

POLIO

PERSPECTIVES

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Promoting Understanding Through the Michigan Polio Network, Inc Since 1986

DIANNE DYCH-SACHS AWARDED “CAREGIVER AWARD OF COURAGE”



Pictured Dianne, Bonnie Levitan, and Bruce Sachs

Dianne Dych-Sachs has been awarded the Chronic Illness Coalition's Caregiver Award of Courage at their annual breakfast meeting January 4, 2012

Courage – The quality of facing and overcoming dangerous or difficult circumstances with resolve, perseverance and selflessness; to face adversity with resolution and fortitude in spite of all opposing forces.

The Award of Courage is awarded to an individual afflicted with a chronic illness as well as a caregiver of a person (s) with a chronic illness.

While struggling with a chronic illness herself, Dianne has been a caregiver for her husband,

Bruce Sachs, and also her mother. Both Bruce and Dianne had polio in early life and now struggle with post-polio syndrome. Bruce has more severe symptoms, having limited use of both his arms and legs, so Dianne needs to assist him with many activities of daily living. In addition, every evening Dianne needs to prepare dinner for her 80 year old mother, who still lives on her own. In the past Dianne worked as a registered technologist at St. Joseph's Hospital in Mt. Clemens. Now she makes time to co-lead a post-polio support group, server as secretary of the Michigan Polio Network, has served on the planning committees of the last several biennial statewide post-polio conferences, and is a greeter at the St. John Hospital Post-Polio Clinic.

Dianne and Bruce combined have 9 children and 17 grandchildren. Dianne has been there for them, helping with babysitting, whenever possible. Dianne's courage is reflected in her determination to care for all her circle of family and friends without losing her positive outlook and good nature.♥

The Chronic Illness Coalition of Southeast Michigan is a coalition of independent health organizations dedicated to improving the quality of life of persons affected by chronic illness, conditions or disabilities.

FROM THE CHAIR

A thank you to the MPN membership for electing me to another term on the Board and to the Board for electing me Chairman for another term.



With the warm weather upon us we all like to get out and enjoy getting nature's vitamin D, but everything in moderation. A recent news article stated a woman, in a wheelchair, fell asleep in the sun, became dehydrated and later died at the hospital. I have been contacted by several polio survivors with questions concerning breathing problems and day time fatigue. There is a lot of information available on this topic. Post-Polio Health International [post-polio.org] has a separate part of their web site devoted to these problems. Another source is: poliotoday.org, and click VIDEOS, then start with Breathing & Sleep Symposium 2009. Also see the article on pages 3,4 in this issue of Polio Perspectives.

We received news that as of July 1, Barb and Ron Oniszcak moved to Tennessee. They both served on the Board and were active at Bay Cliff. Barb was MPN Librarian and First Vice Chairman. She also organized the Northeast Michigan Post-Polio Support Group and kept our web site up to date. They will be missed. This leaves an empty seat on the Board of Directors. All interested applications should be sent to me.

The MPN Board has been busy planning an Educational Conference for October 5, 2013. Keep watching for further details.

At our Annual Meeting in May I gave the following State-of-the-Network report.

STATE OF THE NETWORK

Chairman Sachs stated that when the Network was established over 25 years ago the polio survivors were 25 years younger and were in search of information on polio. The term post-polio was not in common use and very few polio survivors either knew or accepted that they were having new problems. We had a large number of polio survivors with a number of active Post-Polio Support Groups throughout the state offering monthly meetings. The polio survivors were able to travel and attend 2 day conferences.

Twenty-five years later we have seen our numbers decline and the mobility of our members has also declined. Our members can no longer travel long distances nor attend 2 day conferences. We need to continue to provide information and support for our members, but we have to rethink our delivery system.

Where will we be in 5 years? None of us know where we will be 5 years from now, but if we want the Network to continue, we must continue to provide support for our members.

The Network has 4 major assets, The Quarterly Newsletter "The Polio Perspectives", the Library, the Web Site, and most important our members. We must continue to support these and also provide Conferences and other means of providing information to our members. The Network has been in existence for more than 25 years, we must continue to work on the next 25 years.♦

Bruce Sachs, Chairman

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Your Neurologist Has Sleep Apnea: When Doctors Are Patients, What Do They Do?

Avitzur, Orly M.D.

1. SPEAK UP All of our experts emphasized the importance of discussing one's symptoms with a doctor. Unfortunately, most physicians don't inquire about OSA during routine examinations. If you are experiencing symptoms, ask your doctor if it's possible you have OSA. "Sleep apnea ruins two people's sleep," observes Bruce H. Cohen, M.D., director of neurology at Children's Hospital in Akron, OH, and a Fellow of the AAN. Dr. Cohen admits he was initially embarrassed by his own diagnosis of OSA and understands why patients may be reluctant to bring it up. His OSA became so severe at one point that he was unable to drive to and from work due to fatigue. He often pulled into gas stations on the way home, setting his alarm clock for five minutes in order to nap. When he finally underwent a sleep test, it showed that he stopped breathing every 30 seconds during REM sleep. "We owe it to our spouses to get properly diagnosed," Dr. Cohen says, recalling that his wife's mood improved when he finally began treatment.

2. PRACTICE CPAP BEFORE BED If you are diagnosed with OSA, your doctor will likely recommend CPAP, the treatment of choice for most adults with OSA. Unfortunately, many people don't take the time to get accustomed to using the devices, which is what initially happened to Dr. Swick. Like more than half of his patients, he found himself ripping off his mask in the middle of the night for the first few weeks of use. He then decided to spend 30 minutes each night—before going to sleep—learning how to breathe through his nose with the mask on.

