



# POLIO PERSPECTIVES

(CORRECTION)

Volume 26 No 2 SUMMER 2011

Promoting Understanding Through the Michigan Polio Network, Inc Since 1986

## 24-Hour Pharmacist Pharmacy at the University of the Sciences.

### THE INSIDE SCOOP ON GENERICS.

By Jennifer A. Reinhold, Pharm.D., Prevention

- Are Generic Drugs Safe?
- Tips To Avoiding Drug Interactions
- Are You Your Own Worst Doctor?

**Q:** The last time I picked up my Prevacid prescription, I was given a generic version. The pharmacist said it's just as good. Is that true?

In the United States, pharmacists must give you the generic form of a drug if one exists—simvastatin instead of Zocor, for example—unless you or your doctor specifically asks for the brand name. A version of Prevacid's generic just became available last October, so that's why you got a surprise.

Generics have to be as effective as brand-name drugs. When a company develops a new medication, the FDA requires it to test the drug rigorously. And when other companies are allowed to make a generic form of that drug, those companies, too, must independently prove to the FDA that a dose of its version produces the same results as the same dose of the brand version.

Most drugs and therapies fail in half of all patients. Here's how to figure out what will work for you. You may have heard that the FDA allows a difference of up to 20% between how the brand name affects your body and how a generic does. That's true—but 20% typically isn't enough to make a difference in effectiveness. That said, there are a few drugs for which the 20% leeway could be significant. These include warfarin (Coumadin), levothyroxine (Synthroid), and certain seizure medications. For these particular drugs, switching between a generic and the brand can be a bad idea, so check with your doctor first.

*Provided by Prevention*

## COME JOIN US AT OUR EDUCATIONAL CONFERENCE

### “AGING WISELY WITH PPS”

Saturday August 20, 2011

Genesys Conference & Banquet Center  
Grand Blanc, MI

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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



Post-Polio survivors got a real identity boost with a front page article and a full page 6 continuation in the Sunday June 12th Detroit Free Press. The Free Press Health Writer Robin Erb interviewed several polio survivors for the article.

If you haven't already registered for the MPN one day conference for Saturday August 20, 2011 being held at the Genesys Banquet & Conference Center in Grand Blanc, please use the form in this issue page 19 or from our web site.

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

Plan to attend this educational conference.

Doctor Maynard will again be leading a "Wellness Retreat" at Bay Cliff Health Camp located in Big Bay, Michigan, north of Marquette. The retreat is scheduled for Monday September 12 thru Friday September 16.

The MPN will again offer a scholarship that covers the registration fee for a polio survivor to attend the retreat. See details in on page 4.

Many polio survivors have contacted us about obtaining their polio records. In some cases the records have been moved to another location. Records from St. Luke's Hospital in Marquette have been moved to Northern Michigan University, some records from Children's Hospital in Detroit are now at the University of Michigan. Unfortunately the state only requires records to be kept for a few years before they may be destroyed. If you are searching for your polio records, start with your polio hospital's record department to discover

if they are available, moved or destroyed.

We know there are hundreds of polio survivors that are now experiencing the late effects of polio that may be needing an evaluation of their condition. See below for a listing of available post-polio help.

A research team from the University of Michigan was awarded a research grant to study people with post-polio taking a supplement called glutathione. Dr. Claire Kalpakjian will be heading the study. See related article on page six.

Have a good Summer and we will see you at the conference.

Bruce

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## Currently there are two post-polio clinics in the Southeast Michigan area:

**St. John Post-Polio Clinic  
Center for Physical Medicine &  
Rehabilitation, P.C.  
13850 Twelve Mile Road  
Warren, MI 48088  
Phone: 586-778-4505  
Fax: 586-552-4878**

**University of Michigan  
Post-Polio Clinic  
Eisenhower Park West  
2850 South Industrial Highway Suite 400  
Ann Arbor, MI 48104-0758  
Phone: 734-936-7175  
Fax: 734-975-4726**

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# The Michigan Polio Network

## DONATIONS

*The Michigan Polio Network gratefully acknowledges donations recorded during our previous fiscal year (06/01/10—05/31/11) From the following members:*

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**BAY CLIFF HEALTH CAMP POST-POLIO WELLNESS RETREAT  
SCHOLARSHIP CRITERIA**

The Michigan Polio Network is offering one scholarship, to the Post-Polio Retreat being held at the Bay Cliff Health Camp in Big Bay, Mi September 13 - 19, 2010. This scholarship will cover the entire registration fee of \$250.00.

