



# POLIO PERSPECTIVES

Volume 25 No 4 Winter 2010

Promoting Understanding Through the Michigan Polio Network, Inc Since 1986

## AGING WISELY WITH PPS

The Michigan Polio Network Inc. will be holding a one day educational conference on Saturday August 20, 2011 at the Genesys Conference and Banquet Center in Grand Blanc, MI 48349.

Registration will begin at 8:30 with the program from 9:00 a.m.-4:00 p.m. A plated lunch will be included in the registration fee.

Principle speakers include:

*Professor Mike Kossove, Microbiologist, from Touro College, New York, New York.*

*Dr. Ann Laidlaw, Post-Polio Clinic, University of Michigan.*

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

*Lawrence Walny, MD MS*

Dept of Anesthesiology, Genesys hospital Grand Blanc, MI.

**Directions: Take I-75 to exit 108 Holly Road, follow Holly Road South to the light at the Genesys Health Park main entrance, follow the signs to the Conference Center.**

**Registration forms will be published in the Spring 2011 edition of the Polio Perspectives.**

## Board of Directors Annual Election

The Michigan Polio network will be conducting the Annual Board of Directors election in early April.

Your ballot will contain the list of eligible candidates and a proposed amendment to the By Laws. We encourage you to return your ballot promptly. All ballots need to be returned by May 1st.

**Bruce E. Sachs Chairman,  
Michigan Polio Network  
[besachs@sbcglobal.net](mailto:besachs@sbcglobal.net)**

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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

## **FROM THE CHAIR**



**We hope all of you had a happy holiday season and have now broken most of your New Year's resolutions, except the ones about staying healthy and being careful on the ice and snow.**

**Although August may seem a long way away, we should start to plan to attend our educational conference. [see related article on first page]**

**We encourage you to contact polio survivors you know and invite them to attend our conference.**

**We are spending the winter in Florida and have already met polio survivors from West Palm Beach, Fort Lauderdale, and the Boca Raton post polio support groups. We also met many Polio Survivors (see page 3) from across the United States and Canada on our cruise.**

**As the Michigan Polio Network enters its 26th year, we look forward to continuing to provide information and support to all polio survivors. You can support the Network by renewing your membership and supporting our conference.**

**Have a safe winter.**

**Bruce**

## **FOR YOUR INFORMATION**

**Thank you for your interest in something you heard on Michigan Radio.**

**Here's the copy from the announcement that you heard: Nearly two million Michigan residents have disabilities. They depend on tools and technology like walkers and wheelchairs. A website, A-T-X-Change dot org, connects people who need assistive technology...with people who have used items they no longer need. The site allows people to post classified ads to buy, sell or give away items.**

**That's A-T-X...C-H-A...N-G-E?dot org -from the Michigan Disability Rights Coalition. This message is sponsored by the MAPB."**

**Glad you are listening!**

**Tamar Charney, Program Director Michigan Radio UOM 91.7 Ann Arbor, WFUM-FM 91.1 Flint, WVGR 104.1 Grand Rapids  
535 W. William Street, Suite 110  
Ann Arbor MI 48103 voice: 734.764.9210**

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## **WASP SPRAY**

**If you don't have a gun, here's a more humane way to wreck someone's evil plans for you. Did you know this? I didn't. I never really thought of it before. I guess I can get rid of the baseball bat.**

**Wasp Spray - A friend who is a receptionist in a church in a high risk area was concerned about someone coming into the office on Monday to rob them when they were counting the collection. She asked the local police department about using pepper spray and they recommended to her that she get a can of wasp spray instead.**

**The wasp spray, they told her, can shoot up to twenty feet away and is a lot more accurate, while with the pepper spray, they have to get too close to you and could overpower you. The wasp spray temporarily blinds an attacker until they get to the hospital for an antidote. She keeps a can on her desk in the office and it doesn't attract attention from people like a can of pepper spray would. She also keeps one nearby at home for home protection. That's going to give you a chance to call the police; maybe get out, maybe even save a life.**