"It's not unusual for patients to start to panic when they open their mouths to breathe and feel the pressure rushing out of their mouth," he notes, explaining that the sensation can be so disturbing that it causes people to gulp, swallow air, and develop stomach bloating. He now tells each patient to practice for half an hour before bedtime for as

long as it takes to get used to breathing through the nose while wearing the mask.

3. FIND THE RIGHT FIT Neurologist and AAN member Marc Raphaelson, M.D., a sleep specialist who practices in the Washington D.C. area, was diagnosed with OSA several years ago after his wife expressed serious concerns to him about his snoring. Dr. Raphaelson notes that shopping for the right mask can be as tricky as finding the proper fit in shoes chosen from a catalog. "Since they cost in the range of \$150, you don't just buy a dozen to try," he says. He recommends that his patients select a mask with a 30-day replacement warranty and that they try two masks during that period. This also applies to finding a mask replacement, which he says should be done every six months or so, trying an alternate style or brand of mask with the same return option. Most insurance companies cover sleep testing and treatment, which includes CPAP.

4. LOSE WEIGHT When sleep specialist Mark R. Ippolito, M.D., a neurologist and AAN member in Charlotte, NC, began to see a large number of patients with OSA, he recalls thinking, "Hey, that's me!" in response to their stories. Fatigued during the day and fighting to stay awake on his commute home from work, Dr. Ippolito began to suspect that his snoring could be something serious.

His suspicions were confirmed by home testing, which has become increasingly reliable over the years. He started CPAP, but what he really wanted was a "cure." He eventually decided his body mass index (BMI) of 30 was something he could change. After losing more than 30 pounds, he retested within the normal range of sleep. Indeed, almost all the doctors who spoke with Neurology Now made weight loss a priority.

5. SAY NO TO THE NIGHTCAP Several of the experts we interviewed mentioned that alcohol, especially before bedtime, worsens OSA. Studies show that alcohol impairs breathing—even for otherwise unaffected people—but significantly worsens the problem in people with OSA.

"A small beer or glass of wine is fine on occasion if

Continued next page...

Your Neurologist...continued...

You have OSA, but not at bedtime,” says neurologist and AAN member Stephen D. Feren, M.D., a sleep specialist who sees veterans with a variety of sleep disorders at Charles George Veterans Affairs Medical Center in Asheville, NC.

6. STAY OFF YOUR BACK Neurologist and AAN member Mark Eric Dyken, M.D., director of the Sleep Disorders Center at the University of Iowa College of Medicine in Iowa City, IA, had been a stomach sleeper until a doctor advised him to sleep on his back following a severe neck injury. Dr. Dyken recalls awakening several nights in a row gasping for air after dreams in which he believed he was drowning. It was his physician wife who, pointing out that he was also snoring loudly, suggested that he may have OSA, a hunch that was later confirmed at his university sleep lab. The sleep study revealed that all his breathing lapses occurred while he was lying on his back. After losing more than 50 pounds, he eventually discovered that he could forgo his CPAP by sleeping on his side, a habit that he has been able to continue over the years. Dr. Dyken uses a whole-body pillow to help him stay in that position and sometimes adds a u-shaped pillow to support his neck.

This positional therapy can also be achieved by placing a wedge under the head of the bed to help prop open the airway or by wearing a nightshirt with a tennis ball placed into a sock sewn to the back to avoid lying flat. Dr. Dyken says it's a great addition to CPAP, especially for those with severe OSA and for very heavy patients who are unable to breathe deeply enough despite treatment with CPAP. But Dr. Ippolito also finds it extremely useful for patients who don't qualify for CPAP or fall below the insurance guidelines for medical necessity. “Often, these ‘walking tired’ are ignored, although they could benefit greatly from simple positional therapy,” he says, adding, “And it's cheap!”

7. KEEP A STRICT SLEEP SCHEDULE

Neurologist and AAN member Meredith Broderick, M.D., a sleep specialist in Seattle, WA, recalls being one very sleepy resident during her neurology training. Although she attributed her symptoms to long work hours, Dr. Broderick found that she was still tired when she was getting a full eight hours of sleep a night. She suspected something was wrong, but she didn't fit the OSA stereotype of an overweight, older man with a short, thick neck. Dr. Broderick then learned that thin, young people—especially people of Asian descent, like herself—may also have OSA. A sleep study confirmed her diagnosis. Dr. Broderick has found that, in addition to using her CPAP machine, it's critical for her to maintain a balanced sleep-wake cycle, although she admits that it requires a certain amount of discipline to wake up and go to bed at the same hour, seven days a week. “If you stay up later on the weekends, sleep in on the weekends, or nap after work or dinner, things can deteriorate quickly,” Dr. Broderick says, adding, “like physical fitness and nutrition, a long-term lifestyle change is required.”

8. PACK IT TO-GO The neurologists on CPAP that we spoke with don't leave home without their machines. “My CPAP machine goes with me everywhere,” says Dr. Cohen. “It has been to India, Italy, Canada, and more than 30 states in the United States.” The child neurologist, who takes care of many patients with mitochondrial disorders such as myopathies that increase the risk of OSA, says, “I skipped CPAP one night in the last five years—on an overnight trip—but decided it was silly to have left the machine at home.” He feels so much more refreshed after using it that the only time he does not is on red-eye or overseas flights in which he sleeps upright. Dr. Raphaelson came to the same conclusion after his own improved daytime alertness and says that his device fits very nicely into his computer bag where it goes through airport security along with his laptop without a problem.♦♦

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This article edited for space.