Applicants must:

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

Applications must be received by August 15, 2010

**INFORMATION ABOUT BAY CLIFF HEALTH CAMP.**

The Camp is located about 30 miles West of Marquette on Lake Superior

The Camp continues to provides help for handicapped children in the summer

On site housing is wheelchair accessible and all meals are home cooked on site

A scooter or power chair is recommended for those with mobility issues

For more information visit their web site at [www.baycliff.org](http://www.baycliff.org) For an application to the Wellness Retreat contact Bay Cliff Health Camp, P.O. Box 310 Big Bay, Michigan 49808 (906)345-9314

**SCHOLARSHIP APPLICATION TO BAY CLIFF POST-POLIO WELLNESS RETREAT**

NAME \_\_\_\_\_ M / F

ADDRESS \_\_\_\_\_ CITY \_\_\_\_\_

STATE \_\_\_\_\_ PHONE \_\_\_\_\_ E-MAIL \_\_\_\_\_

ATTENDING WITH CAREGIVER / SPOUSE YES / NO

SHORT STATEMENT WHY YOU NEED A SCHOLARSHIP TO ATTEND THE RETREAT

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**THIS APPLICATION MUST BE RETURNED BY AUGUST 15, 2010 TO:**

**BARBARA ONISZCZAK ,52 N. PLAZA BLVD APT.428, ROCHESTER HILLS, MI 48307 or  
DIANNE DYCH-SACHS, 1070 BALMORAL, MT. CLEMENS, MI 48043**

# LIBRARY CORNER

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



Hello and happy summer, Dear Readers!  
I hope that things are going along well for you and yours on these warm July and August days. Among other books I'm reading these days, Rebecca Skloot's prize-winning **THE IMMORTAL LIFE OF HENRIETTA LACKS**, reviewed in this space a couple of issues ago, is wonderful. I notice it's still on the NYT Best-Sellers List(6/19/11), on both "real" book and e-book lists, at that! Anyway, we have this book in the library, and I hope you'll let me know if you're interested in borrowing it.

We have a few new purchases in the Library. Two of them are books written by Dr. Paul A. Offit and their titles are: **DEADLY CHOICES; HOW THE ANTI-VACCINE MOVEMENT THREATENS US ALL** and **VACCINATED: ONE MAN'S QUEST TO DEFEAT THE WORLD'S DEADLIEST DISEASES**.

Regarding the first book, David Oshinsky, Pulitzer Prize-winning author of **POLIO: AN AMERICAN STORY** and Jack S. Blanton Chair in History at the University of Texas has stated the following:

"A medical crisis has come to America. Diseases of our grandparents' generation are making a deadly comeback as more and more parents choose not to vaccinate their children. How did this happen? Who is responsible? And what can be done to reverse this unconscionable assault upon our nation's public health? For the answers, provided in clear, common sense, page-turning fashion, I recommend **DEADLY CHOICES** by Dr. Paul Offit--a timely and courageous call to arms by the nation's foremost expert on pediatric infectious disease."

Dr. Offit's second addition to the MPN Library is about Maurice Hilleman, described as the father of modern vaccines. As the narrative on the book cover mentions, Hilleman's accomplishments number nine vaccines which "practically every child

gets, numbering formerly deadly diseases--including mumps, rubella, and measles--nearly forgotten."

Dr. Offit's book "details Hilleman's research and experiences as the basis for a larger exploration of the development of vaccines, covering two hundred years of medical history and traveling across the globe in the process." As the New England Journal of Medicine commented, **VACCINATED...** is "an enlightening glimpse into the complex interface between public health and private industry, chronicling the ability of a singularly tenacious person to save more lives than perhaps any other scientist in history."

A new member of the Southeast Michigan Post-Polio Support Group, Mike Davis, commented that he'd contributed to a book on polio which had been published by the University of Rochester Press. Internet investigation led me to the site from which I ordered the book (very easily...I just love it when that happens!), and the book was quickly delivered. **POLIO**, published in 1997 and edited by Thomas M. Daniel and Frederick C. Robbins, is a collection of essays on the subject. In the New England Journal of Medicine, Dr. Maynard commented, "POLIO will be most appreciated by... those who seek an objective, firsthand account of the polio story from notable participants. Its scientific objectivity may well make it a classic reference book that will long be used by medical historians."

In *The Lancet*(5/9/98), Henry Hull stated that "Each of these personal histories is a valuable piece of history, allowing us to see how incredibly far we have come in the past half century."

Please let me know by phone(989-739-4065, MPN Internet "Message Phone," which is what I call it, or 248-853-5465, my home) or e-mail ([denilaur@sbcglobal.net](mailto:denilaur@sbcglobal.net)) if you would like to borrow these or any other books in the MPN Library. Enjoy the summer. If it stops raining here today, I'm going to "enjoy" mine by going out to do battle with some of the weeds in the perennial garden. I think the weeds are winning!

'Bye for now,  
Laura Barbour  
MPN Librarian

## **POLIO SURVIVORS NEEDED FOR RESEARCH**

Dr. Claire Kalpakjian and her team from 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. People in this study will take glutathione (an antioxidant) for 3 months while their levels of their sleep, activity and physical symptoms are measured.

"As a population, polio survivors are very engaged and proactive about finding ways to optimize their health", remarked Dr. Kalpakjian, who previously studied the health of women who had experienced polio. "With this study we hope to see whether or not glutathione shows any positive effect on health and well-being."

A total of 20 people are needed for this two year study. This will require two visits to a clinic in Ann Arbor for an examination by a physician, some simple testing and a blood draw. Those in the study will also periodically keep a food and sleep diary and wear a special device, called SenseWear that records physical activity.

