

# **POLIO**

# **PERSPECTIVES**

Volume 25 No 1 Spring 2010

Promoting Understanding Though the Michigan Polio Network, Inc Since 1986

# Assessment of and Managing Fatigue In Individuals With PPS

From Post Polio Health Tenth Int'l Conference

#### Assessment

- 1. Medical evaluation— It is very important to start with a thorough medical evaluation to exclude other pathologies.
- 2. What is meant by fatigue? The next thing is to go into a full consideration of the complaint of fatigue. Is it local or general, related to activity and which activities, does it increase over the day, does it respond to rest.
- 3. Are other contributing factors present?— Consideration has to be given to sleep quality, mood disorders and coping styles.
- 4. What is the activity pattern?— The activities of daily life have to be inventoried. What is the activity level of a person, what kind of work does someone do, what are social and home activities, how is mobility outdoors. Are there any aids being used for walking mobility in the outdoors and so on.
- What is the social system?— How is the person's social environment, does he or she have sufficient support and understanding at home and work.
- 6. What are the own perceptions?— How does someone value his or her complaints of fatigue (and other complaints, post-polio syndrome, polio residuals and so on.

Continued on page 2 Managing Fatigue...

### **MPN Board of Directors Meetings**

2010 Board of directors Meetings begin promptly at NOON at TONY M'S RESTAURANT

3420 S CREYTS RD

LANSING, MI 48917

Your board members are very interested in what you have to say. Consider attending one of these meetings. Every member of the network is invited to attend.

Dates: May 15, July 17, October 16.

#### NSIDE:

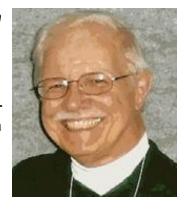
Assessment and Managing Fatigue	Pg 1,2
FROM THE CHAIR	Pg 2
SUPPORT GROUPS	Pg 3
Louis Roussey Polio Story	Pg 4
Patricia Staege Polio Story	. Pg 5,6
Library Corner	Pg 6
Vickie Wharton Polio Story	
Brace Maintenance and Care	
Lorraine Sattelmeier Polio Story	Pg 10,11
<b>Dynamic Brace Beats PP Boomerang</b>	Pg 12-15
PBS SHOW ON SERVICES FOR DISABLED	
SURVIVORS SHARING	Pg 17-19
MPN WEB-PP CLINIC- MEMBERSHIP FORM	PG 19
BOARD OF DIRECTORS	Pg 20

Polio Perspectives is the newsletter of the Michigan Polio Network, Inc. It is published four times a year. (January, April, July, and October) Send articles, information, personal accounts to:

> Vera Hazel, Editor of Polio Perspectives 15235 Ackerson Drive Battle Creek, Michigan 49014

# FROM THE CHAIR

By Bruce Sachs
It looks like Winter is behind us and we can again see and feel the sunshine.
For those of you that went South, welcome back.



This year is the 25th anniversary of the establishment of the Michigan Polio Network and although we are not having a conference, we are planning to have one or more picnics to mark this anniversary. We are presently looking for someone to coordinate a picnic on the West side of the state. If you are interested, contact me for details.

Many polio survivors continue to look for new information on Post-Polio. Although there is no cure, there are some web sites that will help keep you informed, the MPN site

www.michiganpolionetwork.com the Post-Polio Health International site <a href="www.post-polio.org">www.post-polio.org</a> and a site that is quite new from the Salk Institute in California <a href="www.poliotoday.org">www.poliotoday.org</a>

These are only a few of the sites available for polio information.

Thank you to the people that have submitted their Polio Story. We will continue to collect these stories, so send your story to The Perspectives editor. Bruce Bruce E. Sachs Chairman Michigan Polio Network besachs@sbcglobal.net

## Managing Fatigue from pg1 continued ...

- 7. What are the physical capacities?— what is somebody able to do given the polio residuals and co-morbidities. What is the physical burden of activities such as standing, walking, transfer, stair climbing, and the individuals various activities.
- 8. Conclusion—finally a conclusion can be made on which factors cause or sustain fatigue.
- 9. These are to be targeted in interventions.

#### **Assessment tools**

Tools that may be of value in the assessment of fatigue are validated questionnaires to assess fatigue severity, pain, coping styles, mood, and physical functioning.

Diaries to inventory daily life activity are extremely useful to gain insight in what someone's life looks like, in what a person actually does over the days. A common finding is that people with PPS appear to be much more active than they spontaneously report.

Clinical tests may be included to determine the extent of the polio residuals, and capacity tests to assess physical abilities.

#### **Management**

The first important thing is that the person obtains Insight in the factors contributing to fatigue. The next and crucial thing is readiness to change. Many factors contributing to fatigue are related to behavior and to cognitions. For instance, if someone is constantly overusing oneself, but considers that as normal, it will be impossible to obtain any change in behavior. It is well known that many polio survivors are so-called "over achievers" who are not easily prepared to reduce their activities. Occasionally, the reverse is also seen that some polio individuals my avoid physical activity, for instance if they think that this may damage muscles, and they may very well be mainly fatigued due to the vicious circle of fatigue, inactivity, physical deconditioning and so on.

To diminish fatigue energy conservation skills are often to be learned. This may be done individual or in group therapy programs. On the other hand regular physical activity is advised to maintain physical functioning. This implies an individual non-fatiguing exercise program that can be easily done at home, or in an (adapted and accessible) fitness setting. Environmental adaptations at home or work, transportation aids, braces and assistive devices may all be needed tailored to the individual's needs. Rehabilitation therapy is therefore usually multidisciplinary organized and may involve physical and occupational therapists, social workers, psychologists, orthotists, shoe technicians and adaptation technicians. Preferably, the effect of multidisciplinary interventions to reduce fatigue should evaluate the achievements obtained after the program and during

follow-up. ♦

#### SUPPORT GROUPS AND CONTACTS

**ANN ARBOR (PPSG) Thumb Area PP Support Group** 

(734)332-1715 Liina Paasuke Rita Wall

**Sunny Roller** (734)971-1335

Meetings 3rd Tues. of August and December.