The Michigan Polio Network
GRATEFULLY ACKNOWLEDGES DONATIONS

FROM THE FOLLOWING MEMBERS

recorded during our previous fiscal year (06/01/11 - 05/31/12)

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LIBRARY CORNER

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Greetings, Readers, and best wishes for a happy, healthy summer of 2012!

I'll start out with a gentle reminder to you that one of my librarian's tasks is to pack up and mail books for your perusal. I am ready to carry out this job. I even bought some new packaging tape, so I'm re-e-e-e-ally ready. All I need is requests from you. Please check the booklist, which is part of the MPN Website

(www.michiganpolionetwork.com).

If you find the name of a polio/post-polio-related book, DVD, or CD, and you need to know if we have it in the collection or recommend that we purchase it, contact me at the MPN phone number(989-739-4065), my home phone number(248-853-5465) or via the Internet(denilaur@sbcglobal.net).

NEW BOOKS

We've had some interesting guest speakers at the Southeast Michigan Post-Polio Support Group in both May and June.

On May 26, our speaker was Aletha T. Kuenstler, retired nurse and social worker. Mrs. Kuenstler spoke of the challenges she has had to face from a variety of chronic illnesses, including Crohn's disease, lupus, diabetes, and post-polio syndrome. It became plain to all who listened to her that she was quite fortunate to still be alive and able to speak to us about her experiences with illness. The book she wrote, in which she shares her ideas and coping skills is entitled **CHRONIC ILLNESS: FACING ITS CHALLENGES**. As stated on the back cover, Mrs. Kuenstler presents her suggestions in a "professional manner." She "addresses the challenges you may face prior

to receiving a diagnosis as well as learning to live life to its fullest with a chronic illness."

On June 23rd, Carol Green spoke to us about the importance of humor and a good attitude when dealing with illness of any sort. She mentioned the lessons taught by her own mother, Lila Green, who was a nationally-known speaker, writer, and consultant on the topic of humor in health care and life. Ms. Green just happened to have a few copies of her mother's book, which is entitled **MAKING SENSE OF HUMOR: HOW TO ADD JOY TO YOUR LIFE**, so I purchased a copy for the MPN Library. If you would like to borrow either of these books, or any of the others in the MPN Collection, don't be shy!!

BEST WISHES AND HAPPY NEW HOME

Those of you who've been MPN members for awhile know that, before I took over the use of the copy machine and the sticky tape and became the librarian of this Organization, the job was held by Barbara Oniszczak, who was a hard act to follow. Well, she and her husband are making a move, down to Nashville, TN, where one of their sons lives with his wife. I thank Barb for her support, for her company on those drives to and from Lansing for MPN Board meetings, and wish both Barb and Ron the very best in their new location in the Volunteer State. Good health and happiness to you both!!

As I watch the Rochester Hills fireworks out our study window(not quite like "being there," but with far fewer mosquitoes), I once again wish you all a great summer. 'Bye for now!

Laura Barbour, Librarian

Ray Kaczarowski Remembered

Ray Kaczarowski died on March 30, 2012 as recorded in The Alpena News. He left behind his wife Elizabeth, dearly known as Beth to those who know her.

Ray was a pioneer of sorts in many ways. When the Michigan Polio Network was young, and in formation, Ray became an active facilitator to a group of polio survivors living “up North” who often were forgotten and not known by the general population in the Network or southern residents of Michigan.

Ray informed a group of polio survivors about the dilemma facing most polio survivors in the future. Post-polio was a real threat which would cut a happy, otherwise successful life to a halt. A brighter future as we retired would require a shifting of priorities; change our lifestyle as we drew nearer to retirement age. This unfair beast of a disease would come at a time when most of our peers were traveling and enjoying retirement.

Ray attended Bay Cliff Wellness Retreats with his wife Beth and continued to live life despite bracing, limited mobility and finally when the use of crutches and braces would no longer support him, the use of a scooter. Ray attended our educational conferences, gambling at St Ignace and the Soo while trekking up to Bay Cliff, MI. One year Ray won enough to get a newer van so he and Beth could get around more easily.

When I lived up north, Ray gave me the courage and support I needed to look into my future and assured me that life was good always. We had a support group “up North” for a few years from 2004 to 2008. Ray was always present, sharing his story and was glad to extend his friendship to all at the meetings.

I may not see Ray anymore when I go up north to visit with friends, but he will always have a place in my heart as will Beth. Ray, you will be missed by many. You gave much love, told many stories and became family♥

Respectfully submitted by Barbara Oniszcak

MMJ (Medical Marijuana), A Research Project Part 3: Real Medicine

PPS MANAGER

By RE Van Der Linden

It may take generations to overcome the stigma of cannabis as a powerful, illegal drug, but evidence continues to pile up in support of the medical value of this effective herb in improving the daily lives of those with neuromuscular diseases.

In Part 2 of this series we met 5 people who have found MMJ a valuable part of their daily management. Since then another PPS person posted on PolioToday.org claiming that MMJ seems to be reversing PPS.

Can MMJ reverse or cure PPS?

That’s a mighty big claim unsupported by any formal scientific study known to this reporter.

However, there is anecdotal evidence that it can help in several ways if it’s used properly. But first: just how does it work, and if it’s such a miracle drug, why has it been kept a secret?