**Thought this was interesting and might be of use. Did you also know that wasp spray will kill a snake? And a mouse! It will! Good to know, huh? It will also kill a wasp!!!!**

## **CRUISING AGAIN**

**Dianne & Bruce Sachs**

**As the sun was beginning to set, the Royal Caribbean Jewel of the Seas left Port Fort Lauderdale on a 10 night cruise to Panama. On board were 32 cruisers under the leadership of Maureen Sinkule from the Boca Area Post Polio Support Group.**

**This years group consisted of people from Canada, Hawaii, Arizona, Missouri, Kansas, Michigan, Connecticut, New Jersey, Maryland, and Florida. Many of us were returnees and were joined by some first timers. We all enjoyed the ports at Aruba, Columbia, Panama, Costa Rica, and Grand Cayman along**

**with the several days at sea. Maureen had arranged handicapped accessible shore tours at all the ports, so we were able to see more than the shops at the pier.**

**Although we had a couple of days with rain and some high winds at sea, nothing deterred us from enjoying the food, the live shows, the casino, and all the other activities on board the ship. Most of all we had the opportunity to meet polio survivors from many different areas and to exchange ideas about living with post polio. As we were packing to leave the ship, we were also reserving cabins for the next cruise, to the Eastern Caribbean, on board the Royal Caribbean Celebrity Cruise Lines Solstice with the Boca Area Group on January 29, 2012. Make plans to join us.**

**Contact Judith at Travel Group International for booking. 561-477-0705 ex 102, 1-866-447-0705 or [Judith@travelgroupint.com](mailto:Judith@travelgroupint.com) Mention Boca Area Post Polio Group**



# Stem Cell Research - The Miami Project

Query:

The site of The Miami Project to Cure Paralysis claims that 82 cents of every dollar goes directly to research. I have been unable to verify this but it is accurate that seems to me to be a good ratio. Does anyone have any insight into the possible ramifications this research could or would have for Polio victims?

Ron Magnuson

Response:

There have been significant advances in stem cell research in the past few years. In 10 years, I feel, they will be shoving them into everyone.

In the long run research on paralysis should make a difference. In the short run my sense is we will not see anything of value to Polio survivors from one research project. However, the scope of research and the speed of neurological research is breathtaking in it's entirety. I think we will see things that can help us from the broad area of neurological research, so subscribe to a news feed from a neurological watch site.

The Miami Project stresses adult stem cell therapy in their promotion. I am still not clear about how much promise it holds for the Post Polio experience.

The work of Drs. Pantelis Tsoulfas, Dan Liebl and Jacqueline Sagen is cited:

Dr. Tsoulfas' lab is working with induced pluripotent stem cells to understand how these stem cells differentiate what their properties are and to transplant them and integrate them with the injured spinal cord.

Dr. Lieble has discovered that the gene for EphB3 is important in the generation of new nerve cells from adult stem cells already present in the brain. In the spinal cord this could be significant in the Re-establishment of functional circuitry following injury.

Dr. Sagen's laboratory is using stem cells to replace those lost during injury and to provide targets for re-growing axons. Her current strategies for neural stem cells include modification before transplantation, co-grafting with growth factor-producing cells

and combinations with nerve bridges in order to promote more complete restoration of spinal circuitry. The Miami project, if my memory serves me, was dedicated to a quick cure, the kind envisioned by Chris Reeve. I think this is unrealistic and the cure will come from neurological research unrelated to one project. I think more value can come from advocating for more medical research period. Unfortunately in the current climate this is not likely to be strongly funded as cuts come.

Also, it occurs to me that spinal cord paralysis cures will involve effectively fusing a broken cord at some place along it's length. PPS, on the other hand is a disease of the end fibers at the muscle interface. So we are interested in keeping nerve cells that have been working hard with extra end fibers remaining healthy and continuing to produce new connections. It seems to me that the Miami project is not centered on that but rather on effectively reconnecting a broken or damaged cord. In such patients, of trauma for example, the end fibers are intact. Ours are not. So they have to keep the end fibers and muscles healthy while they reconnect the cord where it has been damaged. There have been significant advances in stem cell research in the past few years. In 10 years, I feel, they will be shoving them into everyone.

