

POLIO PERSPECTIVES

VOL 27 NO 1 SPRING 2012

Promoting Understanding Through the Michigan Polio Network, Inc Since 1986

Waiting For Your Polio Story LETTER FROM THE EDITOR

Hello survivors,

I am still waiting for those survivors who have not sent me their Polio Story! Our membership has enjoyed reading about all the Polio Stories that I have received and now we would like to hear Your Polio Story!!

Here is a recap of what you might like to share in your Polio Story:

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 ever try to get any medical documentation regarding your polio?

Have you ever had any corrective surgeries due to 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?

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

Share any interesting story of your life that was affected from you having polio.

COME ON SHARE YOUR STORY!!!

Vera Hazel, Editor

Board of Directors Meeting

The next Michigan Polio Network, Inc. Board of Directors meeting will be held on May 19, 2012 at TONY M'S 3420 S Creyts Rd, Lansing, MI.

The MPN invites you to consider attending our board meeting to give your input of ideas on where we might go in the future of the Network and our conferences.

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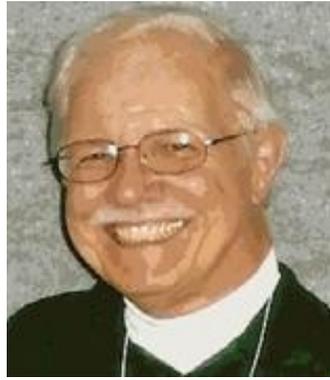
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Send articles, information, personal accounts to:

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FROM THE CHAIR

Bruce Sachs, Chairman



Welcome to Spring, although we had a very mild winter, we can now look forward to longer and warmer days.

We have returned from Florida where we cruised again with the Boca Area PP Group. We had a total of 40 cruisers with 12 being from Michigan. [see articles on page 6-7] While there we also heard Professor Mike Kossove as he spoke at the Boca Area PPG. He said he had nothing new to say, and an hour later he was still answering questions. Also in this edition is part 2 of the article on medical marijuana from California, an up date on the New York Taxi problem, and a question and answer on Post-Polio from Dr. Maynard.

Although we are not having a conference this year, we continue to be available to provide information on Post-Polio and how to deal with living with PPS. Check out our web site at

www.michiganpolionetwork.com and also the MPN Library

989-739-4065 or denilaur@sbcglobal.net

Dr. Bill Waring contacted me asking for our help with a polio project from the University of Wisconsin. This project will be part of a grant proposal for funding from Post-Polio Health International and will initially contain a short survey. I will have more details as they become available.

Barbara Mayberry from the Naples FL PPG forwarded information on a polio project by an 8th grade student named Hannah who lives in Seattle, WA. She wrote a Polio History project. Hannah asked me to share her project with our members. Here is the URL to her web site:

<http://69152045.nhd.weebly.com>

Have a safe Spring.

Bruce

Bay Cliff Health Camp

In an effort to expand our programs to serve additional needs that have been identified by the Bay Cliff Program Committee, we will now be having one wellness program per year for polio survivors.

This means we will alternate between the Post-Polio Wellness Retreat and the Post-Polio Wellness Update.

Bay Cliff's next program for polio survivors will be the POST-POLIO WELLNESS UPDATE October 15-18, 2012.

Everyone who has attended a Post-Polio Wellness Retreat is invited. Details and registration information will be sent out in the Spring. Bay Cliff's next POST-POLIO WELLNESS RETREAT will be offered September 9-14, 2013.

We are pleased that Dr. Fred Maynard will once again be our medical advisor for the program.

Christy Osborn Program Coordinator

In the Winter edition of The Polio Perspectives we printed part 1 of a research project on Medical Marijuana from California. The following is an edited summary of part 2.

MMJ (Medical Marijuana) A Research Project Part 2: Who Uses MMJ

By RE Van Der Linden

On the Internet and in interviews I learned about people who use marijuana for various medical conditions such as glaucoma, back pain, nerve pain, MS, neurological disorders, and the effects of chemotherapy. All are mature, sensible adults who had tried traditional medications and found marijuana effective without undesirable side effects when used in moderation.

The following people are PPS folks who wrote or called in response to the first article. The names have been changed to protect the innocent.

Larry in La Jolla

Larry had polio as an infant, leaving him with a weakened left leg. 40 years later, after a long career with the Government, his weak left leg caused him to overwork his right leg as PPS set in. In response, Larry's neurologist started him on pain medications.

Due to the side effects of prescribed narcotics, Larry had to take several other medications to treat things like dry mouth, constipation, and sleep disorder.

In 2008 Larry took advantage of California's Compassionate Use Act, and replaced the narcotics and other medications with medical marijuana.

Larry grows his own cannabis and processes it into edible form. He tried various other methods and, like many others, finds the edible form of the natural plant to be the best way to use MMJ for pain relief.

Tom from Temecula

1) He thinks it's worth trying carefully, first in small amounts. It may take a few times to get benefits.

2) He does seem to get temporary relief from joint pain, seems to increase blood flow and promotes activity such as stretching and swimming. Fatigue late in the day (i.e. "hitting the wall") seems to be often relieved and he can continue working another couple of hours. (His prescribing doctor recommended a bedtime dose but he finds other times can be most useful.)

3) Dosage and route of administration are everything.

-- Too much causes unwanted anxiety and increased heart rate. Smoking or inhaling doesn't work for him. He is longtime user with very good general health, with a healthy heart rate/blood pressure.

-- He uses cooked medicine exclusively (smoking/inhaling unhealthy). Recipes abound on the Internet.

