negative pressure breathing.

Today, ventilators mostly utilize positive pressure breathing, because it is more efficient. Bulbar victims could also die from damage to the swallowing function, because a victim could drown in his/her own secretions unless adequately suctioned or given a tracheostomy to suction secretions before the secretions entered the lungs. It was difficult to have a tracheostomy and still be able to tolerate the air tight collar of the iron lung.

Death also occurred from the overwhelming invasion of the virus into other parts of the brain, causing coma and death. This was found on autopsy in some deceased victims.

Spinal polio involved damage to the anterior horn cells which run up and down the spinal cord. These cells control motor function only. Sensory cells in the spinal cord were spared, thus, we all feel pain and touch.

Spinal polio could damage the muscles of breathing in the chest wall and thus spinal polio victims could also need the assistance of a ventilator or iron lung. Many people had both, spinal and bulbar combined. Actually, many victims, who had bulbar alone and had good recoveries, had good muscular function, because their spinal cord was not involved.

With PPS, many of these people are having swallowing and central fatigue problems or problems with any functions related to the cranial nerves (double vision, for example).

I hope I am explaining this adequately. Statistically, most of us had spinal polio, and most who had bulbar had it combined with spinal. Now we seem to be learning that many of us had brain involvement during the acute infection that did not do any recognizable damage then, but may be giving us problems now with the total body fatigue or central fatigue of PPS.

People who had only the GI form of polio, which we had initially when we became ill (flu like) had the non-paralytic type of polio. The mystery now is whether these people may have had silent central nervous system involvement and are subject to PPS.

This disease, back before Salk and Sabin, and now with PPS, is amazing and fascinating to anyone who studies the natural course of infectious diseases that do not always kill you quickly. Syphilis was this way before antibiotics and AIDS is similarly tragic and fascinating in its specificity for cells of the immune system. Viruses are wonders of nature. I wish I had missed this one in 1950.

Henry Holland, MD, Richmond, VA. E-mail: Henry4FDR@aol.com
Reprinted from The Polio Post, OH, Summer 2010.

“How wonderful it is that nobody need wait a single moment before starting to improve the world.”

-Anne Frank
Medical Marijuana
To Relieve Pain

Michigan Medical Marijuana law came about in 2008 with a registry being administered by the Michigan Department of Community Health. To be considered a patient, over the age of 18, must submit a registration application, a written verification of a debilitating condition by a licensed physician, and the personal information of a designated caregiver—if applicable. As listed in Medical Marijuana, the qualifying medical conditions are: AIDS, Cancer, Glaucoma, Hepatitis C, Multiple sclerosis, Crohn’s Disease, Alzheimer’s disease, and any conditions that cause cachexia, severe/chronic pain, and severe nausea.

www.medicalmarijuanagroup.com/us/michigan

Presently, there is considerable confusion on how to administer the law in Michigan. The following article is from California, but the information is helpful for all with PPS. MMJ (Medical Marijuana)

A Research Project Part 1: Surprise Visit
By RE Van Der Linden

Introduction

Research, hopefully, leads to discovery. That’s the point, right? But sometimes, unexpected discoveries can take you by surprise. Yes, it happened to me. After years of hearing about the potential benefits of medical marijuana (MMJ), I decided to look into it myself. So, as usual, I went online and spent a few hours finding answers to the basic questions: Is marijuana harmful to your health? Is it addictive? Does it really lead to more harmful drugs? From a medical standpoint, does it really help people? Then I made an appointment with a prescribing doctor, and that’s where the surprise came in. But first: Here in California, medical marijuana’s legality is still a grey area. While Federal law forbids it, California Health and Safety Code 11362.5 Compassionate Use Act of 1996 as approved by the voters in proposition 215 permits it. Regulations are strict and exacting. And there is still a lot of adverse public opinion connecting this natural, herbal remedy with the dangerous, processed chemicals that are ruining a large segment of our society. For the purpose of this article, it’s important for PPS folks who are curious to know about MMJ to look at this subject with an open mind as I have done.