One potential new development of promise is trans-differentiation. This means that as we go from a pluri-potent stem cell we can differentiate it into any kind of cell. But it is now clear that we are able to take adult cells from various tissues and back differentiate them into other cell types. Like skin to nerve or muscle. This will have great potential as the donor will be the recipient so there will be no need to worry about rejection. Also, old polio patients need new muscle for the new nerve to connect with. So it may be possible to produce both, or possible to reclaim partially working nerve/muscle groups that are being lost by PPS.

All this takes time and when a breakthrough occurs it is always a surprise. That is why they call it a breakthrough and it is one of the reasons I believe new applications won't come for us through specific research from a particular institution. During the Nixon administration Nixon declared "War on Cancer" and slowed financing of non-cancer research. Even though Cancer was a

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## **Miami Project** *continued...*

priority and got more financing fewer breakthroughs came. But when Biological processes like cell division got more funding as well as other ancillary projects the advances started coming in. This is why I am skeptical about donating to single projects in hopes of curing a complex problem.

**Eddie Bollenbach**

*Since its inception, a goal of The Miami Project to Cure Paralysis has been to increase the number of laboratories undertaking SCI research by recruiting the premier scientists to the field, and by training students who will establish new research laboratories throughout the world. Today, The Miami Project serves as a model for other institutions that are developing centers for SCI research.*

If you want more information on the Miami Project, here is their site: <http://www.miamiproject.miami.edu/Page.aspx?pid=183>

## **An Adventure in Apartment Shopping**

By **Barbara Oniszczak**

Recently, and as well as a few years ago, my husband and I decided to downsize and move from a 1700 sq. ft house to a 900 sq. ft. apartment. What we were looking for and what we found or settled into creates the "adventure".

Despite what the 1990 Equal Housing Opportunity Law set out to achieve, it fell short, and is not what the reality is today. Most apartments and apartment complexes were grandfathered, so nothing short of a few handrails were put up to accommodate someone needing assistance either through aging or due to a disability to climb stairs.

Looking for a handicapped or accessible living unit is next to impossible. Either you climb one or two stairs to go into an apartment complex, or you go down four or five steps to a "level" apartment.

Did I mention that these "lower level" apartments were considered to be accessible because they had the lower kitchen counters and cabinetry for handicapped renters?

More often than not, we were told that there were no apartment entries without some kind of stair or two. We were even told by one management company that we could forgo the stair issue by walking around the building from the parking lot, and then

maneuver through the lawn to utilize the sliding glass doors from the patio. These sliding glass doors had no stairs or door locks on them, so you would still need someone to unlock the door using stairs to let you into your apartment.

My husband and I have gone through Rochester, Rochester Hills, Waterford, Utica, Macomb, Warren, Madison Heights, Sterling Heights and have not found reasonably priced housing, without stairs, curbs or lawns.

The newest apartment complexes still find ways to skirt the laws regarding accessibility. Only a handful of newer apartment complexes offer NO Step/Stair entry, BUT the rent for these units is a minimum of \$100.00 more than the other apartment dwellings within the same complex.

I believe everyone with a physical disability should write municipalities about these issues, attend city meetings and most definitely write the management companies, owners and public servants about inaccessibility. We will never have accessible housing, if we settle, keep quiet or make do.

We did go to most of the "senior" housing units in all of the above mentioned cities as well as a number of those not mentioned. That was part of the misadventure of housing. Not only is there a waiting list of a year or more for a two bedroom apartment, but we were told to get onto the waiting list, we would have to put down \$100.00 deposit, non-refundable, to secure a spot on this waiting list and being on that list was no guarantee of availability within a year or two.

Apartment shopping is an adventure in its own right. When you are being picky, wanting a two bedroom without stairs, well that just makes daily house hunting even more unique and just the kind of daily activity a polio survivor and her spouse don't need.