Bob from Bakersfield

I had bulbar polio as a child, just before the vaccine came out. I was okay for about 40 years, but for the past 15 years I've had problems throughout my body, mostly upper body weakness and pain. I tried a few mild pain relievers and found that they worked okay but made it too easy to hurt myself by doing too much. Not long ago I decided to get a "green card" [prescription for medical marijuana] and learned about a better way to use MMJ, which is ingesting it in cookies or brownies or other foods. Although I haven't been using it for very long, it seems to be helping so far. My wife says I'm more relaxed and easy to get along with. As for pain relief: I don't think it works like other pain medications. Yes, the pain seems to be reduced, but I know it's still there so I still use assistive devices and rest often.

***The Southern California PPS Manager
January/ February 2012***

Question Answered

By Dr. Donohue

Dear Dr. Donohue: I am 78 and had polio when I was 17. I have lived with weakness on my left side. About a year ago, I started feeling a lot of fatigue. I saw an endocrinologist, who tested for low testosterone and thyroid. I took medicines that fixed both problems, but I still feel very fatigued. How do I determine if the fatigue is caused by post-polio syndrome?

T.M.

Dear T.M.: Post-polio syndrome does not mean that the polio virus has returned. It does mean that nerve cells adjacent to those attacked by polio are starting to shrink and die. Those nerve cells took over the work that the polio-killed nerve cells had done. This takes place many decades after the original attack. The result is muscle weakness and sometimes muscle pain. The most prominent symptom is fatigue.

No test proves post-polio syndrome. If a person has a doctor who knows what polio had done to that person's muscles, he or she can detect whether new muscles have been added to the list of those that are not functioning. Rarely does such a lucky knowledge of doctor familiarity with the previous muscle involvement exist.

Fatigue, however, is a classic criterion of post-polio syndrome. If, in addition to fatigue, you have new muscle weakness or new muscle pain, then you can be quite sure it's post-polio syndrome that's to blame.

Although no medicine exists to reverse the weakness, therapy with non-exhausting exercise is helpful. For the fatigue that is so common with this syndrome, pacing yourself and taking rest breaks, even naps, during the day can restore pep.

A neurologist is the doctor you want to consult. You'd be wise to contact Post-Polio Health International, an association dedicated to helping those who were stricken by polio and those who have post-polio syndrome. The phone number is (314) 534-0475 and the website is www.post-polio.org.

ASK DR MAYNARD

Dear Dr. Maynard,

I have a question for your PHI newsletter, "Ask the Doctor" segment:

I have been reading recent articles in various newspapers and magazines about polio survivors dying of post polio syndrome. Can you please explain what would cause death to polio survivors now bearing post polio syndrome? I was lead to believe that post polio syndrome was fatigue, weakness and pain associated with neuromuscular degeneration from having had polio. Aren't the co-morbidities (obesity, heart disease, diabetes) from having post polio syndrome what causes death?

Barb O

Dear Barb,

Regarding your question about if and how polio survivors 'die from PPS', I would say the following: *PPS is never the "Immediate (primary) cause of death", as a physician would list it on a death certificate. Cardiac arrest, respiratory failure, pulmonary embolism, stroke would be common primary causes, and you are right these would usually be 'age-related' co-morbidities.

*PPS can be appropriately considered, and listed by physicians, as a significant secondary or tertiary cause of death diagnosis. The rational would be that it could have led to progressive inactivity and debilitation that caused the co-morbid conditions which were the immediate cause of death to develop. While the relationship between these co-morbidities and PPS is often speculative, or at least unproven from a scientific statistical analysis perspective, it is medically probable that PPS has been a 'risk factor' for some of the diagnoses that directly lead to death. A good example is Coronary Artery Disease in men who are polio survivors with high cholesterol. CAD in older men and high cholesterol are common diagnoses in the general population but have also been shown to be more common among those who don't exercise regularly. Therefore, if polio has left one with sufficient weakness that one can not actively exercise aerobically, then one could consider that PPS (or at least being

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LIBRARY

CORNER

By Laura Barbour, Librarian
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Greetings, Readers!

I hope that all's well with you, and that by the time this issue reaches your mailboxes, spring will be with us for absolutely real, rather than the previous "hotter-than-it-should a-been-in-March" followed by "what-is-this, November-again??"

On my side of this corner, things have been rather quiet, so my offering this quarter will be (blessedly) short.

Since the winter issue of "Perspectives," I've been moving right along, doing Library jobs, sending packets out to current and prospective members. A few books have been sent out to interested readers, as well. I also helped our treasurer, Tim Brown, and his wife, Ginny, get a membership mailing ready. This involved preparing close to three hundred envelopes for mailing to those MPN'ers whose memberships have or are about to expire. Lots of stuffing and stamping involved in that project!

My husband, Denis, and I were fortunate enough to be able to sail on a Caribbean cruise in late January. This was our third, another opportunity to join the Boca Area Post-Polio Group on another successful voyage on the "Bounding Main," a term I remember from the days of my youth, but must admit never having looked up just what the "Bounding Main" means!! Shame on me for not finding my dictionary and checking that term!! Anyway, we had a great time, sailing with 40 cruisers, 12 of them from the Michigan area. We traveled to San Juan, Saint Maarten, and St. Thomas, three enjoyably warm locales.

February found us back at home in Rochester Hills, just in time for Denis's gall bladder to develop rather painful problems (and, yes, we were so happy to be at home when this happened!). Denis is recovering slowly from sacrificing his gall bladder to medical science, having found that he doesn't miss the thing a bit!

Now it's almost April, and I've got to get back to checking out the Internet sites, seeing if there are any new publications which might interest you. Watch this space in the summer issue to see if my luck is good or bad. Meanwhile, take care, stay well, and enjoy spring, no matter what other season it seems to be imitating.