Clio Area Polio Survivors' Support Group c/o The Clio Area Senior Center

2136 W. Vienna Rd.

810-687-7260 Clio, MI 48420

Meets third Friday of every month at 2PM

HARTFORD, MICHIGAN - PPSG

Jeannie Wessendorf

Support group meetings at Hartford Federated

Church, Hartford Michigan for meeting times

please call Jeannie at 269-621-2059 or email

jeanniew@provide.net

LANSING AREA SUPPORT GROUP

**Bill Messeroll** (517)641-6398

Meet 1st Wed of Month (except July & January)

MID-MICHIGAN (PPSG)

(989)539-3781 Jean Iutzi, Harrison, MI

Group info. 1-800-999-3199

Meeting twice a year. June and Nov.

**Northeast MI Support Group** 

meeting 3rd Wed from March to October at Alcona Library.

M 72 Harrisville, MI

**Ruth Wisniewski** (989)-354-4038

**SOUTHEAST MICHIGAN (PPSG)** 

**Bonnie Levitan** 313-885-7855

co-facilitated by Bruce Sachs 586-465-3104

**Dianne Dych-Sachs** 586-465-3104

248-549-2149 **Bobbi Stevens** 

Meets 4th Sat. of the month

March thru October 10am-Noon

(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

Jim Huttenga -Grandville (616)538-3472

George Waddell-Comstock Park and North

(616)785-9440

Michael Balcerzak -Wyoming (616)531-1634

Lynette Acosta -Grand Rapids/E (616)455-5748

Scheduled meetings: Apr, June, Sept, Nov

For time/place email:

bigsteelhead@earthlink.net

#### INFORMATION CONTACTS

Michigan Polio Collection Library

% Laura Barbour

1156 Avon Manor Road

Rochester Hills, MI 48307-5415

989-739-4065 Phone

Fred Maynard, MD

**UP Rehab Medicine Assoc PC** 

580 W College Ave, Marquette, MI 49855

Phone 906-225-3914

fmaynard@penmed.com

Post-Polio Health International (PHI)

4207 Lindell Blvd #110,

Saint Louis, Missouri 63108

FAX (314)534-5070 Phone (314)534-0475

info@post-polio.org

www.post-polio.org

#### POLIO RETURNS

By Louis E. Roussey

In 1947, at age 11, I had bulbar Polio. I was in a coma for three weeks and when I awoke, I was completely paralyzed. I could not lift a finger, and could not speak. Later, I was told that bulbar polio was different than other types of polio, in that more than 90% of those with bulbar polio died. When I came out of the coma there was a doctor talking to a nurse in the doorway to my room. I heard the doctor speak. He Said "he will never walk again."

For the next three months, I remained in the hospital and was given therapy and the treatment developed by Sister Elizabeth Kenney, a nurse from Australia. It was the best treatment for polio at that time. I would guess that in those parts of the world where polio remains a problem, the Kenney treatment probably remains the best treatment available.

When I returned to school I would have lunch in a private room, because my main problem was swallowing and choking. I would have one student with me. It was assumed that if I remained in the classroom (we did not have a lunch room) I might get excited and choke. For the next year, I had therapy at home and as an outpatient at the hospital.

Participating in sports was for me, great therapy. My favorite sports were basketball and golf. I had been a caddy before I came down with polio, and I continued doing that for another three or four years. I had part time fobs throughout my high school and college years.

For more than sixty years, choking remained something of a problem. I drank liquids every time I ate anything, and probably much more than average, whatever that might be.

In 2008, more than sixty years after I had polio, I was rushed to the hospital and was told I had Dysphagia—which is difficulty swallowing. Normally the muscles in a person's throat and esophagus squeeze, or contract to move foods and liquids from a person's mouth to their stomach without problems. Sometimes though food and liquids have trouble getting to the stomach. The muscles and nerves that help move food through the throat are not working right.

This can happen for a number of reasons, including post polio syndrome. This is a condition that can develop several decades after a person has had polio. A tube was inserted through my belly to my stomach. For three months I ate or drank nothing. My nourishment came from cans of liquids (food) taken through the tube. While this was happening, I was getting therapy. After three months I was tested. They told me I failed the test. For the next three months I was again receiving therapy, and at the end I again failed the swallowing test.

Based on recent statistics, there a re nearly 1,000,000 polio survivors living in the USA today. The polio vaccine developed in 1955 has eliminated polio in the USA, although it exists in other parts of the world. It is my opinion that the doctors and therapists who were taking care of me were doing what the medical journals told them was necessary. None of them, however, were alive in 1955 when the polio vaccine ended the nightmare called polio. For this reason, the doctors dealing with my care were at a disadvantage, and they had to rely on what medical records told them to do. My case was different. Something told me that I did not want to spend the rest of my life being fed through a tube, and being unable to eat or drink anything. I began sipping liquids and then eating soft foods-eggs in particular. When I went back to the doctor who inserted my tube I requested that the tube be removed. The doctor did not agree. He made a memo to file saying he removed the tube but indicating he did not agree that it was the proper course of action. Clearly, the people who were caring for me tried very hard to do the right thing, and I appreciate their efforts, but none of them could possibly understand my history. Of the approximate one million people who are polio survivors there may be some. like me who have had a swallowing problem. Some of them may be on a stomach tube and maybe, just maybe, they want to get the tube removed. I am not a doctor and I cannot give medical advice. I can suggest that patients in similar circumstances have a discussion with their doctor. ©

## HOW POLIO AFFECTED MY LIFE

By Patricia A. Staege

I was always an active child. I would spend hours playing with my friends on the playground across the street from my grade school. Life was fun and easy!

Now I am a Post Polio Survivor, and I have a story to tell. It begins back in the summer of 1946, when my life did a turn-about. I was eight years old and out riding my bike. The bike was always hard to peddle, but a bad headache began hampering my efforts. I was forced to head home. Mom sent me off to bed, and when my symptoms worsened, my mother called my dad who was on a fishing trip up north.

When my dad arrived home, I was taken to our hospital in Chippewa Falls, Wisconsin. A spinal tap confirmed that I had Polio, and come to find out, I was the only Polio case in Chippewa County. I was transferred to Luther Hospital, which was a larger hospital in nearby Eau Claire, WI. Luther Hospital administered hot packs, which were strips of wool heated in steamers, and then applied to my arms and legs. Mom said that some of the nurses couldn't handle the heat, so my care was not consistent. Following a lengthy hospital stay, the paralysis became more severe in my left leg. The hospital staff didn't know a lot about Polio, but they monitored my progress daily.