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*Those who decide to use leisure as a means of mental development, who love good music, good books, good pictures, good plays, good company, good conversation—what are they? They are the happiest people in the world — William Lyoh Phelps*

# YOUR POLIO STORY

Most of us had polio more than 50 years ago and did not talk about our experiences of being a polio survivor. It is now time to tell our story, so our children and grandchildren can understand why, we need an afternoon nap, need to use a scooter, or are not as active as other people our age.

We are encouraging all polio survivors to write their "Polio Story" and send it to the Polio Perspectives editor for publication. Our polio story is important to not only our family, but to all polio survivors.

Listed below are some suggestions to help you write your story. Feel free to skip some questions and to add other details.

When and where did you contract polio?

Did anyone else that you knew have polio?

Were you hospitalized? (Where and for how long?)

Tell about either what you remember or what you have been told about your experiences with polio.

When you got home, was there any kind of treatment that you received at home?

How did your family react to the polio?

Did you receive any help from the March of Dimes?

Did you ever try to get any medical documentation regarding your polio?

Have you ever had any corrective surgeries due to polio? Were these surgeries effective? Who paid for these surgeries?

How did your neighbors react to the polio?

Did your having had polio change things for your family?

When you entered school after having had polio, what was your condition at that time?

How did your peers react to you?

Did polio affect your social life and dating?

Were you self conscious about your polio condition?

Have you gone to college? Was there anybody in your school career, elementary, junior high, senior high or college who were polio survivors who you met?

What work have you done in your lifetime?

Did you do that work due to your polio?

How did polio affect your work or career, if it did?

Did you have siblings when you were growing up? Were any of them affected in any way?

Have you been diagnosed with post-polio?

Are there any positive experiences that have come out of the polio experience for you?

Do you think that you are more self conscious now or more accepting now of polio and what it has done to your body?

How has post-polio affected your plans for your –retirement? Leisure? Things like that?

**SEND TO:**

*VERA HAZEL*

*15235 ACKERSON DR*

*BATTLE CREEK, MI 49014*

*This is the second time the above article has been in the Polio Perspectives. I am hoping this will help you to decide to write your Polio Story. –Vera Hazel, editor*

# LIBRARY CORNER

By Laura Barbour, Librarian  
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**Hello, Readers! Happy New Year to you!**

In this issue, I will report about some new books which have been added to the MPN Library. First in line is Nemesis, by Philip Roth. After Bruce Sachs and Joan Swain (from NJ) had recommended that I purchase it for the Library while we were enjoying cruising in the Caribbean with the Boca Area Post-Polio Group, I was planning on ordering it from one of my favorite bookstores/websites upon returning to Michigan. You may imagine my surprise when we joined the Southeast Michigan Support Group at lunch on the day we'd arrived home, only to have Bobbi Stevens, one of the Group's facilitators, hand over her copy for us to keep in the MPN collection.

Thanks so much, Bobbi!!

From Roth's "Nemeses: Short Novels" series, this 280-page tells of a WWII polio epidemic and its effect on "a closely knit, family-oriented in Newark (NJ) community and its children." Its protagonist is Bucky Cantor, who is twenty-three and a local playground director. An athlete, Bucky's poor eyesight has excluded him from active duty in the armed services. The book jacket description says, "Focusing on Cantor's dilemmas as polio begins to ravage his playground--and on the everyday realities he faces--Roth leads us through every inch of emotion such a pestilence can breed: the fear, the panic, the anger, the bewilderment, the suffering, and the pain." As this story moves from "the smoldering, malodorous streets of besieged Newark" to Indian Hill, a summer camp in the much more pleasant Poconos, Roth tells the tale of "a decent, energetic man with the best intentions, struggling in his own private war against the epidemic." The author is "tenderly exact...about Cantor's passage into personal disaster, and no less exact about the condition of childhood."