As discussed in part 1, there are two main compounds in cannabis: THC and CBN. And, there are receptors for these molecules in the stomach, heart, liver, and nervous system. Your body naturally makes something like THC to combat the overproduction of adrenalin when a stressful situation needs calming down.

[Strains: Indica hybrids (Indica + Sativa 60:40) for pain symptoms. Sativa hybrids (Sativa + Indica, 60:40) for all other symptoms such as depression and loss of appetite.]

For centuries people have known of the effects of cannabis. In its natural form it can affect appetite, mood, awareness, and stress level. So, in an effort to take control of the individual effects, drug companies and governments have tried mimicking THC to isolate particular benefits, but to no avail. Products developed in the 1980s and 90s were too strong and fraught with side effects, yet with no real benefits. This may have been partially because THC was the only focus at the time.

As it turns out, THC is more of a stimulant, while CBN has a more relaxing effect. Modern strains of marijuana evolved to focus more on higher THC content of the Cannabis Sativa strain because it’s considered the “party” version of the plant.

Continued next page...

MMJ (Medical Marijuana part 3 *continued.*

Recreational users generally avoid Cannabis Indica because if you want to party or work, the buds and leaves of this strain produce little or no “high” while encouraging relaxation. That’s because of the higher content of CBN molecules in relation to THC.

[I heard about MMJ many years ago, and thought it was just some people’s excuse to get high. To a certain extent I still do.]

Tight muscles are a big waste of energy but hard to avoid when you’re worried, and PPS can cause some serious worries. Imagine a drug with the opposite effects of adrenaline, and you’ve got CBN rich Cannabis Indica.

Why has it been so difficult for me to find hard evidence supporting the use of MMJ for the treatment of neuromuscular disease? The main reason is that there has been no successful attempt to replicate the positive uses of the chemicals in Cannabis in controlled manufacturing. In other words, there’s nothing better than the natural herbal form of the plant. Put another way, the government and drug companies can’t control it any other way, so the best way to handle the situation is to make it illegal. And, being illegal most people don’t want to talk about it.

It’s better now that 16 states have legalized MMJ, but there are still battles being fought between the federal government, states, counties, and cities regarding if and where dispensaries are allowed.

[Cannabis first became illegal in the 1950s at a time when marijuana was used primarily by illegal Mexican immigrants. The US government tried using substance control as a means of immigration control.]

At this time we only have the history of others, and our own research as a guide.

So far those who have tried it and become known to this reporter have had positive and even amazing results.

Among those who have not tried it, there seems to be three camps: 1) Sounds great, I’ll try it.

2) Sounds promising but I’m chicken. And 3) the federal government says no, so I say no.

Follow-up from Bob from Bakersfield

Bob, a new user of MMJ reports that he has been trying MMJ for about 6 months with mostly positive results. He reports that his family and

friends tell him that he seems more relaxed and less likely to “drop out” of social situations.

Bob says he is better able to “tolerate life with PPS” but notes that he is starting to feel “kind of lazy or something” and has been reducing dosage in the hope of feeling more energetic.

At the same time, he thinks this relaxed feeling is probably one of the real advantages of MMJ in that it helps him avoid over-activity.

At one point he tried the Sativa strain and was more alert, but too tense and prone to over-activity.

Finding a balance takes time and attention to details. I suggested that Bob keep a diary of all relative information: strain and dosage, weather conditions, diet, general health, outside stressors, input from family and friends, etc. Another good way of gauging the overall effectiveness is to stop using it for a while and note the changes.

Thanks, Bob, for sharing.

In this, the last installment of MMJ: a Research Project, I’d like to draw some definitive conclusion, but I can’t quite nail it down.

Maybe the Native Americans had the right idea.

We are part of Nature. We are intimately linked to everything around us. Air, water, the plants we eat, the animals with whom we share the Earth...

The plants we can’t eat, and the animals that want to eat us.

Nature gives us all we have, good, bad, and in-between. Plants provide many chemicals that react naturally with our body. There’s aspirin (willow bark), and opium, and all sorts of natural plants with various “healing powers.” Some have weak powers, and some are strong. We must learn to use them intelligently, and with respect.♦♦

HOW MANY “F’s”

COUNT EVERY “F” IN THE FOLLOWING TEXT:

FINISHED FILES ARE THE RESULT OF YEARS OF SCIENTIFIC STUDY COMBINED WITH THE EXPERIENCE OF YEARS.

GO TO PAGE 17 FOR ANSWER

Karen Black: My Story

I was six and barely settled into first grade when on September 22, 1954 I came home from school not feeling well. I complained of my head and neck hurting. I still was not feeling well the next day, but managed to get through school and catechism class. My mom called the doctor who instructed her to bring me in for a check-up. I remember having to wait for my dad to get off work because we only had one car and my mom did not drive. While my mom was getting me dressed my left knee buckled three times. The doctor told my parents he thought I had polio and they needed to take me to Herman Kiefer Health Center or Henry Ford Hospital for a lumbar test. My parents decided to take me to Henry Ford Hospital where a spinal tap was done confirming that I had polio. My mom recorded in her diary that the doctor at the hospital was very mean and that he treated me like I had no feelings. He would not let my parents go with me for the tests. I was admitted to Henry Ford the early morning of September 24th. Once admitted my mom came to my room and as she stated in her diary “the damn doctor told me to get out of Karen’s room”. My mom had to stay outside the room since I was in isolation. However, my mom kept returning to my room several times and was caught by the doctor. I kept crying, sleeping, crying. The doctor finally told my mom that she should have taken me to Children’s Hospital where parents can only visit once a week. He said the best thing for me was for her to “GO HOME”. She did go home then, but when she returned that afternoon and she heard me crying, calling for her that I wanted to go home and that I was scared. I was in isolation until October 6th.