Sister Kenney Hospital in Minneapolis, Minnesota, preferred treating patients that showed signs of long time recovery. So, they would not take me as a patient, as in the beginning I was totally paralyzed.

My dad was the Pastor of the Evangelical United Brethren Church in Chippewa Falls, Wisconsin. He was very dedicated in his service to the church, and my mom was his faithful partner and support system. A daughter with Polio, placed added responsibility on their shoulders. Even so, my parents made daily visits to see me in the hospital. They also had the responsibility of raising my younger brother who was just two years old. Their

first child drowned at five years of age, so they suffered with hardship early in their lives.

Upon leaving the hospital, my parents enrolled me in an Orthopedic School, where I received physical therapy and resumed my studies. I wore a leather brace on my lower leg, and used crutches to move about. My upper body grew stronger with walking.

After three years of Orthopedic School, I begged my parents to attend regular school with my friends, and I was glad to be back with them. That time was difficult for my family and me. Dad drove me to and from school, and at times he even carried me. When I look back, I realize my parent sacrificed a lot on my behalf, and I am truly thankful to them. I soon learned to adapt to a new schedule, but struggled with some of the classes. (I had missed about a half year of school while being hospitalized, and the Orthopedic School majored in therapy and minored in studies).

As a teen I had a couple of surgeries. I felt like an experiment because the Doctor's were learning, and the results weren't that beneficial. A pressure cast had to be removed because gangrene was setting in on the bottom of my foot. That entire treatment was very painful, and I was glad to have the cast removed. My dad faithfully dressed the wound until it healed. My family and friends accepted me as I was.

But looking back, I am saddened because my younger brother didn't get the same amount of attention that I had. How I wish I could make that up to him, It did have an affect on his life. Also, I know that some kids with special needs aren't always treated with love and respect, and my heart goes out to them. In God's eyes we are all special, and He loves us all the same.

Near my completion of High School, I was able to get a Driver's License. After High School, my parents sent me off to College, and I studied to become a teacher. Then I accepted a teaching position in California for one year. I then returned home to get married. My husband suggested I wear a full-length brace for more support. I taught school

#### How Polio Affected My Life continued...

four more years, and then along came three sons. With a very supportive family, God gave me the strength to raise them. I remember walking with my brace and one crutch whenever I would carry them. As I think back on the boys' formative years with dirty diapers and keeping tabs on everything—WOW! How did that all happen? In November of 1984, I suffered a bad break in the leg most affected by Polio. I thought my brace was Locked, but it wasn't, and I came down full force on my leg. I some how scooted across the floor, holding my leg to call for an ambulance. The pain was severe, and when all was said and done, I had to spend six more weeks in the hospital. I still wear the hardware in my upper leg and knee for reinforcement.

Now to fast forward my life. In 2004, I had surgery to shorten a bone in my right forearm. During that recovery, I had to use a power chair to get around, as I couldn't bear weight on my arm for some time. I got used to the chair, because it offered me greater mobility, and my arms were finally getting a rest. While relying on the chair, in my later sixties, I started noticing symptoms of Post Polio Syndrome. My arms and legs were weakening, and I would get fatigued more easily. I also noted intolerance to cold temperatures.

In October of 2009, I visited the Post Polio Clinic in Warren, Michigan. I was advised to wear a leather supportive shoe, and I plan to see them early next year so they can design a more efficient walking brace.

Thanks to the encouragement of a Dear Friend, I will be using my story on Polio to author a series of books geared to young people who have special needs. It will be based on the various stages of my life, and how I coped and overcame. I want these books to encourage and inspire these special children.  $\odot$ 

## LIBRARY CORNER

Michigan Polio Collection Library c/o Laura Barbour, Librarian 1156 Avon manor road Rochester Hills, MI 48307-5415 by Laura Barbour



Dear Readers,

Due to the vacation that my husband and I are taking in Australia, the Library Corner won't be quite so lengthy this issue. In fact, it's almost over now, leaving much more room in "Perspectives" for many other interesting Polio Stories!!

I send you greetings from the Land Down Under, and promise a much longer column next time. Meanwhile, take good care of yourselves!

Laura Barbour

#### THE LESSON

The people who make a difference

in your life are

not the ones with the most credentials... the most money...or the most awards.

They simply are the ones who care the most.

FROM Charlie Schulz's Philosophy

## Vicki Lynne (Narvesen) Wharton Polio Story "Blessed"

It was the first week of August in 1948.two months after my sixth birthday. My parents, a neighbor who was my babysitter and I were preparing to leave for our "up north" camping vacation near Lake City, Michigan. I vomited twice that morning. My parents, thinking I was excited about our trip, made the decision to go ahead with our plans. Once we arrived and got our tent set up, I became increasingly ill as the hours passed. I stayed in the warm tent with my babysitter who was reading to me as I lay on my cot. My parents had gone out to fish. Later, there was a lot of excitement around the campsite besides my being ill, because my parents had been shot at by local Indians while they fished from a rowboat! While my father spoke with local authorities regarding the shooting incident, my mother drove me in to see a local doctor. I do not recall what the doctor who examined me told my mother, but we were given his approval to continue our vacation. I continued to worsen throughout the night, and the next morning my parents took me into Big Rapids to a hospital. There they were told I probably had Rheumatic Fever. My parents decided to terminate our stressful vacation so they could take me home to the care of my pediatrician. I recall the car ride home very well. I lay on the floor of the back seat of the car because I was vomiting. I remember the discomfort of the hump on the floor as I lay with my neck and my body stiffening. My Mom cried as she tried to comfort me from the back seat.

Dr. Brubaker met us at our Lansing home when we arrived. By that time my temperature was 106 degrees and I couldn't turn my head. He immediately called an ambulance to transport me to Edward W. Sparrow Hospital where I was then diagnosed with Infantile Paralysis (Bulbar Polio). A few weeks after my initial care and diagnosis, I was taken by ambulance to an annex hospital in the Lansing area that was exclusively for polio cases. If my memory serves me correctly, I believe the name of the hospital annex was McLaughlin. I didn't

come out of the hospital until after Christmas. My parents waited for our Christmas celebrations until I got home.