Because of the clinic visits, people must be willing to travel twice to the University of Michigan. If you are interested in being a part of this study, please contact:

Mary Burton

Research Study Coordinator

Phone: (734) 764-1454

E-mail: [mjburt@umich.edu](mailto:mjburt@umich.edu)

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## **MPN NEW PIN FOR SALE**

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

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



## **Welcome to AT Xchange a new Michigan-based website where people can buy, sell or give away assistive technol- ogy (AT).**

Do you have a used AT item in storage that could really help someone who has a disability? It could be anything from a wheelchair, stair lift, Braille reader, or reacher! If so, just post a classified ad AT Xchange.org. Include a digital photo.

ATxchange is open to vendors who have used equipment for sale also. And don't worry about cost, ATXchange is a free service!

Maybe you or someone you know is looking for AT? Check out ATXchange.org! If you can't find what you are looking for, you can post it as an item wanted and receive an email message telling you if and when someone posts the item you are looking for. You may find the AT you are seeking for a bargain price – even for free! We are delighted you decided to join us! You can now view items. Sign up for a new account or log in to post items and view contact information on listings!

If you have questions regarding the ATXchange please visit the Frequently Asked Questions or contact MDRC via email at [ATX@prosynergy.org](mailto:ATX@prosynergy.org).

## **Categories of devices listed on The AT Xchange are:**

- Computers and related
- Daily Living
- Environmental Adaptations
- Hearing
- Learning, Cognitive, & Developmental
- Mobility, Seating & Positioning
- Recreation, Sports, and Leisure
- Speech Communication
- Vehicle Modification and Transportation
- Vision
- Other

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# MY POLIO STORY

by Ellen Scott Luke

In the summer of 1944, when I was 4 years old, my older brother, Johnny, came down with what was diagnosed as Bulbar Polio. Because it struck his respiratory system, and apparently there were no iron lungs available, he died within a month. He was 6 years old. Within two weeks following Johnny's diagnosis, I was complaining of pains in my legs. My parents took me to the doctor and were told just to watch me closely. One morning soon after, I was walking from my bed to my parents' room when I collapsed. Immediately, my parents rushed me to the Oakland County Contagious Hospital in Pontiac. I was 4 years old. I remember being taken up in an elevator which must have had stainless steel walls because I could see myself in the arms of my father.

I spent the next six months in a contagious ward. I was completely paralyzed - from within an inch of my brain to the tip of my toes; but my right leg was affected the worst. I don't remember very much but I do remember how kind the nurses were to me - they even brought me milk shakes once in a while. I remember the taste of drinking milk from an aluminum cup. After the daily routine of hot packs and painful physical therapy, I was allowed to be taken outside on nicer days for a few minutes.

After the isolation period was completed, I was allowed to return home for further therapy and treatment. I attended Kindergarten for a while. My mode of transportation was either a cab or a police car. By the time I was in Kindergarten, I was able to walk with the help of walking sticks. My mother took me by train to Philadelphia, PA for a procedure called a neurotripsy whereby nerves are stimulated in an attempt to revitalize them after the affects of Polio.

When I was 7, my father died of a heart attack. I was allowed to go home for the weekends. My parents would come and pick me up each Friday. One Friday, my mother came with a neighbor instead of my father. I asked where's Daddy and she said, "Your Daddy is in heaven." My mother was left with a two year old son and a daughter needing lots of therapy and doctor's visits. The Red Cross would take us downtown to see my doctors.

When I was 10 years old, I had two surgeries - the first was to insert staples in the growth bone of my left knee in order for my right leg, which was more greatly affected, to grow and reduce the 2" differ-

ence in the length of my legs. A second surgery was done called a triple arthrodesis - the fusing of three joints of the ankle in order to keep my foot from dragging to the side. This operation was considered successful and to this day I am able to walk almost normally with just a slight limp. The staples were removed when I was 14 years old. During this time of recovery and rehabilitation, I attended a fifth grade special education classroom with other kids with varying handicaps. I remember my teacher, Mrs. Spector, who wore dark-rimmed glasses and was rather stern with us.

By the time I had recovered from the surgeries and rehabilitation, I was able to walk to school- a great feeling of freedom for me. From then on I walked to the local public school every day. The high school where I attended was a mile from our house. I had a girlfriend who would walk with me to school. When I would fall down with an armload of books, we would just laugh, pick up my books and be on our way. Basically I have use of all my limbs with the exception of my right leg which remains the weakest.

After I finished high school, having passed the Civil Service Aptitude Test, I was hired by the Army to work as a Stenographer. I was married to a wonderful man at the age of 23 and lived in Germany for almost two years to be with my husband who was drafted in to the Army. While in Germany we had our first child, a son, born in Heidelberg.

Returning home at the end of that tour, life took on a sense of normalcy. I had a little girl in 1968 and another boy in 1970.