My second purchase this winter was also recom-

mended by a Caribbean cruiser, who really felt that The Immortal Life of Henrietta Lacks, by Rebecca Skloot, would be an excellent addition to the Library. On the New York Times's Bestseller List for over thirty weeks now, this is award-winning science writer Skloot's first book, and an interesting one it is! From the book jacket: "Her name was Henrietta Lacks, but scientists know her as HeLa. She was a poor Southern tobacco farmer who worked the same land as her slave ancestors, yet her cells--taken without her knowledge--became one of the most important tools in medicine. The first 'immortal' human cells grown in culture, they are still alive today, though she has been dead for more than sixty years. If you could pile all the HeLa cells ever grown onto a scale, they'd weigh more than 50 million metric tons--as much as a hundred Empire State Buildings. HeLa cells were vital for developing the polio vaccine; uncovered secrets of cancer, viruses, and the atom bomb's effects; helped lead to important advances like in vitro fertilization, cloning, and gene mapping; and have been bought and sold by the billions. Yet Henrietta Lacks remains virtually unknown, buried in an unmarked grave." It took Rebecca Skloot ten years to uncover the details of Henrietta Lacks's story, during which time she became well-acquainted with Henrietta's descendents, particularly her daughter, Deborah. It was terrible for Deborah to learn about her mother's cells, and, as the jacket states further, this discovery brought many other questions to the fore: "Had scientists cloned her mother? Had they killed her to harvest her cells? And if her mother was so important to medicine, why couldn't her children afford health insurance?" If you're interested in a "really good read" for a winter's day, you might try looking into the story of Henrietta Lacks.

As I usually write, please let me know if you'd like to borrow these or any other books in the Library Collection. Also, since these are two selections recommended by others, don't forget that you are welcome to bring books you find on the subject of polio to my attention.

Finally, may I write a few words about the cruise we took? I know that others can say more (and in a better style) than I, but I hope that more of you will consider the possibility of joining the Boca Area Post-Polio Group's next voyage, scheduled for late

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LIBRARY CORNER *continued...*

January, 2012. I never thought I'd enjoy this mode of travelling so much, but both my husband and I think it's great! One of the best parts, besides the facts that you can unpack your "stuff" for the length of the cruise, and that someone else is doing the "driving") of the experience was that I got to meet some MPN members in person. People who were names on a membership mailing sticker or at the bottom of an e-mail requesting a book were, instead, folks with whom we were able to get acquainted during our eleven days on the "high seas." I hope that we can do this again, because, in my "book," it's an experience not to be missed. Till next time, when it will absolutely be spring, take care. - Laura

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## MY POLIO STORY

By Shirley (Sandy) Loewe

It was 1931. I was four years old and I lived with my Grandma and Grandpa as my mother worked. I came in from playing outside and I lay down on the loveseat with the velvet pad and I couldn't get up. My grandma called the Dr. and he said, "Don't move her." The next thing I remember the ambulance was taking me away on the cushion and I was hollering for my grandma. They took me to Herman Kiefer hospital where they stuck a needle in my back and the pain was excruciating!! I had Dr. Peabody and Dr. Fisher. I was told later that the germ had gone up my foot, right leg and spine and if they hadn't stopped it, it would have gone to my brain and killed me.

I was taken to Sigma Gamma Hospital School. Another girl and I were in isolation for 2 weeks. We raised Cain! At the time they quarantined my whole neighborhood. They thought polio was catching but it was later found out it was a virus. They told my mother I would probably never walk again but was going to try a series of operations. The first one worked — they took a muscle from the top of my leg and put it in my knee and I could raise my leg over my head!! (praise the Lord!!) You could only have visitors on Sunday and that was the day the Drs. came also. I dreaded that as they probed around in my knee which hurt. There

was the "Big girls ward" across the hall and the "Little girls ward" where I was. One night I talked too much and they put my bed and all in the sun room and closed the door. It was so dark and I was scared to death!

I was in that hospital for a year and I was so glad to go home. Of course I wore a brace on both legs. The March of Dimes gave us a lot of trips, like on Boblo and Put-in-Bay Boats.