I'm sure there are many things I have forgotten about those months in the hospital, but there are others I remember as if they were vesterday. I was in isolation for the first ten days or so, and my parents could only peer at me through a very small window in a closed door. I could only see their eyes and their fingers as they tried to wave at me. They had been told I would not live. I can't imagine the anguish they must have suffered over those days and nights. With the passage of time, my parents were told I had a "50 - 50 chance" to live, but that I would be in a wheelchair for life. I was paralyzed from the neck down. My long blond hair was cut short because it was matted and sweaty and I couldn't move for anyone to comb or brush it out. What I remember most is anguishing with the hot packs wrapped around all of my limbs, neck and trunk. The nurses would come in with the rolling steamers that held pieces of green, wool army blanket. They would place them on your body, cover them to hold in the heat, and then cover that laver as well. The smell which I can still remember to this day was horrible! Then they would leave the room for what seemed like hours until the packs were cool and damp on your skin. It felt miserable. I cried more than once, but to no avail. To this day, I still have a strong aversion to wool, especially wool army blankets! As difficult as these treatments were, I now credit them for saving my muscles if not my life! I spent a short time in an iron lung, but not extensively. There was a mirror that was attached so you could look at yourself and look around some of the room. When I was well enough to swallow, they brought me a shot glass full of orange liquid to drink each day. It tasted like the liquid inside of the centers of vitamins in those days. Not good! After further improvement and as part of my rehabilitation, I was sent to a silver metal hydro-therapy tank where warm waters would swirl all around you. I was in the tank with a therapist who held me up and helped me with movement. I loved it! Continued next page...

#### Vicki Wharton Polio Story continued...

On a personal level, I remember the many cards and letters from my family and friends that I looked forward to each day in the hospital. My Mom made me a scrapbook of those cards which I still have today. It is very special to me.

When I left the hospital, after a lot of rehabilitation therapy, I had had miraculously improved to the degree that I only suffered a left-side facial paralysis. I returned to school in January with the start of the new semester. Living with my left-side facial paralysis wasn't always easy. Other children can be so critical and brutally honest in their observations, but when I think of what might have been, I am so very thankful. The March of Dimes was such a significant help to my parents. I remember my parents singing their praises for all of the help they were able to give them. My Mother always went out on the 'Mother's March' to collect for them, and gave me folders to fill up with dimes to be turned back in.

The interim years were good. I married, we had four children, and I was an active typical 'type A' personality for many years. Finally, the years caught up with me. I now suffer the effects of postpolio syndrome, and continue to push forward, although now at a much slower pace. I worked for 31 years at Michigan Bell/Ameritech in various job titles. Finally, in April of 1999, my physical job demands and mental stresses became overwhelming, and I made the decision to retire. It is so interesting to hear the polio story of others when we talk at our appointments with Dr. Daniel Ryan at the St. John Post-Polio Clinic in Warren, MI. The things we talk about always awaken other memories of my personal polio experience. When people hear my polio story, they tell me how "lucky" I am. I tell them that truly, I am blessed!

Vicki Lynne (Narvesen) Wharton ©

# BRACE MAINTENANCE AND CARE GUIDELINES

Tamara Treanore CO, ABC, Certified Orthotist Complete Orthotics (Affiliated with the St John Post Polio Clinic)

13850 East Twelve Mile Rd

Warren, MI 48088

Brace maintenance and care will improve the function, extend the life and improve the comfort of the brace. The following guidelines are provided for your use.

#### I. Plastic braces:

-Check for discoloration in the plastic on a regular basis. Discoloration indicates that the plastic in those areas is excessively stressed, creating the possibility of breaking and/or plastic failure with the associated incident of falling or injury. Bring this to the attention of your orthotist!!

-Cracks. Look for cracks in the metal joints-esp. around rivets and by any joints. Again, bring this to the attention of your orthotist.

Clean plastic with a damp wash cloth using the same soap that you use on a daily basis. Wipe out well. If no padding is present, the brace can be rinsed under water. If pads are present, this is not recommended as the water can become trapped between the materials and cause separation.

Wipe pads Off in the same manner but do not scrub the pad as it will roughen the surface and cause either friction or further soiling. Alcohol pads can also be used to wipe down the brace/pads. The brace should be wiped out on a regular basis to reduce the incidence of dermatitis and odor. Using a-sock or interface between your skin and the brace is standard-this will reduce the need for cleansing and protect your skin. Socks should be cotton/polyester blend with low-profile seams and no heavy banding, sewn in designs or anti-slip pads. If your leg size precludes you from using standard socks then a section of thermal underwear can be used to cover the calf area.

Check your shoes on a regular basis-removing the brace, the insole and shake out any sand, gravel, animal hair, etc. All these can abrade the bottom of the plastic brace and can be the site of plastic fracturing. Shoes should be leather, full cut, removable insole, Velcro or lace closure. There should not be any significant heel and the width of

#### Brace maintenance & Care continued...

the sole should be appropriate for the size of your be secured in order to achieve the outcome the foot and the type of stability you need.

the forefoot and make sure the shoe holds your foot strap to the brace for signs of failure. Remove any into the brace securely. The shoe is a functioning hair, fiber or debris with fork tines, a toothpick or part of your brace -it secures the brace to your foot a comb. The exposed surface of each part of the and aligns your foot/ankle to the ground. Replace strap is what determines the contact and security when the upper becomes stretched and sloppy-you of the strap closure-keep 'em clean so that the are reducing the function of the brace and in effect, straps close securely. your safety

per glue, solvents, torches, tinsnips, dremels, hack new strap, removing the old rivet, attaching the saws or band saws. Stay out of the tool shed! If you new strap and cleaning up the rivet site. The addiof mine.

#### II. Metal and Leather braces:

basis especially around the rivets, the knee joints Maintenance has an associated cost. and the ankle joints. -Check that any moving parts Covering the rivet site inside of the brace with a noted, speak to your orthotist.

hinges with a cloth, a toothpick or with a can of times impossible. compressed air. Use a dry silicone lubricant on the Straps can be washed and squeezed dry-use a soft cate the hinges at night, thus permitting any excess care guidelines for additional help. to drain out, hopefully avoiding soiling your VI. Miscellaneous clothes. Wipe off the hinges again prior to wearing -Hold onto old brace for emergencies!! the brace. If crunching or grinding is heard at any -Replacement of braces is covered by insurances to lock/unlock when needed.

Do not add anything to your hinges unless your and increase the possibility of falling.