My husband is a finish carpenter - he built houses as well. He promised the kids that he would build each of them a house when he retired. He kept his word - we retired in 2002 - I had been a Personnel Secretary for Clarkston Community Schools for the previous 24 years - and he began building houses. It wasn't until about 1997, when my husband was building our second house that I began to have problems with my right ankle. It was then necessary for me to use an ankle/foot orthotic (AFO) brace. I think it was due to walking around on all the uneven ground around the building site and, of course, the years of use up until then. I remember how traumatic it was for me to give in to wearing the AFO because I would be very limited in my choices of shoes. You know how women like shoes-: Finally the pain drove me to go ahead and wear it.

*Continued next page...*

# MY POLIO STORY

by Mae Foley

Some of this I remember but mostly this tale came from my mother's daily diary.

I started the first grade in September 1927. I was delighted to be a big girl and go to school like my big brother Billy.

Approximately two weeks into October I became suddenly very sick in the middle of the night. I knew I would feel better and safer if I would crawl into my mother and daddy's bed. After all there was a picture of Jesus on the wall and a cross on the dresser. Where else would I feel better but between my parents in their bed?

My mother brought me downstairs the next morning and put me on a cot. For several days I slept off and on and felt sicker.

Our Doctor was called and he came to our house to check me. He consulted with another doctor and both of them came to the house. I was given ether and my spine was tapped. Yes, I had Infantile Paralysis (Polio) as both my parents and doctors had feared. I was carried upstairs to bed. A sign was attached to the front door saying "do Not Enter" "Quarantined House". My brother could not go to school. My mother could not leave the house. She called on the phone and had groceries delivered. The boy who brought the groceries put them on the back porch in a box and never came into the house. Any children who passed our house on the way to and from school would cross the street so they would not be near our house. My dad was allowed to go to work.

I was completely bedridden. My brother Bill

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## Ellen Scott Luke Story *continued...*

Currently, I'm experiencing pains in my legs if I overdo. I need to learn to pace myself for each day. I'm using a cane when I leave the house because I feel unsteady when I'm out of our home. I don't know if my balance issues are a result of post-polio or not.

I feel amazingly blessed with my life. My kids are all wonderful, loving and caring citizens of their communities, my husband is my rock upon whom I depend for so many daily living chores, I have strength to travel and enjoy God's many blessings of nature and this grand world He has created. ☺

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would stand in the doorway and talk to me. We were playmates and we missed playing together. One day he coaxed me to get out of bed telling me I could do it. Of course I tried and screamed and screamed with pain. My legs and body just didn't work anymore. My mother ran up the stairs and lifted me back into the bed.

The doctor came every day until I was able to get out of the bed. In November the sign was taken off the front door and my brother had a written release to return to school. My mother could go out of the house to do the grocery shopping. I was sleeping on the cot downstairs. I'm sure my mother was happy with these events.

Also in November my dad cut my hair and I was carried and put in the bath tub for the first time since I got sick.

When I was able to walk pretty well my mother took me to the Doctor's office once a week. Electric pads were put on my arm and other weak spots on my body. I assume this was to try to stimulate the muscles.

In the spring my mother borrowed a baby buggy for me to ride in and get fresh air. I was so embarrassed!

The doctor had said I should get out in the sun and play like an Indian. I took this to mean he wanted me to get an Indian outfit with a fringed shirt and feather head band. I bugged my parents with "but the doctor said".

I missed a year of school.

Actually I was very fortunate as the polio left me only with a very weak right arm and weak, awkward fingers on my left hand.

I taught elementary school before the children were born and after they were all in school.

I had seven children and I'm close to 90yrs old. I live alone and able to do household jobs and some of the yard work.

Hey, I'm a happy person.

Sincerely, Mae Foley ☺

I'm in the initial stages of  
my golden years.  
SS, CD'S, IRA'S, AARP...

# LIFESTYLE OF A POLIO SURVIVOR

By Nancy Durston

“Life is good”, everything is exciting and new. I’m 18, I married my best friend, and we have a new baby. I am the main pitcher for the Root Beer Girls Baseball Team, and an avid figure skater. I love to ski and play tennis-you name the sport and I will play it. Things are going great until November of 1949 when my husband was almost killed due to a head injury in a construction accident. Because of the circumstances we had to rent a small 2 room house that sat behind a gas station. This house had no bathroom. We had to use the one that was attached to the station. It wasn’t very clean but we did what we had to do and managed as best we could. In August of 1950 my husband was finally able to go back to work and I had a job working for the University of Michigan as a key punch operator. Things were looking up. Life was once again good, and we were finally on our way.

As I remember September of 1950 was very hot. On about the 20th of September I started feeling bad. I thought I was coming down with the flu. I went to the doctors on Friday the 22nd and he diagnosed it as the flu and treated me for such. I went home and went to bed. I didn’t wake up when my husband left for work at 5am the next morning-he let me sleep. My son, who was now 14 months old, woke me about 8am. When I got out of bed I fell down and when I was finally able to get up I could walk, but I had a bad limp. I called my husband but his job would not allow him to leave at this time. So I called our neighbor, the owner of the gas station. Since this was Saturday the doctor said he would meet me at the hospital. My neighbor’s daughter came over to take care of our son and my neighbor drove me to the hospital. She dropped me off in front of Saint Joseph Hospital in Ann Arbor, MI at noon on September 23rd 1950 and I limped my way into the doctor’s office. That was the last time I walked for many months and I never walked normally again.