Laura Barbour, Librarian

ASK DR MAYNARD *continued from page 4*

severe polio survivor) was a 'significant contributing diagnosis' to the death. ***What physicians actually list on Death Certificates is not very uniform and is definitely a "judgment call" for the physician completing the form and influenced by their knowledge, experience and biases.**

***It would be my personal opinion that being a polio survivor or developing PPS is only frequently a significant factor in 'earlier in life than would be expected death' among severely affected polio survivors, primarily those who have had chronic, or develop new, respiratory failure requiring some type of mechanical ventilator assistance.**

***This topic is one reason it is so relevant for polios to be leaders in the field of discovering how Health & Wellness can be best promoted among people with neuromuscular diseases that result in weakness and mobility disability.**

I hope this is helpful. It is OK to share it under my name, and I will share it with Joan Headley at PHI. Best regards, Dr. Fred Maynard ☺ ☺ ☺

THE FIRST OF MANY CRUISES

Jane and Ron Berman

We are not only new to cruising, but new to the Boca Area Post Polio Group as well. As first time cruisers, there was only one thing wrong with the week we spent cruising with BAPPG on *Celebrity Solstice*—it wasn't long enough!

Our cabin was roomy, comfortable and completely accessible. Our cabin steward was always helpful and ready to meet whatever our needs might be; whether it was a fresh pitcher of ice water or clean towels, seemingly immediately after they had been used! I was especially thrilled to have the opportunity to speak with so many folks who had the same, and many different polio experiences during their lifetimes. This was a perfect chance to learn about new ways to make my life easier and pass on the things that I had learned and implemented. The cruise allowed us to mingle with members of our group but also gave us plenty of time to meet many other cruisers, or just spend some private time.

The activities were wide ranging and both my husband and I were able to fill our days with many different activities. We both enjoyed participating in a wine tasting one afternoon, while I had a chance to stroll through the ship's many stores when he sat in on a historical lecture. He was thrilled to have a chance to tour the ship's bridge and watch as the Captain pulled out of port one afternoon. I was equally happy to sit in on a computer lesson detailing the building of picture albums, scrapbooks, and calendars.

It was a great opportunity to explore and learn, and I haven't even touched on the wonderful dining, including room service (especially nice for early morning coffee), and amazing specialty restaurants in addition to the gourmet menus available in the main dining area! The entertainment each evening was top notch and available in many forms throughout the day, and this was just what was happening on the ship! Remember, we also were able to go ashore and explore the sights and sounds on three separate islands.

As travel has become a little more physically challenging for me, I found this to be a very easy way to see places I hadn't yet been. Did we enjoy our cruise? We most certainly did and we've already signed up to cruise another set of islands with BAPPG next year. While it was snowing in our home state of Rhode Island, we were basking in the sun of the Caribbean. We hope that you'll consider joining us next January and we will be afforded the opportunity to meet many more new folks while uniting with old friends.

CRUISING THE HIGH SEAS

My name is Jim Dougan and I am a member of the Naples Area Post Polio Group. I also support the BAPPG as much as possible.

About 5 years ago my wife and I went on a cruise through the Panama Canal. At that time the ship was one of the biggest and newest with accessibility all over the ship. I was quite mobile on wooden crutches but also had a Pride celebrity scooter which I took on the cruise.

I found accessibility in the common areas to be good. There were two banks of elevators which with 1,800 people on the ship was in my opinion a little bit of a problem. A smaller GO-GO type scooter would have been preferable.

The accessible state room we had was not a high deck suite and had a porthole as a window. The bathroom was large but using the shower left something to the imagination.

My upper body strength then was very good. Everything worked as long as you could adapt to slight inconsistencies. After that cruise my arms lost a lot of strength and I told my wife that I could not go on a cruise any longer, as the accessibility, even though good would be a worry for me. So we have not cruised in 5 years.

At the same time I was receiving the BAPPG news letter. There were comments from people about the great cruises they were going on and also an honest comment that from their point of view the cruise ships are extremely accessible. Low and behold,

Continued next page...

CRUISING *continued...*

this year my wife and I went on a cruise with the Boca group and I am here to say access is first on the minds of the people who design the ships now. I found that the number of disabled people on the cruise was phenomenal. Many more scooters than I had ever seen. Also the crew on the ship was trained in dealing with different problems whether it be at dinner or going ashore. They were there at all times.

We had a water view accessible cabin on a lower deck. The accessible room was large, roomy and you were able to maneuver within the cabin. The bathroom had all the bells and whistles that make an accessible area accessible in the true meaning of accessibility. I had my crutches with me but only used them within the room for mobility at times. The only problem that was encountered by me was the hallways from front to rear where cabins are located. When the cleaning carts are in the hall it is a tight fit to get around them but was always possible. If there was any question the house keeping people would move the cart long before you arrived at their location.

Now for the final accolade!!! The ship had a bank of three sets of elevators (front, middle and rear of the ship) which dispersed the use by people so that there were no long waits for an elevator no matter where you were on the ship.

Here is hoping that my wife and I will get to meet some new people next year. OH YES---- we are going again.

Join BAPPG in 2013

Celebrity Cruise Line's - Silhouette

January 13 – January 20, 2013

Port Everglades 7-nights

Western Caribbean Cruise

WE ARE GOING, AGAIN!!! CRUISE 2013

By Bruce Sachs

Join the Boca Area Post-Polio Group on our tenth trip – an exciting 7-night cruise to the Western Caribbean.

Celebrity's Silhouette will depart on Sunday, January 13, 2013 from Port Everglades Ft. Lauderdale, FL. visiting Mexico, Grand Cayman, Jamaica & Hispaniola.