I have several memories of my time in the hospital. I remember sharing a room with a boy whose mother did not visit him because she could not tolerate him crying every time she left. My parents told me not to cry or they could not visit me either. I believe this is the reason I would not cry in front of anyone. It wasn’t until I was in my 30s that I would cry in front of others. I remember the smell

of the brown hot packs – to this day I believe I would recognize that awful smell. I remember not liking the orderly that would tickle me, but loving the nurse who took care of me. I also remember that my classmates sent me homemade cards – I still have them.

My mom recorded all my visitors and when they visited. However, I do not remember any of the visits except my grandma from Georgia. My two sisters did not visit me. I remember waving to them from a window, though. They spent a lot of time at my grandparents’ home. My mom did a lot of traveling on the bus between work, home, the hospital, and her parents’ home to pick up my sisters.

Polio affected my left leg. While in the hospital I had therapy and was fitted for a brace. After almost three months in the hospital I came home on December 18, 1954. However, I still had to have therapy treatments three times a week. When I started back to school it was to a new one – Leland School, originally built to serve children with disabilities. A bus picked me up from my home. I also attended Oakman School, similar to Leland. I was behind in school by half a year.

Almost a year to the day I was diagnosed with Polio, September 22, 1955, I was back at Henry Ford Hospital to have surgery on my left leg and foot. Some muscles were moved; others removed. After the surgery I was left with some permanent changes and limitations on my left side: my left leg was smaller in size than the right, I wasn’t able to bend my big toe, I became flat footed, and I couldn’t withhold all my weight on my leg. There were four scars that were very noticeable, but have faded somewhat after 56 years. My parents were thankful that my dad just started working for General Motors and had health insurance; so, with the March of Dimes and the insurance, the financial burden was lifted. I arrived home again on October 1st with a cast and a big screw coming out of the top of my big toe. After the cast was removed I was fitted for a brace. On December 14, 1955 the brace was removed and my mom’s words were,

Continued next page...

Karen Black: My Story *continued...*

“Karen’s leg and foot are just as good as new”. I do not recall being treated any differently at home than from my sisters. It didn’t appear that relatives were afraid to visit me in the hospital because they came quite often except for my sisters. I do remember the Halloween after the surgery when I still couldn’t walk so my dad pulled me in a wagon and my older sister asked for candy for me. She came back a few times and said the people would not give any for me because I should walk to the door. That hurt my feelings.

My mom enrolled me in ballet lessons around the age of 10 or 11. I really liked taking classes, but the instructor told my mom I would never be able to go any further than the basics because my left leg and foot were not strong enough; I would not be able to put the weight on my toes. I was really disappointed about this.

Through the years some would ask if I hurt my leg because I was limping, but I could never feel myself limping. I did not like people mentioning the limping and I definitely did not want to discuss it. I believe this was due to the fact that I wanted to be “normal”. I never felt normal. Polio affected me not just physically, but emotionally. I never felt like I was “good enough” in a lot of areas. It wasn’t until my 50s that I was comfortable just saying that I had polio. I guess I wasn’t alone in that way because I found out many years after high school that a classmate had polio and no one knew it. His one leg was shorter and he disguised it by walking on his toes to cover up the limp.

The only other people I knew personally that had polio was a neighborhood friend, Margie who wore braces and walked with a limp; and a girl who lived in a house near my grandparents’ home. I could see her bed by the window on the way home from visiting my grandparents. My mom told me that she had polio and had to be in an iron lung. I was in my 50s when I started to notice that I was losing strength in my leg. I had difficulty getting out of the car and up from the floor. I was getting tired a lot and had trouble climbing stairs. I wear

a brace now and try to take rests before I get too tired.

I have come a long way since my diagnosis of polio. I am a proud mother to a beautiful daughter and had a great career with the government. I was blessed to retire early to fill my days with playing with my two grandchildren, as well as be able to care for my mother.

Despite the limitations I faced, I always felt so blessed that I was able to walk without a brace and that God healed me of all the emotional “stuff” of having polio. I have great compassion for those with disabilities and children that are ill and hospitalized. ♦♦

SENIOR TEXTING “*Senior Texting Code*”

ATD: At The Doctor's
BFF: Best Friend Fainted
BTW: Bring The Wheelchair
BYOT: Bring Your Own Teeth
CBM: Covered By Medicare
COEPS: Can Only Eat Pureed Stuff
CUATSC: See You At The Senior Center
DWI: Driving While Incontinent
FWB: Friend With Beta Blockers
FWIW: Forgot Where I Was
FYI: Found Your Insulin
GGPBL: Gotta Go, Pacemaker Battery Low!
GHA: Got Heartburn Again
HGBM: Had Good Bowel Movement
IMHO: Is My Hearing-Aid On?
LMDO: Laughing, My Dentures Out
LOL: Living On Lipitor
LWO: Lawrence Welk's On
OMMR: On My Massage Recliner
OMSG: Oh My! Sorry, Gas.
ROTFL-ACGU: Rolling On The Floor Laughing
--And Can't Get Up
SCD: Still Can Drive
SGGP: Sorry, Gotta Go Poop
TTYL: Talk To You Louder
WAITT: Who Am I Talking To?
WTFA: Wet The Furniture Again
WTP: Where're The Prunes?
WWNO: Walker Wheels Need Oil ☺ ☺ ☺

NEW VACCINE TO ASSIST WORLDWIDE ERADICATION OF POLIO

Scientists at the University of Leeds are joining the global fight to eradicate polio by developing a new type of vaccine that can trick the body to develop immunity against the disease.