In this article I hope to make sense of the things I’ve heard about MMJ. I won’t condone or condemn its use. Online Research “Health risk and side effects.” Marijuana smoke includes three main ingredients: tar from the basic plant materials, and the active ingredients THC and CBD. Using a search engine I asked: does marijuana cause lung cancer? What I found is that it apparently does not. Formal studies of long term marijuana smokers indicate that there is no increase in the incidence of lung cancer. In fact, one study showed that people who smoke both cigarettes and marijuana have slightly lowered chances of getting the disease. In the case of every day marijuana smokers, holding the unfiltered smoke in too long can encourage the loss of the fine cilia in the lungs increasing the odds of chronic bronchitis.

Marijuana can be taken orally as a tea or in food such as chocolate, and other edible forms bypassing the lungs altogether. Other methods of delivery include inhaling by way of a vaporizer and a water pipe. A vaporizer delivers only the active chemical, THC. But, there is another active ingredient, CBD, which acts to produce a more relaxed effect. Without CBD, there is a higher likelihood of experiencing an unpleasant mood. A water pipe or bong, filters out much of the tar and some of the active ingredients. There is also some risk to the heart.

Marijuana use can significantly reduce blood pressure. As dosage increases, heart rate can also increase to offset reduced blood pressure. This can be bad for people with certain heart problems. The most obvious health risk is the potential for physical injury while under the influence. However, while other substances, such as alcohol, tend to encourage risky behavior, the high experienced from marijuana tends to make the user lazy. People just don’t smoke pot and get into a fight, or generally run wild. One is more likely to sit back and listen to music, or focus on something pleasant. In social

Continued next page...
Medical Marijuana continued...

situations, there’s a tendency to act silly due to a side effect referred to as giddiness, but this not considered harmful or risky. From a medical standpoint, intoxication should be considered an undesired side effect. In large doses marijuana IS intoxicating. Effects of mild intoxication include feelings of euphoria, release of muscle stress, increased appetite, and restfulness. Symptoms of heavy intoxication include distorted time, poor judgment, paranoia, release of adrenalin and/or other stress hormones, distorted vision, and impaired coordination. Operating heavy equipment is very dangerous. Driving is out of the question for several hours after use. For medical use, marijuana is normally taken in small, non-intoxicating doses.

Another interesting point: No one has ever been hospitalized or had his or her stomach pumped for a marijuana overdose. On a side note, it should be mentioned that there is great danger in the illegal drug trade. If the government labels a substance illegal, the value goes up and bad people will kill, not for the product itself, but for the money it represents. *Addictive? There is plenty of evidence that if a person finds marijuana use a pleasing or medically helpful experience, they are going to want to do it again. But, there is a big difference between “want to” and “steal and kill for it.” There is some evidence of physical addiction in that prolonged heavy use of marijuana can temporarily suppress the body’s production of natural THC. However, people are not known to rob liquor stores to satisfy their need for another smoke.

A psychological addiction has been reported in people who start smoking marijuana at an early age and continue using it daily for years. In this case, quitting may include irritability, sleeplessness, and depression, though symptoms only last a week or two. It’s commonly accepted that young people should not use marijuana. Use before the age of 16 may cause permanent changes in the brain.

*Gateway Drug? Marijuana might lead to the use of harmful drugs such as cocaine, amphetamines, and heroine if you are a stupid kid, and the creep on the corner you’re getting your pot from is also selling harmful drugs, and he talks you into trying something stronger. That, obviously, isn’t the case with legal medical marijuana.

*Does Medical Marijuana Work? There are two active ingredients in marijuana: THC and CBD. THC is naturally produced by our bodies and used by receptors in the hypothalamus to, among other things, help us focus, and forget stressful events. A heavy concentration of THC alone in the hypothalamus can result in, at worst, hallucinations and paranoia. CBD is received by the brain in the same way as THC, though its effect is to encourage relaxation. In combination, the two act to focus the mood on the present, and disrupt information between the brain and body. This disruption can result in pain relief, though loss of coordination is a side effect to be carefully considered as dosage increases.

Should I Try It? That’s a question that brings up several other questions. If it’s just another pain medication, why should I even consider it? I have moderate to severe pain and fatigue as a result of PPS. I have occasional neuropathy in my extremities. I don’t like medications. For me pain meds hold the hurt behind a wall. The pain is controlled as long as I keep taking that pill (or a stronger pill), but as soon as I stop taking it, all the pain that was held back comes flooding in. Better to stay on a solid pain management program in the first place. Besides that, the side effects of prescription pain medications can be worse than the cure. I will continue to avoid them as long as I possibly can. [Good PPS management involves rest, diet, stress control, and assistive devices. Also helpful: warm water therapy, dietary supplements, and non-western medical techniques.] I will, however, take a daily vitamin, and I take a thyroid pill (doctor says it’s not a medication but a hormone supplement), and an extra vitamin B, and C in the winter, so I’m not afraid of the more natural kinds of things in moderation. Oh, and I take a bad kind of pill to prevent that weird TIA I had now and then.