#### III. Straps

-Straps hold the brace onto the leg and provide biomechanical alignment between the brace and your

body-each strap has a unique function and needs to brace was prescribed for.

Avoid man made uppers, avoid heavy seams across -Always check the rivet/screw that attaches the

If the Velero becomes worn, it needs to be replaced. DO NOT USE THE FOLLOWING: Febreeze, su- Replacing a strap requires measuring, sewing the have a problem with your brace or with the func- tion of pads can increase the amount of work retion of your brace- TALK TO YOUR ORTHO- quired. There is a cost associated with this-a pre-TIST OR YOUR DOCTOR! I promise to stay out scription can be provided to cover the cost but of your professional field if you promise to stay out there is no guarantee of payment by your insurance company. However, just like the tires on your car, the sales on your shoes or the clothes you are -Check for cracks in the metal joints on a regular wearing-things wear out and need to be replaced.

or aligned hinges are moving freely without any piece of moleskin or bandage will reduce any skin halting, binding or squeaking. If concerns are irritating from the metal. Raised edges must be addressed by ... your orthotist. Again, please do not Joints need to be cleaned and lubricated on a regu- hammer, grind, drill or modify your brace in any lar basis. Remove any fiber or debris out of the way. Repairing "repairs" can be costly and some-

hinges and wipe off any excess. It is best to lubri- scrub brush if needed and follow the brace wear/

joint, you need to see your orthotist. Parts break, based on each companies own protocols. In genwear out, get out of alignment and get rusty. Most eral, it is once every 3-5 years unless there is a springs or ball bearings can be easily replaced, re- change in function, change in weight, brace breakalignment is a tougher job. A metal hinge requires ing or change in physical status. This must be smooth function in order to move with your leg and documented by your physician and a certificate of medical necessity provided with the prescription.

Again, there is no guarantee of payment by your orthotist approves. Materials added to protect insurer. We will try our best to verify your coverclothing can impede the secure locking of the hinge age, your deductible and your co-payment and will work with you to procure coverage if possible. ♦

### **Lorraine Sattelmeier Polio Story**

It was a very hot. August 1935. I had a cold but woke up and could not stand and had a high fever. I was rushed to the Bay City Contagious Hospital where I was for three weeks and on the verge of dying. My pain and paralysis started at my feet and traveled upward. I remember the pain, the fever the cold water, the hospital and nurses who spoke a strange language. They spoke English and I only knew German. I was from Franken1ust Township near Bay City, Michigan. We lived on a farm and we were members of St. Paul Lutheran Church with a membership of over 600. The next closest church was St. John Amelith, five miles away. Trinity Monitor was about 10 miles away all farming areas. My parents knew all of them. Zion Lutheran was in town about 6 miles away. I had not been anywhere for the past few weeks and yet I was the only child in that area that contracted Polio. I was very sick and the doctor said I would die because the polio paralysis kept creeping toward my heart, lungs and head.

But the Doctor wanted to try something that might save me. A young teen age girl had polio but was back to school, in therapy and had a brace on her one leg. The Doctor got permission from her and her parents to bring her to the hospital where she would donate some blood that would be given to me. The Doctor thought maybe, just maybe, there would be something in the blood that would stop the paralysis. She came in five days in a row and the paralysis stopped before it hit my lungs right arm and head. I was sent home. My mother said I was like a rag doll. My parents were advised to just take me to an institution because "nothing would become of little Lorraine". My father and mother said. "No Lorraine is our daughter-we will do as much as we can for her."

My mother gave me hot pack treatments like I had at the hospital. Then she massaged me three times a day. Then I had therapy, water baths etc. at Saginaw General Hospital three days a week. At age 5 my Dad took me to the Orthopedic School in Bay City. The staff spoke English. I spoke German but by December 1st I was reading right along with the rest of them. We were given Therapy three or four times a week.

I received an excellent education. By the time I was eleven I was already doing 10th grade math, English, Geography, etc.

At age 11 I could finally get rid of the shoes and heavy clumsy braces and wear regular shoes. I had a bad limp but could walk, so I went to St. Paul School. There I learned about the Bible and had to memorize my catechism sections in German and English but since I was so far ahead in my other classes, I had the time to learn my Catechism. One day Mr. Winter our teacher told us about heaven and how we will have perfect bodies in heaven. I really listened to him because I so really needed a perfect body. This one didn't work too well and my skinny legs didn't look so nice either. I went to high school where I wanted to take precollege courses, but was told that I probably could not get around in college and was advised to take a secretarial bookkeeping course which I did. Central High School in Bay City had three floors and my classes were up and down and allover. I was exhausted. I asked to be excused ten minutes early from every class and have a classmate carry my books. The offices said O.K. Then I went campaigning for an elevator.

The Bay City Junior College was on the third floor and soldiers were coming back using crutches and what nots. We got the elevator! Then when I entered my Junior Year of High School we had to go to Handy. Again I asked to be excused 10 minutes early and I went about asking for an elevator. We got the elevator!

Graduation was outside in the stands and the stage was on the football field. I walked it all but I was exhausted.

Because I lived on a farm, my Dad taught me how to drive the tractor and the car. I had my license when I was 14 and drove into town by myself. I got a job at Peet Packing Company and was Assistant Office Manager three months later. Six years later I was a private Secretary and then worked for doctors in Essexville where I was the Office Manager.

In 1966, I married Glenn Sattelmeier, a minister, whose parish was in Oak Hill, New York a pretty little village in the Catskills.

In 1967, our son Kirk was born. Then in 1970, I gave birth to Elizabeth, Katherine, and Rebecca. All were natural births and never a moment of nausea. Our little Rebecca died at the hospital due to a mistake by a an emotionally disturbed Nurse. Very sad!

Lorraine Sattelmeier Story continued...
In 1972 we moved to Lewiston, Michigan where Glenn was the first full time Pastor. We had a new home built for us, a ranch with laundry on the first floor. Then the congregation built a new church. The congregation grew greatly. To this day, it is a very lively, thriving, and energetic church doing a lot for others.

I was very busy with Glenn, busy with the children; I had a garden. I canned, cooked, spent a week annually at my Dads when we cleaned his house from top to bottom. The children thrived and were active in school and church activities. They were all Valedictorian or salutatorian and all have great jobs now. We are very proud of them. I was active in the Lutheran Women's Missionary League and was the State Treasurer for four years. In 1975 I was the Michigan State Fair Grand Champion Home Maker of the Year.