The doctor checked me over and he had me touch my chin to my chest-which was very painful. He then took a pin and checked my arms and legs for sensations and came to the conclusion that it might be Polio. They called an ambulance and transported me 3 blocks from Saint Joseph hospital to the U of M Contagious Hospital for a spinal tap. It was confirmed that I indeed had Polio. The contagion hospital was an old wooden building

that was located behind the old U of M hospital. It was a real fire trap with a wooden, glassed in porch all around the building. The rooms all had big windows. Visitors had to stand out on the porch and talk to you through the window. I spent 3 or 4 weeks in this contagious hospital being wrapped in these hot steamy wool-like army blankets. I’d cringe when I heard them coming down the hall with their fancy little steam machines. I hated this part; I would come up with any excuse I could think of to get out from under those itchy, burning blankets. It was hot that September-about 98 degrees outside and no air conditioning, and I am all wrapped up in these nice hot teaming blankets. There was a little 10 month old red haired boy, I don’t remember his name, but he would not stay under his hot packs. So they would wrap him up with me and I would talk to him and keep him covered. That was the only thing that kept me from hollering “I have to go to the bathroom”.

After my stay there I was moved to an 18 bed ward in the main hospital. What a trip that turned out to be. Nine beds on each side of the room with marble floors and bed pans dropping on the floor all night. People were hollering and snoring. Wow-just what a 19 year old wanted to be doing! After I got settled in it was determined that both legs and both arms were affected to some degree so they started therapy right away. Therapy consisted of lots of stretching. If you experienced that I know you can relate. They would stretch me. I would swear, and then we had the hot tubs and weight lifting, more stretching, and then more swearing. That went on day after day. The only time there was any fun was when we were brought back from therapy on the gurneys and would be left stranded in the hallway. That was a mistake. Those old gurneys had the big tall wheels and we would be on our stomachs so it made it easy for us to push the wheels and race around the halls-we said we were exercising our arms! It took a month or so before it sunk in that things weren’t going to get better. We all know throughout our life that we will face many natural but expected changes so we are prepared to take them in stride. But when changes are forced upon you that is a different story-you are not prepared and you wonder why. I can’t say if it’s harder when something this devastating happens to you when your real young and you have not experienced a life of running, dancing, playing ball and all the other fun things or when you are older and know you

*Continued next page...*

## **LIFESTYLE *continued...***

will never be able to do these things again. One thing that kept me going was my grandmother. She was 72 years old and walked over 3 miles every day for the months that I was in the hospital just to see me for a few minutes. She was my inspiration. My mother and my husband were also my strength that kept me going.

I ended up with drop foot on my left leg and had to wear a brace with old ladies shoes. How embarrassing at 19!! I was in a wheel chair for several months but was allowed to go home if I came back every day for therapy. Since I lived outside of the city with no transportation I stayed at my mother's house in town. Every day a taxi would pick me up-it was necessary to send a man so that he could carry me out to the taxi-and take me to and from the hospital. Carrying me out wasn't really a problem as my weight had dropped from 105 lbs. down to just 64 lbs. One day I was home alone and I thought for sure I could walk. They just weren't letting me try. I stood up and tried to take a step but fell flat on my face. I had a hard time getting back into my chair so I never tried again. I also had a sling on my wheel chair for my right arm so I could exercise it.

During this experience I'm happy to say I became pregnant and in September of 1951 I had a little girl. In November of 1951 it was necessary to have surgery to fuse my drop foot. It was a success but for all these years I have had a problem finding shoes the right height. At least I didn't have to wear the brace and the old ladies shoes any more. In October of 1952 my leg turned blue from lack of circulation so I had to have surgery to take care of that problem. I was in a wheel chair and on crutches for the next several years. I took care of my son and daughter by myself since we could not afford to hire any help. I would put the baby on my lap and have my son stand on the front of the wheelchair so she wouldn't fall off. I remember I used to sweep the carpet and floor with a whisk broom leaning over the side of the wheelchair. I did whatever I had to just to get the job done.

I learned to cope and have patience and take each new improvement with enthusiasm. I graduated to a cane and eventually walked with a limp-but without aid-for several years. I raised my family and became president of the PTO. I was the treasurer of the school board, taught 4-H, Brownies, Girl Scouts, Cub Scouts, Sunday

School and anything else my children ventured into. I also chaired the county March of Dimes fundraiser for several years. When my son and daughter were in High School I went to work for Bendix Corp. in the quality control dept. working on a program to put the first camera on the moon. I also worked in quality control at Sarns and was responsible for the testing and the final inspection on their Kidney Dialysis machines and their Heart-Lung Consoles. For years I had my own business painting and participating in art and craft shows until it became too hard to set things up so in 2002 I retired. I have also worked on and chaired the elections for 57 years.