The project has been awarded \$500,000 from the Bill and Melinda Gates Foundation, through the World Health Organization, and aims to be effective against all polio subtypes. Led by Professor Dave Rowlands and Dr. Nicola Stonehouse from the University's Faculty of Biological Sciences, the research team will design a replica virus particle that looks and behaves like the real virus, but is actually an empty protein shell. The researchers believe the hoax virus will trigger the body's immune system, but because it does not contain the genetic blueprint that replicates the virus inside the body, has no chance of causing or helping to spread the disease. "This is an entirely new strategic approach against polio," says Dr. Stonehouse. "This project is not about improving the efficiency of the current types of vaccine. Our intention is to design and produce a replica virus particle that carries no RNA cargo. This means it will be entirely safe to use as it can't ever cause the disease, and unlike current vaccines, can be produced without needing to grow large amounts of the infectious virus."

The team, led by Leeds, brings together researchers from Harvard University, the University of Oxford and the UK's National Institute for Biological Standards and Control (NIBSC), a centre of the Health Protection Agency. The first stage of the research will focus on proving that the new approach is viable against the virus.

Current polio vaccines in use around the world are either delivered orally or injected, but contain either a weakened form of the virus, or an inactivated virus to kick start the immune response. Whilst these have been extremely successful in reducing polio globally, the virus persists in several countries and unexpected outbreaks still occur. "What excites me about this project is that we're working towards a risk-free vaccine that will be essential for the complete eradication of polio from the globe," adds Dr. Stonehouse. "As well as being safe to produce and use, it will be stable enough not to need refrigeration and could be injected as part

of current childhood vaccination programs." Although a similar approach using replica virus particles has been used successfully to create the human papilloma virus (HPV) vaccine against cervical cancer, the complexity of the polio virus creates significant additional challenges. "With polio, the virus particle's surface matures and changes because of the genetic material inside, and so ensuring that our replica particle mimics this surface exactly is not going to be easy. Since it's essentially an empty protein shell, it also has to be robust enough that it doesn't fall apart," explains Professor Rowlands. "This will be an iterative process, where we keep testing, refining and improving the particles we design until we achieve exactly the right structure and surface." "We believe that if the project is successful, this new approach could help to completely eradicate this disease for good."

Source: James Hogle, Harvard University Featured In: Academia News.

EQUIPMENT NEEDED

A polio survivor has asked PHI (Post-Polio Health International) to alert post-polio groups and polio survivors that she is looking for older respiratory equipment. Do you have any of these pieces of equipment unused and stored away?

Monaghan 170-C
Thompson Portable
Zephyr Blower

There is also a need for NEV-100s and pneumobelt corsets and bladders.

If you have any of these pieces of equipment to donate, please contact

mail to: info@ventusers.org or
mail to: info@post-polio.org.

Joan L. Headley

SUPPORT GROUPS AND 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 SUPPORTGROUP

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 each month at 9:00-10:30am.
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

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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“I Understand Where They’re Coming From”

by Beata Mostafavi, contributing writer, PRMC

Prosthetist Mark Taylor’s own bout with polio brings a special touch of care to U of M’s post-polio clinic. Once a week, University of Michigan certified orthotist/prosthetist Mark K. Taylor, MLS, C.P.O, helps treat people for a disease that was declared dead in the U.S. years ago. Many of his patients—now in their sixties or older—were the children of the 1950’s polio epidemic.

Today they suffer from joint pain, loss of balance, fatigue and weakened muscles that hinder daily activities like brushing teeth, climbing stairs, getting into a car or walking – a phenomenon known as post-polio syndrome. The U of M Orthotics and Prosthetics Center’s post-polio clinic is among few places in the region offering highly specialized therapy for these patients.

Taylor, 60, brings a special passion to this rare clinic. At nine months of age, before he was even old enough to walk, his left leg was paralyzed by polio. “People don’t realize that we are still here,” Taylor says of polio patients. “Many people are still feeling the effects of polio or are experiencing symptoms for the first time decades later.

“Polio really affected my family and I’m finding that many of my patients’ stories are similar to mine. I understand where they’re coming from and how important it is to them to maintain independence and mobility.”

The summer of 1952 was heartbreaking for Taylor’s family who lived on a farm in Southern Idaho at the peak of the U.S. polio outbreak. Not only did Taylor’s mother learn her baby boy had polio – but her husband, Taylor’s father, lost his own battle with the disease.

Taylor, who uses a brace to walk, was told at age 25 that he’d be lucky if he was still mobile at 40. But as he says “I’ve cheated that by 20 years so far,” which he credits to orthotic interventions.



When he was just nine months old, Mark K. Taylor, MLS, C.P.O was diagnosed with polio, which paralyzed his left leg.

Now a certified orthotist/prosthetist, Taylor credits orthotic interventions for helping him maintain mo-

bility and he helps others do the same at the U-M Orthotics and Prosthetics Center’s post-polio clinic.

Post-polio syndrome affects up to half of people after the initial infection, with symptoms sometimes surfacing 15–30 years later and progressively attacking muscle strength. A sliver of patients at U of M are younger than 30, born in a country without the vaccine, and who came to the U.S. through adoption or other situations.