I also served on the Johannesburq Lewiston School Board for 4 years. I helped with Secretarial work at the church, was a Sunday School Teacher, VBS Director, sang in the Choir, led the Youth Choir for a while, was active in the ladies group; played the guitar for our group and was the lead female soloist. Our group was constantly asked to perform somewhere and of course in church.

In 1979, I felt weaker. I went to the doctor. He said. "Now Lorraine you are getting to be about that age". I said, "Don't give me that age bit, there are women in their 80's and they run rings around me." So he sent me for three months of therapy and exercise.

I got weaker. We were at the Alpine Fest in Gaylord when I saw a lady I had not seen in many years and she asked me how I was doing. I told her about my weakness. She asked me if I had gone to the Post Polio Clinic in Ann Arbor. I knew nothing about that and she gave me a card. I called them and had to wait 6 months for an appointment. I walked into the room with Dr. Warinq and Dr. Maynard and they both said. "Yep, you've got it. Get a little scooter, conserve your energy and let the little dust bunnies run around". So that is what I did. I couldn't garden anymore, so had my husband and children do it.

Glenn retired in 2000. We did some traveling and he helped other Lutheran Pastors in the area. In 2002 Pastor Heuser called to see if we could come to Rochester to help out for a few months. We agreed and got a one bedroom apartment put some furniture into it and Glenn started working. He had the three sermons every other Sunday and visited about 60 sick and shut-ins monthly. This was a congregation of about 2,000. We really enjoyed being active.

In May of 2002 our Beth got married and in March 2003 Sarah was born. Beth wanted to go back to work so I took care of Sarah. Eighteen months later I also started taking care of Luke. They were happy little children and I was so thankful to take care of them. We decided that we really enjoy being around the children and grandchildren so we purchased a little retirement home. The grandchildren still come part time. Next year they will both be in school all day. I will be an empty nester so I'll invite them more often for sleep-overs.

I have been active at St. Johns with the OWLS-Older Wiser Lutherans in Service .. I have taught ESL (Enq1ish As A Second Language) for three years. and I have had a monthly cooking class for the ESL group for about five years. I have been on the committee to start a gift shop which is doing real well. We attend a twice-a- month Bible Class and was recently nominated Woman of The Year for St. John Lutheran Church-Rochester. I am presently writing my life story. I am up to page 14 and have shared 185 stories so far. I am so grateful to God, my parents, husband, and family for all the blessings I have and do enjoy. ©

How far you go in life
depends on your being
tender with the young,
compassionate with the aged, sympathetic with the striving, and tolerant of
the weak and the strong.
Because someday in life you will have
been all of these.
- George Washington Carver

\*\*\*\*

# Dynamic Brace Beats Post-Polio Boomerang By Miki Fairley

Content provided by The O&P EDGECurrent Issue - Free Subscription - Free eNewsletter - Advertise When a 72-year-old retired physician with postpolio syndrome (PPS) presented at Prosthetic Orthotic Associates (POA) in 2008, he was unable to ambulate and used a scooter for mobility. He suffered from left knee pain, medial and lateral knee instability, genu recurvatum, and low endurance. He now can walk, clean the swimming pool, and help his wife with household chores and meal preparation.

Another PPS patient previously had a difficult gait and could walk for only about 10 minutes before becoming exhausted. After treatment, she called David Guy, MS, PT, and said, "Guess where I walked today? I spent two hours in the grocery store and then drove to Kohl's department store and spent another two hours. I was on my feet for four hours—and I'm not tired!"

"We're seeing similar results with all our postpolio patients," Guy says.

These are not instant, miracle cures, but rather the result of a unique combination of innovative orthotic design, an exercise program, and highly motivated patients. This combination has resulted in astonishing improvement for these patients, along with some unexpected results.

The unexpected aspect is that the treatment not only provides joint stability and less energy expenditure but it also appears to provide motor and sensory input. This input is thought to stimulate the production of cytokines, neurotransmitters which stimulate muscles, causing them to work again after many "dead" years.

Cytokines are proteins, polypeptides and glycoproteins, Guy explains. "They act as neurotransmitters that are secreted by specific cells in the immune system. They then carry signals locally between cells. It is our belief that the DBS causes these cytokines to be released by the immune system, and the result is the increase in muscle

activity."

Guy and Sander Nassan, CPO, FAAOP, owner of POA, have performed extensive testing to monitor patients' progress and verify results via electromyographic (EMG) and manual muscle testing along with cardiopulmonary testing.

#### The Program—a Closer Look

The orthotic technologies used by Nassan and Guy were developed by Marmaduke Loke, CPO, and Jean-Paul Nielsen, CP, owners of Dynamic Bracing Solutions Inc., San Diego, California. The technologies are based on concepts Nielsen developed and taught in the early 1990s along with Loke's innovative ideas and experience.

Guy and Loke presented a case study by the retired physician during the 2009 American Orthotic & Prosthetic Association (AOPA) National Assembly, and Guy and Nassan have submitted the study to a peer-reviewed journal. "Results in the case study and other data suggest that the accepted neuropathology of polio might need to be reexamined," says Guy, who would like to see a larger-scale study undertaken.

Guy believes it is the combination of the Dynamic Bracing Solutions (DBS) orthotic technology and the exercise program that has stimulated the regaining of muscle strength and function thought to have been permanently lost. He says that he has not seen similar results with the exercise program used with other types of orthoses, and even though the DBS orthotic system has produced some striking results on its own, it has not had the same neuromuscular recovery effect without the exercise program.

"The exercises and the brace are producing, first all, stable walking, the return of muscle strength in muscles that haven't worked in many, many years, and an increase in endurance," Guy says. "But most importantly, people who were dependent are becoming independent."

#### **PPS—What Happens**

Polio survivors often think that all the damage the disease will cause has already occurred. Then, as they get on with their lives, the boomerang—new

#### DYNAMIC BRACE BEATS.. continued...

or worsening symptoms—strikes many years later. The National Institute of Neurological Disorders and Stroke (NINDS) of the National Institutes of Health (NIH) defines post-polio syndrome as a condition that affects polio survivors years after recovery from an initial acute poliomyelitis virus attack. PPS is mainly characterized by new weakening in muscles that were previously affected, as well as muscles that seemingly were not affected although some PPS patients experience only minor symptoms. Symptoms include slowly progressive muscle weakness, unaccustomed fatigue, and sometimes muscle atrophy. Pain from joint degeneration and increasing skeletal deformities such as scoliosis are common. Researchers estimate that PPS affects 25-50 percent of polio survivors, or even as high as 60 percent, with some 440,000 survivors at risk in the United States.