Twenty-six (26) accessible staterooms are reserved. Ship is accessible as seen by my eyes! Where else can you get your room, unlimited gourmet food, entertainment, room service, Ports of call, numerous activities, casino and shopping all for as little as \$133- \$383 a day?? All inclusive stateroom rates begin at \$932 Inside; \$1182 Ocean View; \$1131 Balcony; \$1230 Concierge & \$1982 Sky Suite, based on double occupancy.

So, if you just think you'd like to go, a deposit will hold your stateroom.

Deposit is 100% refundable until October 1, 2012.

Contact Maureen at 561-488-4473 or

BAPPG@aol.com for questions, roommates, scooter rentals & onshore tours.

Call Judith at 561-447-0750, 1-866- 447-0750 or

Judith@travelgroupint.com for booking/transfers/hotels & mention BAPPG.

Fourteen people are already booked!

We had 12 people from Michigan this past January.

Dianne & I have already booked.

Five simple rules to be happy:

- 1. Free your heart from hatred.***
- 2. Free your mind from worries.***
- 3. Live simply.***
- 4. Give more.***
- 5. Expect less.***

AT Xchange.org

Welcome to AT Xchange a new Michigan-based website where people can buy, sell or give away assistive technology (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.

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

Maybe you or someone you know is looking for AT? Check out AT Xchange.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 AT Xchange please visit the Frequently Asked Questions or contact MDRC via email at 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 Modifications and Transportation
- Vision
- Other

1. Who can use the AT Xchange?

The AT Xchange is primarily for residents of Michigan, although we do accept entries from neighboring states.

2. What type of equipment can be listed?

Any device that assists a person with a disability to live more independently or safely (assistive technology) may be submitted.

3. What type of equipment will not be listed on the AT Xchange?

MDRC reserves the right to exclude items deemed to pose a hygiene risk. We can and will not, however, certify in any way that items are hygienic or safe for any individual use.

4. How can I access the AT Xchange if I do not have internet access?

The Xchange is an internet-based tool. If you do not have Internet access, call your local Center for Independent Living or public library for referral to computer with internet access that is available for public use.

5. How can I browse the listed items?

You can view all available items by selecting the "View Items Available" button. If you are interested in viewing items sought by others, select on "View Items Needed". Both of the resulting lists can be divided into equipment categories.

6. How can I add an item to the AT Xchange that I wish to sell or donate?

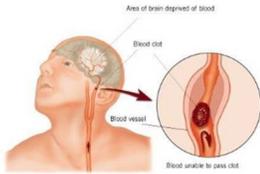
If you have an item you would like to offer for sale/donation, select "Sign-up Now" or "Log In". Once registered and logged in select "Post an Item for Sale/Donation". You will then be prompted to complete a form regarding the equipment you are interested in placing on the AT Xchange.

7. How can I add an item that I am looking to purchase?

To add an item you are looking for, select "Sign-up Now" or "Log In". Once registered and logged in select "Post an Item Needed". You will then be prompted to complete a form regarding the item you are looking for.

Stroke has a new indicator.

Blood Clots/Stroke - They Now Have a Fourth Indicator, the Tongue



STROKE:

Remember the 1st Three Letters..... S. T. R.

STROKE IDENTIFICATION:

During a BBQ, a woman stumbled and took a little fall - she assured everyone that she was fine (they offered to call paramedics) ...she said she had just tripped over a brick because of her new shoes.

They got her cleaned up and got her a new plate of food. While she appeared a bit shaken up, Jane went about enjoying herself the rest of the evening. Jane's husband called later telling everyone that his wife had been taken to the hospital - (at 6:00 pm Jane passed away.)

She had suffered a stroke at the BBQ. Had they known how to identify the signs of a stroke, perhaps Jane would be with us today. Some don't die they end up in a helpless, hopeless condition instead.

It only takes a minute to read this.

A neurologist says that if he can get to a stroke victim within 3 hours he can totally reverse the effects of a stroke...totally. He said the trick was getting a stroke recognized, diagnosed, and then getting the patient medically cared for within 3 hours, which is tough.

RECOGNIZING A STROKE

Thank God for the sense to remember the '3' steps, STR. Read and Learn!

Sometimes symptoms of a stroke are difficult to identify. Unfortunately, the lack of awareness spells disaster. The stroke victim may suffer severe brain damage when people nearby fail to recognize the symptoms of a stroke.

Now doctors say a bystander can recognize a stroke by asking three simple questions:

S *Ask the individual to SMILE.

T *Ask the person to TALK and SPEAK A SIMPLE SENTENCE (Coherently) (i.e. It is sunny out today.)

R *Ask him or her to RAISE BOTH ARMS.

If he or she has trouble with ANY ONE of these tasks, call emergency number immediately and describe the symptoms to the dispatcher.

New Sign of a Stroke ----- Stick out Your Tongue

NOTE: Another 'sign' of a stroke is this: Ask the person to 'stick' out his tongue. If the tongue is 'crooked', if it goes to one side or the other that is also an indication of a stroke.♦

NEW ASPIRIN

Heart attack info

Serious stuff, no joke!!

Why keep aspirin by your bedside?

About Heart Attacks

There are other symptoms of a heart attack besides the pain on the left arm.

One must also be aware of an intense pain on the chin, as well as nausea and lots of sweating, however these symptoms may also occur less frequently.

Note: There may be NO pain in the chest during a heart attack. The majority of people (about 60%) who had a heart attack during their sleep, did not wake up.

However, if it occurs, the chest pain may wake you up from your deep sleep.