At three years old, Kathryn Hall contracted polio in her native country of England. She was separated from her family for three months of quarantine and one of her legs was four inches shorter than the other, which was ultimately corrected by surgery.

Hall, of Lakeland, Mich., said weak muscles in her left leg triggered chronic neck and back pain. She found relief at U-M through orthotics that provide extra support and ease muscle strains.

“It’s been tremendously helpful, lessened the pain and changed the way I walk,” the communications manager, gardener and golfer, now 64, says of the therapy. “I could have a fuller life.

Continued next page...



My Home Modification Experience

by *Liina Paasuke*

Last summer, I had some big decisions to make! All of my life, since contacting polio at the age of 17 months, I had worn crutches and braces. As my arms were becoming weaker from overuse and as I was experiencing increasing fatigue, I was becoming reliant on my scooter. By last summer, I had reached the point where I was dependent on the scooter 98% of the time. I had purchased a ranch house 32 years ago and had a ramp built to the back deck when I began using a scooter. That was the only home modification I had made. However, it was clear that more changes needed to be made. I had many difficulties in the kitchen in safely reaching things, and in using the oven. I had 3 small bedrooms, and could not get my scooter into even the largest. The worst difficulty was that my bathroom was tiny and I could no longer access the tub safely. It was becoming evident that I was either going to have to have home modifications done or I would have to move. I am retired and I did not know where the money for these modifications was going to come from. I was overwhelmed!! I attend the First Congregational Church in Ann Arbor and belong to a Women's Group there. During one of our meetings, I shared my feelings and frustrations. Much to my surprise, the group decided to involve the church membership and spearhead efforts to come to my aid! My project "Liina's House" took on a life of its own! Scott Allen, who is an Architect, donated his time to help to develop the plans for the modifications. Nancy Krzesicki, an interior designer in the community also donated her time. Thus over the winter of 2011, Scott, Nancy, several women from my church group, and I met to explore options and make decisions and then Scott developed the final design plans. Also during this time, the Women's Group organized a Silent Auction at the church which raised \$10,000 toward the costs involved! The church also enlisted a corps of volunteers who would be willing

Continued next page...

Mark K. Taylor, MLS, C.P.O and clinical assistant professor Ann Laidlaw, M.D, help post-polio patient Kathryn Hall, of Lakeland, MI, adjust a supportive orthotic device on her leg, which lessens chronic pain in her neck and back.

"This clinic is a refuge for me," Hall says.

"It's especially wonderful to have someone who knows what it means to go through this," she adds of Taylor, who supports clinical assistant professor Ann Laidlaw, M.D. with the post-polio clinic. "This clinic is a refuge for me, the only place I could come and find people who know what I'm dealing with and how to help."

Each year, the clinic offers hundreds of patients, prosthetics and orthotics, from crutches and walkers to braces, scooters and special shoes. Experts also provide physical therapy and help guide patients through the emotional challenges of post-polio syndrome.

"These are all patients who succeeded and thrived in life and slowing down can be devastating because they're used to their independence," Taylor says. "They want to do everything as good as or better than everyone else. We want to help them achieve that goal for as long as possible."

The U of M Orthotics and Prosthetics Center celebrates its 100th anniversary this year. For more information on the center, visit their website. <http://www.uofmhealth.org/medical-services/orthotics+and+prosthetics> ♦

My Home Modification...continued

to work on the construction with the contractor. Scott also volunteered to organize these volunteers and work on the construction as well. We met with several contractors and selected the one who was known for their work and also was willing to work with volunteers, Valley Builders. Bob Loeffler is the owner of Valley Builders. He and Scott had worked on some Habitat for Humanity Houses in the past and knew each other. I remortgaged my house to obtain the funds for the rest of the project. The volunteers helped with demolition, painting, electrical and plumbing work and general construction **tasks**. Overall, through their work and generosity I was able to save at least 30% on the costs of the job.

It was estimated that the time to complete the project would be 3 months. I was to move out for this time. I needed a small apartment that had a short term lease, was accessible and allowed dogs! Nothing which met those specifications was available in the Ann Arbor Area. I ended up living in Novi, about 25 miles east of Ann Arbor. I needed to pack up for the move as well as for the construction. More volunteers helped me to pack and unpack at the apartment for my July 9th move to Novi and then yet again when I moved back from the apartment to my “new” house at the end of September. The kitchen had been overhauled. I had new cupboards with pull out and pull down shelves. A new more accessible side by side refrigerator, a cooktop, a wall oven at the right height where the door opened to the side so I could get close and safely access the oven. Two of the bedrooms had been combined into a “master suite “ This included a larger bedroom where I could get around the bed on my scooter, a large closet, and accessible bathroom. The stackable washer and dryer was relocated from the utility room to this bathroom so I would not have to lug clothes through the house. And, best of all, I was able to obtain a rising wall Kohler tub that had just become available last summer. Nancy was aware of this tub and we were

able to use her discount to purchase it. I can thus back my scooter in next to the tub, transfer directly in and just lift the side up to take a nice, warm, safe bath! Hooray! When the side is up, a seal engages that keeps the water from leaking out, I press a button which releases the seal and it quickly drains the tub at which time I can push the side down. I call it Goldie as it is worth its weight in gold! While they were at it, they also refurbished my old bathroom, painted a lot of dark paneling, and repaired the roof! Non slip flooring and new carpeting was also installed. It is not only functional but it looks great! It feels like a whole new house!