Continued next page...
Medical Marijuana continued...

Some things can’t be helped. So far it looks like there is a possibility that during periods of MMJ pain relief, the effect of relaxation and focused attention could mean a tendency to sit around and do nothing. As we know, overuse of motor units can mean permanent loss. [A motor unit includes the nerve pathway, or axons, from the brain, through the anterior horn cells, all the way to, and including, the individual muscle cells innervated by those axons.] Why now? I’m 65 years old. I’ve had PPS for about 17 years. At first, the progress was rapid. Pain and fatigue was increasing so fast that I was sure I would be dead within 2 years. Then I learned how to manage PPS and I got better. Not good, but a lot better because I made some very good decisions. But eventually things stabilized and started slowly declining in spite of my best efforts, and every winter I would hit a new low in pain and fatigue. Now I face another winter knowing that eventually the winter may come when I ask my doctor for pain medication. But before I step off into that abyss, could there be a vitamin or herb or some other natural treatment I can try? What if? What if I’m experimenting (at home of course) and I try too much and something comes up that requires my immediate attention? For the past 8 years I’ve been looking after my aging mother, and been on call 24 hours a day. Even a prescription narcotic would prevent me from properly handling an emergency. “You’ll have to wait a couple of hours” would not be the best response. Sadly, Mom passed away in July, and released me from that responsibility. In general it could be said that there are precautions to consider with any new medication. If I really wanted to try it, what would I have to do? First you have to get a doctor’s prescription. Taking Action I asked my regular doctor and he said, “No way.” He had no opinion one way or the other about MMJ’s usefulness, he just wouldn’t prescribe it. So I shopped around and found a licensed medical doctor who specializes in prescribing MMJ, and made the call. On the day of the 10 AM appointment, I was nervous. It was about a half hour drive, and I knew I would be a little stressed, so I asked my wife, Sandy, to come along. In the office I filled out the standard first-time patient forms and waited. Around noon, I was called into the doctor’s office. Doctor K (his last name is Greek to me) casually glanced at me as I walked in, looking from me to my chart as I followed his instruction to sit on the examination table. “What brings you here today?” he asked. “PPS pain. I wondered if medical marijuana would help the pain in my breathing muscles, legs, and arms. My VPAP ST helps when I’m resting, but I can’t be on it all the time.” And now for the Surprise … and the main reason I was compelled to share this tale. Dr. K proceeded to listen, poke, prod, touch and rub me all over. Then he started making some insightful observations, and here is where the title of this article comes in. The Surprise Visit… this doctor knew about PPS and he was giving me a full-on neuromuscular examination! [... this doctor knew about PPS] He pointed out weak and missing muscles I never noticed before. He turned to my wife and said, “He has a hard time getting out of the car, doesn’t he?” Sandy just looked at him dumbstruck, her head bobbing. He poked around my belly, told me that I had the thin muscle wall typical of a polio survivor, and suggested that much of my lower chest pain was from the down-pulling weight of my guts trying to rip my diaphragm lose from my ribs. He suggested I get an inversion bed, set it with my feet 10 or 20 degrees higher than my head, hook up to my “little machine”, and lay like that for 10 or 20 minutes a day. That should give it a rest. Then he told me to hold up my right arm (like shaking my fist at him), he grabbed it and pulled as I resisted. “Pull harder.” I pulled. My arm began to twitter and shake. “Aha!” he said, “That’s called clonus or myoclonus muscle movement. It comes under the heading of spasticity and qualifies you.” [myoclonus muscle movement -- spasmodic, jerky contractions of groups of muscles -- is sometimes a symptom of PPS.]