If that happens, immediately dissolve two aspirins in your mouth and swallow them with a bit of water. Afterwards: CALL 911

- say "heart attack!"

- say that you have taken 2 aspirins.

- phone a neighbor or a family member who lives very close by

- take a seat on a chair or sofa near the front door, and wait for their arrival and...

DO NOT lie down!!

Just a reminder to all: purchase a box, keep one in your car, pocketbook, wallet, bedside, etc.

Bayer is making crystal aspirin to dissolve under the tongue. They work much faster than the tablets

Bobbi Stevens Polio Story

My life started on February 6th, 1955. I was born at Selfridge Air Force Base Hospital, as my dad was serving in the Air Force at the time. Whatever life awaited me, whoever I was going to be changed drastically on July 16, 1955. That was the day I was diagnosed with polio. After that day, I started a new, different life. I was left with a different body, one that would never dance, or run, or even walk without assistance. But my spirit was intact. My love of life was there, as was my (according to my parents) quirky and (to them) unfathomable sense of humor. From my earliest memories, I was determined that I would not be just a spectator to other people's lives, but live my own as best I could. I was diagnosed at St Joseph Mercy Hospital in Pontiac, then transferred to University of Michigan, where I lived, on and off for the next two years. After my dad was discharged from the service we settled in Royal Oak, Michigan, My father went to work for Michigan Bell and my mother settled into being Susie homemaker (with an attitude). My first memory is from the age of around 2 years. Understandably, the memory is nothing but a fragment, but telling, none the less, of the future. I had leg braces strapped on, and I had tiny crutches that a Physical Therapist was trying to get me to use. I looked up; saw a person in a white coat headed toward me. Since, in my mind, that meant I was going to get hurt again, I threw down the crutches and refused to try. Unfortunately for me, I couldn't stand without them, so I quickly followed them down to the floor with a crash. I was going to be one of those children who have to learn most of life's lessons the hard way. Sigh. I was a poster child in my county twice for the March of Dimes, in 1956 and again in 1960: It meant that my picture was in the paper and I had to appear at fundraisers. I would go door to door with my mother to collect money, always sweetly saying, "thank you", while looking as adorably pathetic as possible. I remember one banquet where they hoisted me up to stand on a very rickety table (with the braces and the crutches) and as they made their plea for

money, kept pointing at me and saying, "don't let this happen to your child!" "Hey", I thought that's not very nice; I'm more than just the braces and crutches! " My early years were marked with lots of visits to the University of Michigan Medical Center, where I would see doctors who would gauge my strength and progress (or lack of) and try to make it better. That meant lots of corrective surgeries, lots of summers in leg casts. Oddly, I learned to love the hospital, the clean smells, the nurses, the orthotists (brace-makers), and the doctors. There I wasn't so abnormal and everyone was kind. My mother, on the other hand, hated these visits. It was a long drive to the hospital from our home and she was always cranky and complained of headaches. When I was hospitalized after a surgery, my parents didn't come to see me every day. I'm sure the long drive and the fact that they just had one car (and my dad had to work) were factors, but, I always watched the other kids in the ward whose parents seemed to be there from morning till night, and wondered why I was different. I made friends with the other patients and their families. The other mothers would hug me when I cried because my legs hurt or I was lonely. When I was going to be in traction in the hospital for 2 months, my parents packed up my sister and went on vacation without me! I was outraged and still am! One time when I was about five, we went to an S & H Green Stamp Store. My mother had been saving her stamps from her grocery shopping trips, as most women did back then. My mother had been in a terrible mood, snapping at everything I did or said (or so it seemed to me) I saw a teddy bear - yellow with a blue and white striped shirt and a stocking cap to match. I fell in love with him and wanted him and asked my mother if I could have him. She told me no, I was too old for teddy bears and to stop being so silly. I remember crying as we left the store. A few weeks later, I started my summer as I started quite a few of my childhood summers, back in the hospital having surgery on my legs. When I woke up from the surgery, that teddy bear was on the pillow next to my

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Bobbi Stevens Polio Story *continued...*

head. I will always love my mother for giving me that bear that meant so much. I still have him and I still don't get my mom and she still doesn't get me. We used to have big family get togethers and I remember afternoon games of baseball, football, or hockey, depending on the season. Most of the time, I was content to watch and be a "cheerleader", but I remember one baseball game, when I was 7 or 8, I really wanted to play and my dad said that I could lean on one crutch and bat with the other. Everyone was surprised when I actually nailed the ball and it went flying, and to my great delight, my dad picked me up and ran the bases with me tucked under his arm. By the time we made it to home base, my ribs hurt a little, but we had scored!! I will always love him for that. My relationship with my mother has always been complicated and confusing. At times, she was over-protective and smothering and then the next day she would seem resentful and aloof. I always wondered: did she feel guilty? She shouldn't have. A virus is a virus. We have always had a strange relationship. Did I feel loved? Well, if you can feel loved, but unwanted, then yes, I think she loved me as best as she could. But she resented the extra trouble and expense of a special needs child and never let me forget it. I was always clean, clothed and well-fed and had plenty of toys and books. My parents always insisted that I not indulge in self-pity, (my mother was always a "no matter how bad things are, they can always get worse" kind of girl.) and I was not to evoke pity from others, you know the "poor little crippled girl" routine. My mother was extremely thrifty and would buy popsicles and other ice cream treats at the grocery store and dole them out one per day. (I was scandalized the first time I was at a friend's house and they actually ate two fudgesicles in a row! I thought there was some kind of a law!) Anyway, one day the Good Humor man was making his way down the street while I was outside playing with my friends. I had already had my ice cream allotment from the freezer, plus my mother thought the ice cream man charged too much