The cause is unknown although NINDS notes that the new weakness of PPS appears to be related to the degeneration of individual nerve terminals in the motor units (neurons and the muscle fibers they activate) that remain after the initial illness. The poliovirus attacks specific neurons in the brainstem and the anterior horn cells of the spinal cord. To compensate for the loss, surviving neurons sprout new nerve terminals to the orphaned muscle fibers, resulting in some recovery of movement and enlarged motor units.

"Years of high use of these enlarged motor units adds stress to the neuronal cell body, which then may not be able to maintain the metabolic demands of all the new sprouts, resulting in the slow deterioration of motor units," NINDS theorizes. "Restoration of nerve function may occur in some fibers a second time, but eventually nerve terminals malfunction and permanent weakness occurs. This hypothesis is consistent with PPS's slow, stepwise, unpredictable course."

If this hypothesis proves correct, how the treatment program implemented by Guy and Nassan may be involved in regaining muscle function could provide a promising area for future research.

#### **Exercise Program**

In developing the exercise program, Guy explains, "We treated the brace as though it were an artificial limb. With an artificial limb, first we concentrate on stabilizing the trunk, so the patient has a stable platform from which to move the limb. We then work on stabilizing the hip joint, and then we move down the leg to the knee and the ankle. The exercises are in four stages and start off very slowly and gradually increase."

Post-polio patients often have learned to walk in particular patterns to compensate for various weaknesses, deformities, and balance issues. These patterns often become automatic but are inefficient, energy-consuming, and can even add further stress and damage. "Getting people to take the risk of doing something that caused them to fall in the past is extremely difficult," Guy says. "Helping them to break these old habits is probably the biggest challenge we face."

### **DBS:** Concepts behind the Technology

The main concept behind the DBS technologies is "true triplanar orthotic management," Loke says. "A skeleton comprises three dimensions, and we need to manage musculoskeletal structures in all three dimensions. Most AFOs—both custom and prefabricated—often only partially manage the sagittal and coronal planes. Very rarely is the transverse plane considered with traditional designs."

Loke's goal is for orthotic users to be able to achieve the same ease and smoothness of walking that many persons with amputation accomplish. Gait that is closer to normal translates into less energy expenditure and physical strain, enabling the patient to have a better quality of life both physically and psychologically.

Loke is well-versed in gait training. He began his career in a children's hospital, where he "gait-trained about 10 kids every day for several years," he says. "When I entered the O&P field, I noticed a lack of orthotic education to enhance function of ambulation with lower-limb orthotics. Because of

#### DYNAMIC BRACE BEATS.. continued...

my experience, I had a good understanding of how the 'bio' and the 'mechanical' work together—the patient working with the device for better outcomes."

Even before the development of the DBS exercise program, Loke, Guy, and enthusiastic DBS orthosis user Marny Eulberg, MD, a polio survivor, have strongly stressed the importance of an almost symbiotic relationship between gait training and the orthotic technology.

Loke says he spends hours studying gait videotapes of his patients. "I use a videotape of patients' gait to find out what their deficiencies are in each dimension and develop a walking solution to counter that, looking at issues such as balance, security, mobility, and alignment. It's very meticulous and time-consuming." Loke videotapes patients before designing and fitting the graphite composite orthoses as well as during fitting and often during follow-up.

Some of the concepts now used in DBS orthotic technology are discussed in a paper by Nielsen and Deanna J. Fish, MS, CPO, FAAOP, titled "Clinical Assessment of Human Gait," published in the April 1993 issue of the JPO. "Functional activities of daily living rarely occur in one plane; therefore, motion can be described as triplanar or occurring in all three planes simultaneously," the authors note. Nielsen and Fish discuss the external rotary and the internal rotary patterns of motion in the transverse plane and their role in orthotic evaluation and design. Medial or internal rotation refers to rotation toward the center of the body. Lateral or external rotation refers to rotation away from the center of the body.

"The ability to walk efficiently is based upon the proper alignment of the bones of the feet, which in turn affect the alignment of the ankles, knees, and hips," Loke notes on the DBS website (www.dynamicbracingsolutions.net). "Muscle strength from above is also a factor. Weak or missing muscles create abnormal rotational patterns causing malalignment of the joints below. An effective brace must provide for triplanar control of the

foot and ankle while providing triplanar support for weak muscles. It must work from the ground up and the top down simultaneously."

Marny Eulberg, MD, DBS Enthusiast Eulberg's experiences with post-polio and the DBS bracing system are enlightening. Named Colorado Family Physician of the Year in 2005 by the Colorado Academy of Family Physicians (CAFP), she conducts a post-polio clinic at St. Anthony North Family Medicine Center, Westminster, Colorado. Before trying a DBS orthosis, Eulberg had been using an AFO that controlled her foot drop and provided some knee control. She used a single forearm crutch when walking more than one block, such as when making hospital rounds.

However, she was experiencing increasing quadriceps weakness and feared that her knee would buckle and she would fall. "I thought my only option was a long-leg brace with a knee lock, and I wasn't crazy about that," she recalls. "It's very inconvenient to have to lock or unlock the brace every time you stand up or sit down, and the joint usually chews up pants like crazy." Eulberg also worried that she had enough hip flexor strength to manage the weight of the brace.

Then a patient came in for a re-evaluation, displaying a striking improvement in her gait after being fitted with a DBS orthosis. Eulberg decided to try one for herself and has been delighted with it ever since. "I walk hands-free, only using a cane occasionally in very uneven terrain."

In fact, she was so happy with the brace that she asked Loke to make her another one as a backup. "I didn't want to be without it for a few weeks if it broke." Eulberg describes an unexpected benefit: "I felt so much better about myself and had so much more energy that I was motivated to lose 50 pounds." Then, because of becoming slimmer, she needed a third orthosis for a snug fit.

Does Eulberg recommend DBS orthoses to her patients? "It depends," she says, "on things such as how they present physically, their financial resources, and their motivation."