I have been back to using a cane for several years and am now trying to get used to wearing a brace on what used to be my good, but now over-used, leg. Sometimes I need crutches. I'm slowly going backwards. I hate winters as I cannot tolerate the cold and I cannot walk on the snow and ice. My feelings now have changed as I am more self conscious and embarrassed than I ever was before. When I was young it didn't bother me when people looked and asked why I walked like I did. When I got a little older and using a cane people would just say, "Oh, you broke your leg" and I would just nod my head and not have to explain.

Now in later years I have to depend on others to do certain things for me and I feel like I am imposing on them and that's the hard part. I have always been so independent. It's beginning to get harder to cope with the new changes because I know things aren't going to get better and I am going to have to depend on others to take care of me. There are times when I see others running or dancing or just doing normal things that I feel sorry for myself but that doesn't last long. Especially when I look at my 6 year old great-granddaughter and see that she is so much like I was when I was young. I know that she won't ever have to worry about getting Polio.

Needless to say I still have to admit things are still exciting when you live your life the best way that you can. I enjoy my friends, my kids, my grandkids and my 6 great-grandkids. They keep me young and happy. I am thankful for my husband for standing by me for over 62 years even when things got rough. "Life is good". ☺

# 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

## INFORMATION CONTACTS

### MICHIGAN POLIO COLLECTION LIBRARY

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

### FRED MAYNARD, MD

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

### Post-Polio Health International (PHI)

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

# 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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### PolioToday.org

I wanted to let you know about PolioToday.org, a website created by the Salk Institute for Biological studies in La Jolla California. The mission of the site is to educate and provide resources to people with Post-Polio syndrome. The community pages offer forums where members from all over the world discuss their conditions, provide support and offer advice. I invite you to check out the site.

<http://poliotoday.org/>

Since it is an online resource, it can be helpful for folks who may be homebound and feeling isolated.

Liz Hincks, Webmaster, Communications

Salk institute for Biological Studies

10010 North Torrey Pines Road

La Jolla, MA 92037

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## Request to all membership

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

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

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

**Tim Brown at 313-886-6081  
([tpbrown@frontiernet.net](mailto:tpbrown@frontiernet.net))**

or

**Laura Barbour at 248-853-5465  
([denilaur@sbcglobal.net](mailto:denilaur@sbcglobal.net))**

## TOO MUCH TIME IN THE KITCHEN



**POLIO AND ME *continued...***

# **Polio and Me**

**By Judge Deborah Thomas**

**We were at Children's Hospital, me and my mother. It was late at night and the Emergency Room was full. Doctors were running from bed to bed and the room was filled with tears; children were crying, parents were crying and staff was stressed unto tears.**

**The doctor said, "I am going to give her a shot in her back". Yes I remember, although I was only three years old at the time. He told my mother, "She can't move while I do this! Hold her down! Make sure she stays still". My mother grabbed me and while she leaned over my body to make sure that I did not wiggle or flinch, the Doctor shot me with a needle in my back. The pain, I have always remembered the most horrific pain of my life. More than fifty years later, fighting to survive another life threatening illness, once again a Doctor told me he was going to put a needle in my lower back, and once again, my mother held me tight to make sure I didn't move. She did not recall our earlier experience, but yes, I did. As a screaming three year old, I know I blacked out. When I awoke, I was in a small dark room with one other child and my mother standing out of reach outside the door.**

**Awakening in the little dark room, I remember a light shining above and behind my head. I thought it was the light from the nursing station. As the years have passed I have often wondered if the light I saw was the light of return from heaven above. Calling out to my mother I said, " Mommy come here" only to hear her say, "They won't let me"; I passed out again.**

**In the days that followed I remember my stay at the old Children's Hospital. Often I have told people that in my lifetime, there have been three buildings housing Children's Hospital of Detroit. There was the old gothic building (a sand colored stone structure), it had an underground tunnel which led to the then "new" Children's Hospital (a blue colored building); that's where they took us for therapy.**

**My Dad did the visiting while I was hospitalized at Children. I was now in a hospital ward with six beds. One day Daddy brought me a coloring book. While turning the pages of the coloring book I came across a picture of a little girl dressed as a ballerina standing on one toe. Looking up at my father I asked, "Daddy, will I be able to walk again one day?". Without pause, my Daddy said, "one day you will be able to dance". To this day I love to dance; I may not be a very good dancer but I dance very well.**

**Daddy was with me on that day in therapy when I walked the parallel bar without help or support. Then they told me to climb the wall of wooden planks; I did that too. Shortly thereafter, I went home. There were a lot of hot baths at home and stretching of my body after each bath. While those childhood hot baths weren't much fun, now I find that when my muscles are tight and sore I look forward to a good hot bath. I often got sick and missed a lot of school. My Daddy was there through it all. Each time Daddy was there until he became ill and died at home in his bed when I was ten.**

**My mother became a nurse. She worked at Harper Hospital. Every time I became ill we were at Harper together. She worked midnights and would always stop by to see me before going home each morning to get my two sisters off to school. The elementary school we attended was directly across the street from our house. I had restrictions. I could not always go up and down the stairs or even leave the front porch. I could not run and play with the other children and was not allowed to be a hall monitor girl like my sisters. Back then, the Detroit Public Schools had teachers who would come both, to the hospital and your home to give you lessons. If you were well enough to complete your assignments they would check the lessons and leave you with another set to complete by the time they came again. My grades were o.k. but my sisters often got straight A's. I grew up thinking that in addition to being sickly, I wasn't too bright either, not**

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## **POLIO AND ME *continued...***

realizing until years later that it helps if you can attend school on a regular, consistent basis.