It wasn't until I was 12 that I started getting headaches and found out that I needed my spine fused. Back to Sigma Gamma Hospital where I lay on the board with a hole in the seat and sand bags on each end (chin and waist) for another year!!! I had a body cast when I got home and was home schooled. I also went to Leland and Oakman School and rode on a bus.

Later I got rid of the braces and high top shoes and my mother bought me a beautiful pair of patent leather shoes. My ankles were strengthened wearing these. I also walked a mile to school when we lived in Jackson, MI. and my legs filled out to normal. I finally graduated from Mackenzie High School and you couldn't even see that I had polio. Of course I would never go swimming with anyone because of my back.

I had 3 beautiful healthy children. The Dr. had told my mother I would never have kids!!

I'm now getting Post-Polio Syndrome (PPS) and have a brace on my leg. I gave up driving 3 years ago when I got shingles, but I'm going to drive soon. ♦



This is the Michigan Polio Network, Inc new PIN  
It will be on sale in the next Polio Perspectives.

# MY POLIO STORY

By Daniel A. Matakas 10-13-10

It was a hot August day in 1939 that I had the misfortune of being infected by the polio virus. According to what my mother told me, she called me in the house to take a nap before supper.

I was hot and sweaty from playing with my neighborhood friends. I was laying on my roll-away bed in the corner of the living room (can you tell we were poor?) when she called me to get up and eat. I told her I couldn't. I guess she thought I was being a brat and said if I didn't get up I would go to bed without supper.

During the night I was crying and fussing so she took my temperature and I had a fever. I still had a fever in the morning so she called the doctor. The doctor sent me to Sigma Gamma Hospital (now St. Johns North) and after a spinal tap it was determined I had polio. None of the kids I was playing with or my two sisters were infected. The things I can recall from my time at Sigma Gamma were the hot wool towels, the big board I laid on in the warm pool, the long time between visits, and the planting of a corn seed in the partial egg shell.

The doctor told my mother I would never walk again and she said "oh yes he will" and I did. I have to give my grandmother a lot of credit for recovering as well as I did. I remember her putting me in the hot tub, as hot as I could stand it and massaging my leg. Then she would put Ben-Gay or Sloans Linament on it and wrap it in towels. I'm sure this helped improve the circulation.

I remember when my grandmother visited me I would ask her for her wide black shiny belt, because I liked to roll it up as tight as I could get it. One of the unhappy memories was when I soiled my diaper once too often, the nurse or volunteer said if I did that again she would put it in my face. Well, I did, and she did ugh!!

My care at Sigma Gamma must have been good, because I started kindergarten at Oakman School for crippled children ( in Detroit) right on time at

five years old. I had a long leg brace, a corset that attached to my brace with 2 straps and I used crutches.

I attended Oakman school from kindergarten thru the ninth grade and graduated in January 1952. This was a great school and the teachers were even greater! The patience, kindness and understanding they had they must have been saints. The school had a mixture of every problem a child could have, Polio, Cerebral palsy, spina bifida, cardiac, you name it! We even had a couple of mid-gets.

On Mondays we had a dentist and on Wednesday and Friday, we had a doctor and 2 nurses who would give us treatments and check ups. The school also had buses with an attendant (Otto) who would carry or help us on and off the bus right in front of our home.

This school also had shop, band, home cooking, jewelry making, art room, library, printing, and a conservatory. I had good marks so my art teacher, (Mrs. Spenser) recommended that I go Cass Tech and major in art, so I did. Cass had 6 floors but it also had elevators, Thank God.

When I started Cass I had a problem. The books I had to take back and forth to do homework were too big and heavy and I had to take 2 buses each way. I made the decision to try going without my crutches. I had to leave much earlier but I got used to it. It was a lot easier to get on and off the buses and handle the books at the same time.

Sometimes ya gotta do what ya gotta do! Because I graduated on the honor roll I received 3 job offers, (something today's graduates would die for!)