money. (But some how, that ice cream was SO much better!) But my friends had money and were going to get ice cream, so I walked over with them while they made their choices. The man asked me what I wanted and I politely said, "No thank you", he said, "Come on honey, what would you like?" I explained that I had no money and I was just with my friends. You can imagine the scene as the pathetic little girl balancing on crutches bravely says "no thank you" to an ice cream bar. The man said there would be no charge; he wanted me to have it. I told him my parents wouldn't like it and started to move away. He caught up to me (it wasn't difficult, I was hardly Speedy Gonzales) and tucked the ice cream in the pocket of my jacket. I didn't know what to do; accepting free ice cream from a sympathetic stranger was a big no-no. I should have just ditched it, but I was told it was wrong to litter, and I couldn't throw it away in the house without my mother seeing me, she watched us like a hawk. So, this not being my smartest day, I just left it in my pocket and forgot about it. I went home took off my jacket, and my mother hung it in the closet, not realizing she should check the pockets. The next day I heard her shrieking like a banshee when she saw the mess in the closet, my jacket, the coat next to mine and the drippy, sticky, mess on the floor. Jeez, I was the only kid I knew who could get into trouble for TRYING to be obedient! TV is one of my best friends. It has always kept me company and entertained me. While kids were outside playing running games, I didn't feel bad; I would just go in and watch "Queen for a Day", or "The Match Game" or the soaps. That was one area where my mom and I could bond, we would watch the soap operas together and she would keep me updated on what happened when I was in school. Back in the old days, Sunday mornings they would show Shirley Temple Theater and I loved to watch all of her movies. In fact, when adults asked the inevitable, "what do you want to be when you grow up?" I would always answer, "A dancer!" Then they would get this stricken look on their face and pat me on the shoulder and walk away.

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Bobbi Stevens Polio Story *continued...*

My mother smacked me and told me to stop saying that; I was making people feel bad. Now, I knew from a very early age that dancing would never be in the cards for me, but they asked what I wanted to do, not what I thought I would do. Adults, sheesh! I was mainstreamed into a normal elementary school at the insistence of my parents. I did most of the normal things that kids of that age do - I liked the swings and the monkey bars at recess, although I had to stay inside in the winter because my legs were very sensitive to cold. For the most part the kids were nice to me, although there were occasional cases of name-calling (cripple, four-legged monster, etc.) , but most of the time I was treated like the other kids which was exactly what I wanted. When I was in fifth grade I had my first experience with someone who was NOT kind to the disabled and, in fact, resented all of us. She was my teacher. I was allowed to leave class 5 minutes early, so that I would not get pushed down in the scramble to be free of school at the end of the day. This teacher hated that and told me repeatedly, in front of the class, that I might think I was special, but I wasn't. I never understood where all this hostility was coming from and it never occurred to me to tell my parents how mean she was to me. In our house, the teacher was always right. In the years that followed, I have found people who feel like that, resent special parking privileges, or government disability allowances, or God forbid, big bathroom stalls, or any other real or imagined "privileges" that the disabled are privy to. I still don't understand that attitude, except it is more common than you would believe. Most people are kind, sympathetic and willing to help, but there are always people who will race you to the door of a store and quickly slip inside so they don't get stuck holding the door for you give you dirty looks as you get out of your car, parked in a handicapped parking space. Believe me, there is not one disabled person who would not give up their "privileges" for the healthy bodies that these jerks possess. Instead of worrying about someone getting away with

something, or "living off the government" these creeps should be counting their blessings and hoping that they never get "lucky" enough to deserve these "privileges". Every few years I would miss some school because of corrective surgeries and then I had a home-bound teacher who would keep me up to date on my school work. She was a lovely woman, fiftyish, friendly and giggly and would come up with little surprises for all "her kids" (that's what she called all her ailing students). Once, when I was studying India, she brought an Indian exchange student with her, so that I could ask questions about her country. We visited for a couple of hours. The exchange student brought me a small brass vase that was hand-carved by her father in India. It has a place of honor in my home to this day. One autumn, as the holidays were drawing near, Mrs. Castleman loaded me in her car, along with some of her other "kids". We went for a long drive to see all the trees changing color and stopped at a drive-in restaurant (Ted's) and we all ate lunch in her car and then we drove some more, singing Christmas carols as Mrs. Castleman tooted her car horn to the music. I'm sure we looked like a earful of lunatics, but we had the best time. As time went on, my condition stabilized and the end result was that my left leg was almost completely paralyzed - I had a few muscles in the upper thigh that would allow me to swing my brace-encased leg. My right leg was weak, but I could walk on it without a brace. My arms appeared to be unaffected. Both my ankles had been surgically fused because my feet were flail and it was hard to keep a pair of shoes on. So much for my love of stiletto heels. I was going to be a loafer or oxford girl. My lower spine was paralyzed and I needed crutches to stand upright. The next summer was my turn for another round of surgeries. It may surprise you that I did not dread all of the hospital stays. Yes, the initial surgery had pain associated with it, but that faded after a few days and then the "recovery period" began in earnest, usually with physical therapy. There was always the chance that the surgery would improve things some