When it came time to advance from elementary school, the nearest middle school was at least a couple of miles away from my home. My mother and Doctor agreed that I should attend an Orthopedic School. Off I went to White Orthopedic School on Detroit's east side. The yellow bus came each morning to pick me up. I met many other children with a variety of disabilities. Some used crutches, some had braces, others were in wheelchairs, some like me just walked a little funny, were always tired and had more restrictions than the law should allow. For me, going to White Orthopedic was a great experience. We played baseball! Some children could hit but not run, some could run but not hit. Some couldn't do either but they could referee, cheer and keep score. Together we could play baseball, something the other healthy children never wanted to do with us because we all had disabilities and just messed up their game. Playing baseball gave us the pride of being a part of the all American pastime. It also taught me that everyone has something they can contribute if given a chance and together all of us can achieve a better good. Attending White was my first experience at being in an integrated school. Among the students, differences in race, creed, color and religion meant very little. Each of us had already experienced the sting of discrimination, based on disability, we were sensitive not to inflict that pain on each other.

I went to summer camp for children with disabilities; that, was fun too. We all could contribute something and the nurse was on duty just in case we over did it. One time we went on an outing sponsored by a boating club. Each child was placed on a boat and we went up the Detroit River that day. I now own a boat, love to fish.

For high school, I went to Cass Technical High. In those days children with disabilities either went to Cass or Henry Ford. One had elevators, the other was all on one level. At Cass I was to leave my classes five minutes early so that I could ride the elevator from floor to floor and be out of the halls

before the mad rush of students overpowered me. Unfortunately, some of my classmates from White did not live long enough to graduate from high school. Their memories live on with me. Their courage, strength, and every success achieved through sheer willpower and determination, has helped me to face all of my lifetime challenges. When I graduated from high school I was accepted at Western Michigan University. The State of Michigan paid for my vocational training. It made sense to the government that better I be trained to work and thus pay taxes than to collect disability checks and receive taxes. I agreed with such sound foresight. The folks at Western knew that a student with a disability was coming. My dorm room was next door to the apartment of the dorm Mom's and on the first floor. It was at Western that I first truly got to pass myself off as being fully able bodied. It was also one of my most rebellious times. I stopped taking my medication and participated in every campus activity that I believed I could achieve. Pledging for a sorority proved to be impossible however. The rigors of the pledging process was more than I could do. I had to settle for being a GDI.

My dating experience began at Western. Being overly protected at home, I knew little about the dating scene. Once I began a seemingly meaningful relationship with a young man I would disclose my medical status. I soon discovered that strong healthy college men wanted strong health college women for their wives. These men did not want to be weighed down by a sickly woman or get caught up in the cost of medical bills, possibly not have children and oh so much more. Eventually, I did marry a man 15 years my senior, a relationship based more on convenience than on love. Now that I am in my 50's and single again, I find that similarly aged men are still looking for young healthy wives to care for them in their old age. Oh well, such is life.

I completed college in three years. Like most polio survivors I proved to be an overachiever. My first effort to find employment as a disabled worker was an education in and of it's self. Private companies did not want me because they assumed I would be absent a lot. They also did not want to incur the anticipated medical expense. I had a State Vocational Counselor well into my adult years. I was advised that the State would subsidize the health

*Continued next page...*

**POLIO AND ME *continued...***

insurance cost of employers if I advised them that I was a state certified handicapper. Sounded good, but eventually only governmental agencies were impressed. I taught school as my first job. The field of teaching was over crowded, so I went back to school. Eventually I went to law school. Never did I tell anyone at law school that I had a disability. By now I was pretty good at passing for an able bodied person. Getting a job after law school brought me back to facing the same old challenges. Government agencies would hire good workers no one else wanted. Looking in the private sector I kept my secret however. For a while I had my own private practice. After a few years the long hours and constant travel began to take its wear and tear. I knew I would have to go back to work where I would have both a steady income and health insurance.

Still relatively young, I decided to run for "Judge". I didn't mention while campaigning that I had a disability. I knew better than make my health an issue during the campaign. After a couple of efforts I won election. Reporting to work, I made sure that my polio history remained my secret. I never took all of my vacation time, never missed much work, because then my passing would be disclosed. I worked when I was sick, I worked when I was in pain, I reported for work come hell or high water because no one was going to tell me that the handicap are a burden to society and can't pull their own weight.