I served an apprenticeship at an art studio where the executives from G.M. would come for Tuesday morning meetings. One of my jobs was to serve them donuts and coffee. After 2 weeks of struggling with a big awkward box and spilling coffee as I limped, I got smart and designed a box with the handle in the middle that I could carry with one hand. After one and a half years I got hired at

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## **Matakas POLIO STORY *continued...***

Ford Engineering, became a product design engineer and retired after 42 years.

Some of my (special) experiences related to having polio follow:

- Falling and doing the splits caused me to scream in pain.
- When I was about 12 or 13 I threw a fit about wearing my corset. Mostly because I got teased about wearing a girdle and also it was very hot and uncomfortable. I tried to throw it to the ground many times to break it but it just kept bouncing around, which made me madder yet!
- I was consistently breaking my brace and crutches which must have cost the March of Dimes a lot. When I was about 11 my mother showed me a stack of bills about 1 1/2 inches high and told me the March of Dimes had paid about \$5,000.00 in bills for me. My mother went door to door with a canister collecting dimes.
- When my mother took me downtown shopping I would race through the crowd ahead of her on my crutches, stop real quick, turn around and get a kick out of the look on peoples faces.
- When I fell I learned to get up real quick because if I didn't, 2 or 3 people would come running to help me up (good intentions). They would pull me in 2 or 3 different directions and made things worse.

If you are getting bored with all this go to the last 2 paragraphs. (Hope you are not)

I had a most exhilarating experience when a good friend of mine (Bill Davis) taught me how to ride a bike! My dad bought 2 old bikes from the police auction for \$15.00 and asked me to see if I could make one good bike. It took a lot of work but in a week I had a fine bike! After much patience and several falls my friend let me go and I was riding a bike! I will never forget how great the feeling of freedom and independence felt. The best I could do before this was run on my crutches and now I could zip around the block in no time and not even feel tired. I loved it! To go extra fast I would push my right knee down with my hand to make up for

the weakness. Because of my upper body strength I had fun beating the 15 and 16 year olds at wrestling and hand squeezing when I was only 13 or 14. Another thing that was fun was at the playground I would impress the other kids by going hand over hand up the poles that held the swings. I could go completely up and across and back without touching the ground.

The worst thing that ever happened to me as a result of having polio was on Halloween 1944. I was 7 yrs old and it was my first time to dress up and go begging. I went with my older sister and some neighborhood friends and was all excited about collecting all those goodies! My excitement quickly changed to disappointment as I discovered I only had a few candies and pennies in the corner of my bag! What had happened was the bag was rubbing against my crutches as I ran from house to house and put a big hold in the bag and my goodies kept falling out!

I remember at the show between movies the March of Dimes showed a movie of a little girl walking with 2 braces and crutches and playing "You'll Never Walk Alone". A lot of people donated and cried including me!

Some of the negative experiences I had follow:

One time I was on the beach and a mother came by with her little boy and he said, "look at that man with the skinny leg". That bothered me for about a month. I got over that in a hurry because I loved swimming and the beach.

One time I pushed a schoolmate who would run up to me, slap me, and run back. I happened to catch him and pushed him backwards into a big door with a large plate glass window that came crashing down around him. I thought I killed him. He turned out to be ok. He didn't bother me after that! A kid in the neighborhood would take my crutches whenever he had a chance. One time he only got one, so as he was running away, I threw the other one like a spear and hit him right in the middle of his back. When he let out a yell and fell down I thought I killed him too. He was ok because it was winter and he had a heavy coat on.

*Continued next page...*

I lifted bar bells when I became a teenager and would put on a little show in the backyard. I would put the weights on real loose so they made a lot of noise. The neighborhood kids got a kick out of that. I played baseball and could bat pretty well. I had someone run for me. I could pitch but if another kid wanted to pitch I'd play the outfield. I caught a lot of fly balls (with my crutches) that a lot of kids thought I couldn't get.