All in all, this event in my life was an incredibly affirming experience! I am a private person and asking for help is not my strong suite! Initially, I felt awkward being the center of attention. Thus the situation itself presented many lessons to be learned. I am still astonished that I had all of this support from my church, the community, and my friends. It felt like getting a big group hug, so many people were so generous! The moral of the story is that you need to speak up about your needs and to network, and you will find that more help is available than you can imagine!

ANSWER TO HOW MANY “F’s”

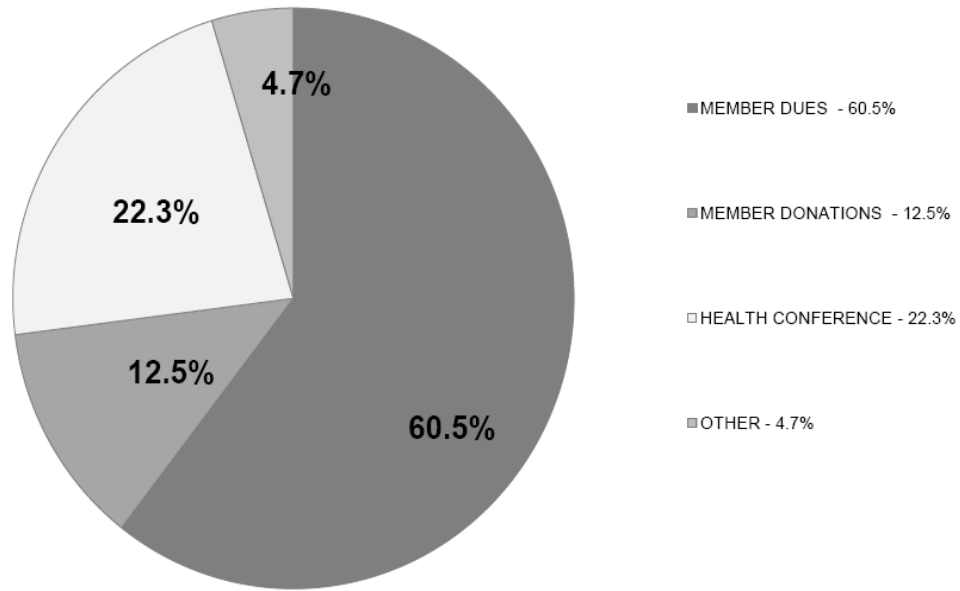
THERE ARE 6.

*THE REASON BEHIND MISSING
SOME OF THE “F’S” IS —
THE BRAIN CANNOT PROCESS
“OF”*

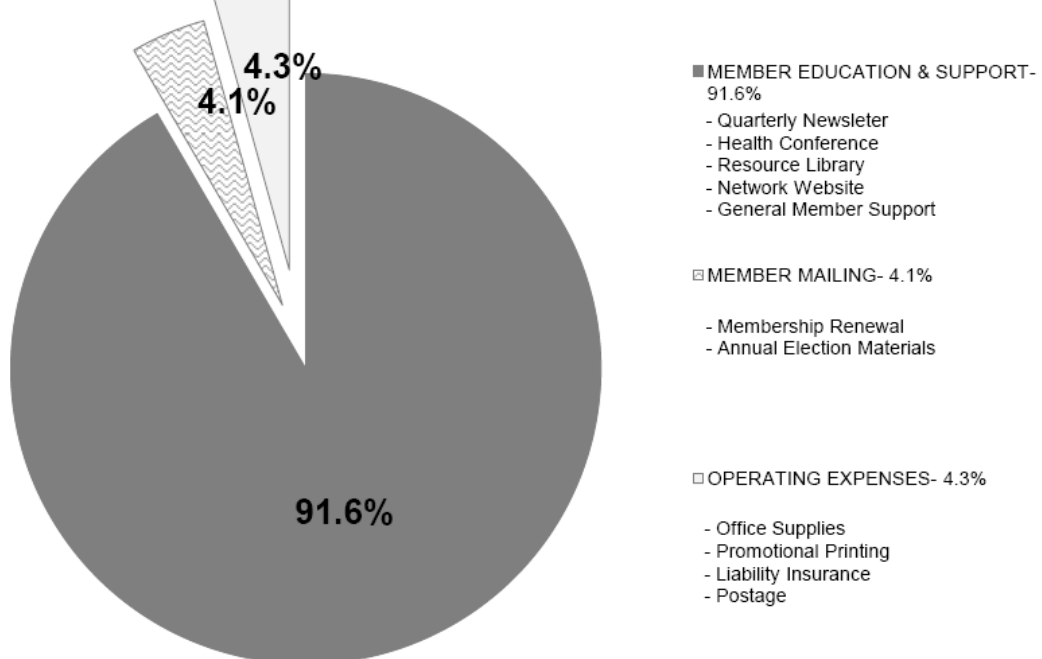
*ANYONE WHO COUNTS ALL 6
“F’S” ON THE FIRST GO IS A
GENIUS. THREE IS NORMAL,
FOUR IS QUITE RARE*

Michigan Polio Network, Inc Financial Results from Recently Completed Fiscal Year

**MICHIGAN POLIO NETWORK, INC. SOURCES OF FUNDS
FOR FISCAL YEAR 6/01/2011 TO 5/31/2012**



**MICHIGAN POLIO NETWORK, INC. USES OF FUNDS
FOR FISCAL YEAR 6/01/2011 TO 5/31/2012**



Request to all membership

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

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

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

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

or

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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

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

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

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AND mail to:

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