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Bobbi Stevens Polio Story *continued...*

did, some didn't) and I always made new friends. I think I got some social contact and acceptance that was lacking in my regular life. Back then, hospitals were not air-conditioned, you stayed in a ward, which was a large corridor with 12 beds lining each side. Privacy was a thin, yellow curtain. There were no telephones at bedside. TV's were in short supply, for rent, first come, first serve (and with no remote, a pain in the butt for the staff). I can't remember one time that I had a TV. So, instead, I read or I yakked at anyone who would listen and I discovered something very enlightening - some people thought I was funny, interesting, we had conversations, we had affection, they didn't roll their eyes when I talked, or ask me what was wrong with me, or just ignore me altogether. When I was 13, I was in a bed next to a girl with rheumatoid arthritis whose name was Debbie. Debbie was profoundly disabled by this disease and could not feed herself or take care of her basic hygiene needs, but she was witty and fun. We were both in traction, following yet more visits to the "Better Living through Surgery Dept.". On Saturdays, we would talk the nurses into pushing our beds together, I would put make-up on Debbie and do her hair and then the nurses would push our beds into the men's ward to visit with the boys our age. Once we even pooled our money and ordered a pizza to be delivered to the orthopedic ward at U of M Hospital. We really thought we were hot stuff. Leave it to me to find a way to "date" in the hospital! When I grew into my teens, I asked my parents if I could have a wheelchair for the times when I wasn't wearing my leg brace. Up until then I had crawled to the bathroom in the middle of the night, if I had to go. They said no, if I had a wheelchair it would be too easy to give up on walking, plus my mother said a wheelchair would mark up the walls. They may have had a point about taking the easy way, but the fact that they wanted to preserve a perfect paint job in exchange for my humiliation and embarrassment at having to crawl to the bathroom when I was well into my teen's pisses me off to this

day. Wheelchairs DO leave marks, it is unavoidable. That is what touch-up paint is for. I started high school in January, (after having more surgery) and I had a hard time at first - the school was SO big. Actually I liked high school quite a bit. I made friends in that building that I have to this day. Walking on crutches is a LOT of work, and trying to get a round a big suburban high school was exhausting, but I could eat as much as I wanted. I weighed 89 pounds the day I graduated. Obviously, I wasn't the cheerleader, homecoming queen type, but I had a group of friends, I worked on the school newspaper, and even became the editor in my senior year. I was boy-crazy, but didn't think I would date at all in high school I just figured that maybe later in life, as the boys matured into men, they might be able to see the person I was and not just the brace and crutches. Surprisingly, I was wrong. They weren't exactly beating my door down, but I did have a few boyfriends in high school, and finally one special boy, my Bill. It isn't easy for a boy to ask a girl out who is different, even if she has the "face of an angel and the mouth of a sailor.", as Bill once said to me and I have always thought it was the best compliment I have ever received!

With a few exceptions, I didn't care for high school girls very much; they seemed very catty and back stabbing. I liked to sit with the boys - they were usually much friendlier and I had a reputation for having a dirty mouth, telling filthy jokes and saying outrageous things. I think that developed because I was so tired of the little goody two-shoes crippled girl image. By the time I got to my sophomore year, the usual gawkiness was departing. In fact, the captain of the football team (extremely cute) told me that I was cute and if it weren't for the braces he would ask me out. I said, in return, "What makes you think I would want to go out with you?" He never talked to me again, but our English teacher, who overheard this exchange, gave me a thumbs up. I took driver's education and passed - even got my learner's permit, but whenever I talked to my mother about getting my license

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Bobbi Stevens Polio Story *continued...*

she would wince, and shrug her shoulders and say "what if your legs get tired and you can't work the pedals?" : What if you kill someone?" Now, I had done just fine in drivers ed, but this was enough to undermine my confidence. So I put it off. My friends drove, so it wasn't much of a hardship back then. I also had a very important boyfriend around the same time, though "friend who was a boy" might be a better way to put it. I had known Chip Teel since junior high and we became close friends in high school. The best thing about Chip was his mother. Mrs. Ann Teel was the first polio survivor I had ever met. (Remember, I came at the end of the epidemic years, after the Salk vaccine). Mrs. Teel had some paralysis in both her arms and legs, but she could walk. She was a young wife with 2 little boys when she was diagnosed with polio and she went on to have 2 little girls after the disease. This was a revelation to me! Whenever I had asked my parents about my future, they were vague and said not to count on having children, or a husband. I'm sure they truly didn't know and thought it was best for me not to hope for too much. Mrs. Teel was a pretty, bright, and cheery person and we took to each other right away. While I don't remember any profound conversations that changed my way of thinking, just her example of optimism and normalcy let me know that my future didn't have to be so grim. By the time I was sixteen, medical science was just about finished torturing me for awhile. They did come up with one last beaut - to fuse my left knee so that it wouldn't bend - therefore I wouldn't have to wear a brace on it. That was the goal back then - BRACE FREE!! My parents were thrilled and made plans for this miraculous surgery. Keeping in mind that I would never be crutch-free, I thought it was the dumbest thing I had ever heard of! What would I do with a permanently straightened leg??? I wouldn't be able to sit in a movie theater, or a booth in a restaurant and just what was I supposed to do with it when I was in a car - stick the damn thing out the window? I said loudly and vehemently. My parents were furi-

ous. The doctors told them that, while I was still a minor, I was old enough to decide and that they needed my cooperation for the surgery to succeed. My parents were upset for a while, but I do think they got over it, though God forbid they admit that it was a mistake to even consider it. You all know the mindset of the medical community where polio was concerned. As I said, the goal was to be as appliance free as possible - to look and act as normal as possible. And you were to remain ACTIVE - push the muscle usage you had left, "use it or lose it" was their motto. In the 1980's they discovered that they had been wrong about that and pushing muscles that were already weakened damaged them further and after about 30-40 years of this abuse new weakness started to show up in polio survivors, sometimes in muscles previously thought unaffected. I use a wheelchair now, not because my legs got weaker, but because my arms, elbows and shoulders could not take the abuse. I was essentially walking on my arms all those years and they were not designed for that. But, as a kid I would walk miles - till I had blisters on the palms of my hands where they gripped the crutches and on my legs where the braces would rub. The orthotists came up with an advancement that changed my life for the better; a foot plate for my leg brace. That meant that instead of having the shoe connected directly to the brace, (and only wearing the same boring, ugly, orthopedic shoes all the damn time) a mold was made of my foot and they made a plastic foot plate that attached to the brace and would then slip into almost any kind of shoe. Hooray!! I could be in fashion! I could wear sneakers, sandals, nice looking, in-style shoes. (In the 70's I actually bought a pair of platform shoes that were so high, the length of my crutches had to be readjusted upward!) It wasn't cheap, and not strictly necessary medically, so the insurance company wouldn't pay for all of it. When it came time for graduation my mother announced that this new brace was my graduation gift. My sister had received diamond earrings and her own sewing machine when she graduated from high school years earlier. My dad