I went to the Detroit Orthopedic Clinic on Woodward Ave. in Detroit every Wednesday for a check up. I would walk back and forth in front of a big mirror and my Dr. (Walsh) would adjust my brace and let my mother and I know how I was doing. I had a knee operation on my good leg when I was about 13 or 14. Dr. Walsh put staples across the growth line above and below my knee so my leg only grew at my hip and my ankle. This helped even up my legs and was very successful because now I only have a 1/4 inch lift on my brace shoe. I'm 73 years old now and I spend most of my time working hard at having fun. I swim, bowl, and ride my bike. I have noticed I'm getting a little weaker and having a harder time walking, probably PPS coming on! My friends in the network are encouraging me to get a scooter. That probably will happen in the near future. At the present time if I have to walk any distance or on uneven ground I go back to my trusty old crutches. I've been a member of the MPN for 9 years. I became friends with some great people and have enjoyed it very much. End of Story, Bye!♦

Dear Marci,  
I have trouble getting into and out of the shower. I was told Medicare won't pay for grab bars in my shower because they aren't considered durable medical equipment (DME). What items are considered durable medical equipment and covered by Medicare? — Marsha (Ann Arbor, Michigan)

Dear Marsha,  
Medicare covers durable medical equipment (DME) in certain situations. Medicare covers most DME if it meets the four criteria below.

1. It can withstand repeated use
2. It's used for medical purposes
3. It's usually not useful to a person who doesn't have an illness or injury
4. You can use it in your home

Wheelchairs, hospital beds, walkers and canes are a few examples of DME.

Medicare Part B, which is Medicare medical insurance, covers DME. Medicare pays 80 percent of the cost of the DME. You or your supplemental insurance pay 20 percent. If you live in North Carolina, South Carolina, Ohio, Kentucky, Indiana, Texas, Missouri, Kansas, Florida, Pennsylvania or California, you may need to get your DME from a specific provider for Medicare to cover it. Call Medicare at 800-633-4227 for information about how Medicare covers DME in your state.

Medicare usually t cover supplies that you throw away after you use them. Medicare also doesn't cover items that anyone who doesn't have an illness could use in their home. Home modifications such as grab bars and door widening also aren't covered by Medicare.

— Marci — [dearmarci@medicarerights.org](mailto:dearmarci@medicarerights.org)

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## LETTERS

*For several years I have attempted to locate and communicate with a room mate at the U of M contagious ward during the fall of 1947. I could not recall his name. We were both farm boys, he lived in Coldwater, MI and I near Ann Arbor. I was hospitalized for 35 days, he was there longer. I noticed an e-mail address for Charlie Gruner of Coldwater in the Perspective listing. In that issue his address had two "n"s and the e-mail was returned as unknown. I shortened the address by one "n" and resent the message. Within 10 minutes my phone rang and it was Charlie. We had both recovered and attended and graduated from MSU in the 1950s. This is an example of the benefit of the listing. Unfortunately Charlie was suffering from cancer and passed away recently. I regret not reconnecting earlier. -K. R. Butcher DVM\*\*\*\*\**

# SUPPORT GROUPS & INFORMATION CONTACTS

## ANN ARBOR (PPSG)

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

## CLIO AREA POLIO SURVIVORS SUPPORT GROUP

**THE NEW CLIO AREA POLIO SUPPORT GROUP** is held at the Clio Area Senior Center 2136 W. Vienna Rd. Clio, MI 48420 On the third Friday of each month at 10:00am and lasts an hour. Facilitator is Dennis Hoose.  
To join our group call 810-687-7260

## HARTFORD, MICHIGAN - PPSG

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

## LANSING AREA SUPPORT GROUP

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

## MID-MICHIGAN (PPSG)

Jean Iutzi, Harrison, MI (989)539-3781  
Group info. 1-800-999-3199  
Meeting twice a year. June and Nov.

## SOUTHEAST MICHIGAN (PPSG)

Bonnie Levitan 313-885-7855  
co-facilitated by Bruce Sachs 586-465-3104  
Dianne Dych-Sachs 586-465-3104  
Bobbi Stevens 248-549-2149

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: linsue@inbox.com  
Chuck Bond Rockford 616-866-1037

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### Post-Polio Health International (PHI)

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

# POLIO SURVIVORS SHARING

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

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- 

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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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