Post Polio Syndrome began to raise its ugly head. Sure I had heard of it. I knew it could happen, but it did not matter. I had a family to support. I was a survivor, I was passing for healthy and I was going to continue to pass. I sought out the medical support of the University of Michigan. At the time it was the only medical facility in Michigan addressing the issues of Polio survivors. I told the doctors that I was passing. No one at the Court knew my medical history. I had to keep passing as fully able body. Living in Detroit, if I treated in Ann Arbor changes in my attendance would become noticeable. Arriving late, leaving early for treatment would have to be explained. A compromise was reached; I would go for therapy before and after work in Detroit. Doctor Laidlaw would give the Detroit based therapist detailed instructions about treating a Polio survivor. My secret was safe, my job was safe, we gave it a try.

This effort worked for a while, but at last, there was this pain, a new pain. Not the pain I had lived with all my life. Not the pain that was my constant companion. Not the pain that let me know each morning that I was still here, still alive. No this was a new pain that I could not shake. This new pain came with an unpredictable weakness in my legs. This new pain was not the pain I had come to know like an old friend. Doctor Laidlaw advised that I had to go into intense therapy. Therapy every day, physical therapy, occupational therapy, and yes, even pain therapy. I had to choose to survive, to protect my mobility. I had to tell the Court that I had been passing for able bodied. I had to take some time from the job to continue to survive. Hoping to minimize any damage to my career I delayed treatment until the upcoming Christmas holiday season. The Courts would be closed for at least one week and I would take only six weeks off instead of the eight recommended by my doctor, so at worst I would only be away from work for about four weeks. I thought I had a good plan. Boy was I wrong. Upon presenting the medical documents to the Presiding, supervising Judge; all hell broke loose. I was lying. I never had polio. I was a scoffer who just did not want to work. The State Court Administrator Office got involved. My doctors were interrogated. I was ordered back to work early despite the recommendations of the medical staff of U of M Hospital. All during treatment I spent as much time fighting for my job as I did trying to heal. Before it was all over I was grieved, had to get an attorney, had to discuss my medical condition publicly, had to endure the stress of being a Polio survivor outted without choice, without privacy, without respect. Several years passed. The grievances continued, I returned to work afraid to go to therapy, leaving the clinic early, without seeing the doctor, if it appeared my return from the earliest morning appointment would result in my reporting to work later than previously indicated to my staff. No I was not entitled to sick leave, no I was not entitled to family medical leave. Those rights did not apply to Judges. I had to report to work, or resign, or be fired. I spent the following few years living the accusations of being a liar and a cheat. Until, finally the Grievance Board ruled, that yes I truly did have Polio, and yes I really did suffer from Post Polio Syndrome, but I should have told someone of

*Continued next page...*

my illness far more in advance of presenting the request for medical leave from the staff of the University of Michigan Hospital.

Do I regret passing for fully able body for all those years? No, that is what I was trained to do. That was the stated goal. Every Polio survivor was taught to seek assembly into the mass public with as few telltale signs as possible. While I did not report my medical history to my employers I always worked in charitable efforts to assist children with disabilities, spoke at schools teaching disabled children. I wanted them to know that they too can master their disabilities and lead productive lives. Once fully outted I became a member of the State Bar's Access To Justice Committee for Disabled Citizens, raising awareness of disability barriers existing in the Court and seeking solutions to those barriers. I also became the lead plaintiff in a federal law suit which resulted in changing the process as to how the public airlines conduct business when it comes to servicing those with disabilities. I remain sensitive to the fact that discrimination against individuals based on any factor be it race, gender, religion, economic status, or disability is wrong and that speaking out against discrimination when it occurs is part of educating the public and creating a better society for both those who are fully able bodied and people like me, who are not. Life is still worth living and fun. I still have my job as a Circuit Court Judge which I greatly appreciate and hope to keep as long as the good voters of Wayne County will have me. Like all judges for the State of Michigan I am aged out once I reach age 70. It is my plan to work up to the last possible day. I have a closet full of shoes. No more brown oxfords. No more black and white oxfords, and no more black on black oxfords but pretty shoes in many colors. I can't wear all my shoes, the heels are too high on some, but depending on my mood I have been known to strap my high heel shoes to my purse and carry them where I go, because I love pretty shoes and still love to dance. ☺

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

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

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**GENESYS CONFERENCE & BANQUET CENTER**  
**GRAND BLANC, MI 48439**  
**SATURDAY AUGUST 20, 2011**

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**TO THE LIGHT AT GENESYS HEALTH PARK MAIN ENTRANCE**  
**FOLLOW THE SIGNS TO THE CONFERENCE CENTER**

**CONFERENCE REGISTRATION FORM**  
**REGISTRATION SATURDAY 8:15—9:00 AM**

Registration fee includes Saturdays lunch One Person Two Persons Total  
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Please return this form with your check payable to: Michigan Polio Network Inc.  
Must be post marked no later than Monday August 8, 2011

**SEND FORM & CHECK TO:**  
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**SHELBY TWP, MI 48316**  
**586-786-1029**

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e-mil \_\_\_\_\_

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Is this your first time attending a Michigan Polio Network Inc. conference? \_\_\_\_\_

Lunch will be plated: SELECT Lemon Chicken \_\_\_ Beef tips \_\_\_ Vegetarian \_\_\_

# MICHIGAN POLIO NETWORK

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