Continued next page...
TESTS FOR BREATHING PROBLEMS IF YOU HAVE A NEUROMUSCULAR CONDITION

Prepared by International Ventilator Users Network (IVUN) www.ventusers.org
Reviewed by Nicholas S. Hill, MD, Tufts-New England Medical Center, Boston, MA

If you have a neuromuscular condition such as post-polio syndrome, ALS, or Duchenne muscular dystrophy, you may not realize that your breathing muscles are weak and can become weaker. You may have difficulty breathing in deeply enough to fully expand your lungs or coughing strongly enough to clear mucus from your lungs. It is essential to have periodic measurement of your respiratory muscle function and strength, and your oxygen and carbon dioxide levels to determine whether you may need to use a breathing machine (bi-level device or ventilator) during the night and/or need help with coughing. If you are a polio survivor, measurements of forced vital capacity (the maximum amount of air one can exhale) should be taken BOTH when you are sitting upright and lying down (in the supine position).

Even after you begin using assisted ventilation (a bi-level device or ventilator), it is critical that you periodically have your breathing monitored to prevent respiratory complications in the future and to improve your quality of life and survival. The recommendations below were written for individuals with Duchenne muscular dystrophy, but they are also appropriate for people with ALS and post-polio syndrome.

Routine Evaluation of Respiratory Function
1. Objective evaluation at each clinic visit should include: oxyhemoglobin saturation by pulse oximetry, spirometric measurements of FVC, FEVi, and maximal mid-expiratory flow rate, maximum inspiratory and expiratory pressures, and peak cough flow.
2. Awake carbon dioxide tension should be evaluated at least annually in conjunction with spirometry. Where available, end-tidal capnography can serve the purpose of monitoring CO2 levels. The need for arterial blood gas analysis will depend on your doctor’s recommendation. If capnography is not available, then a venous or capillary blood sample can be obtained to assess for the presence of alveolar hypoventilation (too little breathing causing CO2 to increase).
3. Additional measures of pulmonary function and gas exchange may be useful, including lung volumes and assisted peak cough flow.
4. Careful evaluation of patients for evidence of other respiratory disorders, such as obstructive sleep apnea, oropharyngeal aspiration, gastroesophageal reflux, and asthma.
5. Annual laboratory studies in patients requiring a wheelchair for ambulation should include a complete blood count, serum bicarbonate concentration, and a chest radiograph.

Reprinted from The Polio Post, OH, Summer 2010.

Medical Marijuana continued from pg 18...

At this point I wasn’t thinking about MMJ, I was just amazed that I’d accidentally found a doctor who knew something about PPS and actually had helpful advice for me. So, 2-1/2 hours and $75.00 after entering the office I came out a card-carrying MMJ user.

Aside from looking forward to seeing Dr. K in a year; now what? There is still a lot of research ahead. In the next episode: MMJ: Rick Goes Shopping, I’ll interview product providers and see what kind of people use MMJ. I’ll ask about the range of disorders and which MMJ products work best. I’ll try to get opinions about effectiveness and side effects. Maybe I’ll be able to interview some actual patients.

Rick—end of part one—
The Southern California PPS Manager
November / December 2011
U of M is Looking for Volunteers

Dr. Claire Kalpakjian and a research team from University of Michigan was awarded a research grant to study people with post-polio who will be taking a supplement called glutathione. People in this study will take the supplement glutathione (an antioxidant) for 3 months and we will measure their sleep, activity and physical symptoms.

We will need 20 people in this study, just 10 per year. The people will be taking a glutathione supplement for 3 months. At the start of the study and at the end they will make a visit to a UM clinic and have an examination by a doctor, some simple testing and a blood draw. Nothing too extensive

During the 3 months of the study people will also be collecting information 4 times. This involves keeping a food and sleep diary, wearing a device on their arm that measures activity and filling out some surveys.

Because of the visits, people will need to live a distance that they are willing to travel twice to get the U of M. We are looking for people who have a very specific level of post-polio symptoms.

**IF YOU ARE INTERESTED IN BEING A PART OF THIS STUDY, PLEASE CONTACT:**

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Research Study Coordinator
Dept. of PMR
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e-mail: mjburt@umich.edu

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Quote:
"May today there be peace within. May you trust that you are exactly where you are meant to be. May you not forget the infinite possibilities that are born of faith in yourself and others. May you use the gifts that you have received, and pass on the love that has been given to you. May you be content with yourself just the way you are. Let this knowledge settle into your bones, and allow your soul the freedom to sing, dance, praise and love. It is there for each and every one of us."
POLIO SURVIVORS
SHARING

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

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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
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Post-Polio Clinic
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MICHIGAN POLIO NETWORK, INC.
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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.

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