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Bobbi Stevens Polio Story *continued...*

got wind of this and once again stepped in and told my mother that I was to get the same gifts that my sister had received. Thanks, dad. Bill and I dated through our senior year in high school and we were pretty serious right from the start. I wanted to go to the prom. My parent's didn't see much sense in going to a dance, since I couldn't dance, and I think Bill agreed to go only because I wanted to, but I didn't want to miss it. My mother had made two different dresses for the various proms that my sister went to. When it came my turn, my mother recycled an old bridesmaid dress from a neighbor, hemming it to fit me. It was a pretty dress, but this kind of thing just reinforced my inner belief that I was too much trouble for my mother to deal with and she took shortcuts wherever she could, both with emotional and financial issues. Bill and I decided to get engaged in November of 1973. My sister, Joan was also engaged at the same time and would marry about a year before Bill and I. My mom, an accomplished amateur seamstress, set to work making a beautiful dress for Joan. With less than a year to go, it was time to start planning my own wedding. I poured through bride's magazines looking for dresses that I liked and my mother said I was wasting my time, that we could use the dresses from Joanie's wedding. I nixed the idea- I wanted my own wedding, not a regurgitated version of Joanie's. My mom said it would start a nice tradition - Passing down the wedding dress that she had made, and it was pretty and I knew how hard my mom had worked on it, so I said ok. I tried the wedding dress on and, of course, it didn't fit. Joanie was about 4 inches taller than I was and 2 sizes larger. When I started to talk about alterations, Joan threw a fit and said that she might want to pass it along to a daughter someday, and that she didn't want it altered. My mom said not to worry, she would just pin it. Well, I knew that would never work, but my mom was firm. That was the only dress she was supplying. Then she started complaining that the invitations I wanted were too pricey, she wasn't sure about the

photographer, etc. I went to Bill, sobbing, because everything that I wanted was being vetoed by my mom. Bill said that he would take care of everything and he did. My parents paid for a nice reception for us, but we paid for everything else. Bill set up an appointment at a Bridal Salon and asked them to send him the bill. I ended up with an original Bianchi dress, custom made for me (size 5) and a cathedral length veil, all paid for by my fiancé. The people at the Bridal salon were so nice; they contacted Bill and said if he would bring my crutches in, they would decorate them with matching satin and lace. Obviously, I needed my crutches, so Bill went out and bought a new pair. When I went for my final fitting, they brought those crutches out and they were SO beautiful, I cried. I knew then I could count on Bill for the rest of my life, he would never let me down. (I know this isn't all that polio-related, but it IS a nice, romantic story). Bill insisted that I get my drivers license and gave me the courage to go for it. After a couple of years, we decided to start a family. Our first child, a son was born premature and only lived a few days. But, as usual Bill was my rock, and got me through the heartache. We went on to have 2 healthy daughters, and now are blessed with our granddaughter, Lily. Post-polio reared its ugly head in the 90s - by 1995 the Dr I was seeing told me to stop using crutches if I wanted to preserve my waning arm strength. So I started using a wheelchair full time. My parents recall 1995 as the year Bobbi "gave up". Sigh. ♥

*Always cherish your friends
& family while you have them, you
never know when the good Lord
may call them home!*

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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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

Meet April thru December (except for July)
Margaret Nielsen Williams (517) 336-5921
nielsenwilliams@yahoo.com

MID-MICHIGAN (PPSG)

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

SOUTHEAST MICHIGAN (PPSG)

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

Meets 4th Sat. of the month
March thru October 10am-Noon

THUMB AREA PP SUPPORT GROUP

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

WEST MICHIGAN PPSG

Scheduled Meetings:
April, June, Sept, Nov
Linda Walthom Grand Rapid (616) 363-7625
Lynette Hooker Grand Rapids (616) 455-5748
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Chuck Bond Rockford (616) 866-1037

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info@post-polio.org www.post-polio.org

Two Post-Polio Clinics in the Southeast Michigan Area

***St. John Post-Polio Clinic
Center for Physical Medicine &
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***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

JUDGE RULES FOR ACCESS IN NYC

TAXI SUIT January 2012

“Meaningful access for the disabled to public transportation is not a utopian goal or political promise, it is a basic civil right, U.S. District Court Judge George B. Daniels wrote.” Under Daniels ruling, the city’s Taxi and Limousine Commission must immediately develop a plan to provide “meaningful” access to taxi service for people with disabilities. Until such a plan is developed and approved by the court, all new taxi medallions and livery licenses issued by the TLC must be for wheelchair-accessible vehicles.

For more on this story, please visit [United Spinal Association’s website](#).

Judge Rules NYC Taxis Violate Americans with Disabilities Act

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The Michigan Polio Network, Inc. is a tax Exempt non-profit organization with 501 (c) (3) status.

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To join it is not necessary to be a resident of Michigan or be a Polio Survivor.

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