**Eulberg echoes Guy on the importance of patients' motivation. "When people start with the DBS** 

#### DYNAMIC BRACE BEATS.. continued...

brace, something happens that doesn't often happen in the traditional orthotic world—and that's gait training, which is a real challenge.

Patients have to unlearn gait patterns they've been using for perhaps 50 years. Walking is so automatic. Unlearning a pattern that has basically become unconscious takes a lot of work and can be frustrating."

Eulberg still sees a physical therapist about once a month, noting that "it's so easy to backslide." She has started a closed DBS users' group on Facebook as well as a group that meets about every six months to exchange advice and experiences. She is one of the instructors at an upcoming DBS Orthotic Triplanar Basic Course in Scottsdale. Besides DBS, other innovative orthotic technologies, such as electronically controlled stance-control knee joints, are emerging for post-polio patients and others with neuromuscular and musculoskeletal pathologies.

#### **New Technology Considerations**

Mark Taylor, MLS, CPO, FAAOP, University of Michigan, Ann Arbor, who has presented at various conferences and published papers on PPS, is enthusiastic about the new technologies, but points out some caveats.

"With new componentry and materials, we have more choices than ever before," Taylor says. "But with this new technology comes more responsibility to our patients. We don't want to put patients at greater risk." Practitioners also have a greater responsibility to their physician referral sources, Taylor adds. With the knowledge explosion in their own fields, doctors are relying more on O&P practitioners and physical therapists to make sound recommendations for devices and therapy. How can orthotists/prosthetists best keep up with new technological advances? "New technology comes with lots of questions," Taylor says. "Ask colleagues who have worked with the technology you're considering, read whatever literature is available, talk with the manufacturers—gain as much knowledge in every fashion that you can." New technology doesn't work for everyone, Taylor points out. Considering such issues as the patient's environment and motivation is important. For instance, a technology that works fine in an indoor or city environment could be a poor choice for a farmer working with livestock and crops in a totally different environment. Finding the right can-

didates—or developing the right candidates through training and physical therapy—can be difficult. "You can't just put new technology on someone and say, 'See you in six months.'"

#### **Future Visions**

Appropriately used, new orthotic technologies are opening up new vistas of function and quality of life for post-polio patients as well as others. What could the future hold?

Guy, for instance, is envisioning using DBS technology for children with cerebral palsy. "We could help them not only maintain strength and balance, but also overcome distracting gait movements that cause social stigma and psychological issues. We could help these kids to have better lives both physically and psychologically."

Loke is enthusiastic about the outcomes experienced by the network of DBS clinicians. "I believe most people needing lower-limb bracing can benefit from technologies with triplanar management and dynamic response because deformities can be prevented and often corrected, surgeries minimized, muscles stimulated to enhance strength, and, most of all, quality-of-life issues improved. "We now have several active-duty wounded soldiers regaining a very high level of activity needed for redeployment," he continues, "and post-polio patients around the world can see great promise with bracing solutions that can offer benefits beyond what was once thought possible."

Miki Fairley is a freelance writer based in southwest Colorado. She can be contacted via e-mail at miki.fairley@gmail.com ◆

Real optimism is aware of problems but recognizes solutions; knows about difficulties but believes they can be overcome; sees the negatives, but accentuates the positives; is exposed to the worst but expects the best; has reason to complain, but chooses to smile.

-- William Arthur Ward

# PBS show on Services for Disabled People is Golden

By Len McCulloch

When it comes to a weekly, televised show about resources for people with all types of mental, physical, traumatic, and/or developmental disabilities, the name Roger McCarville comes to mind among the majority of professionals, family members, and people in need of helpful programs

Roger McCarville was severely handicapped in a boating accident as a young man. One leg was completely severed and the other was able to be reattached. The lost limb was replaced with prosthesis. Roger championed the cause of people with disabilities for many, many years in Michigan, the U.S.A. and around the world with the television program he created called, Disabilities Today. This PBS-TV Special aired nationally for many years to six million potential viewers.

Roger knew that recovery activities for challenged individuals was of paramount importance. He made his career out of researching programs and made them available through his broadcast. He had a tremendous, adaptive view of life after disability and his mission to share this became the passion of his life. He aired programs on adaptive sports, recreational activities, programs for people with autism and paralyzed veterans. He was among the first to show activities for quadriplegics, people with birth injuries and promoted therapeutic choirs.

I knew Roger professionally and personally through his advocacy of our Therapy Choir Programs through which we developed singing groups for people with traumatic brain injuries, mental illness, addictions, developmental disabilities and other problems. Our groups were featured on Roger's show many times over the years.

With my partner, Sherry Cantrell, we created The Therapy Choirs of Michigan, a nonprofit organization promoting choir therapy for rehabilitative experiences for people who have had all sorts of traumas and losses. Roger was a source of encouragement and inspiration.

Unfortunately, for us all, Roger passed away in September 2009 at age 72. He had just returned from Peru, on a mission trip with the MSU College of Human Medicine and the Lansing Rotary Club. His frail health got the best of him. But, his show lives on!

Fortunately, Roger's producer's, Jim Saliba, and Elizabeth Kelly, along with his film crew and researchers have continued to produce and air Roger's show through PBS-TV. The show's name changed to A Wider World - a show which empowers, educates, and entertains.

Elizabeth told me this. She said that the mission of A Wider World is to showcase the abilities of individuals who have overcome obstacles and misconceptions, to educate our audience on the newest technologies for people with disabilities, and to combat the ignorance, stereotypes and stigmatizations that have been long associated with people with disabilities.

Interestingly, although Roger drove his own car and rarely took public transportation, he once chained himself to a bus in Detroit to protest inaccessible transportation in that city. He was very proud that he was arrested for that effort! He was even prouder when that same city later chose him to be Grand Marshal of its yearly St. Patrick's Day Parade.

You see, initially Roger and his producer Jim pitched the show to WTVS Detroit Public Television and initially were turned down. But, Roger was persistent and called on all the advocacy organizations, non-profits, friends, relatives and anyone else he could think of to lobby Channel 56. The station was inundated with calls and letters asking them to air Roger's show and they did so in the fall of 2000. Without much marketing, the show was picked up by 20 more stations over its 10 year run.

In 2009, with the inauguration of A Wider World the show was actively promoted among PBS affiliates and doubled the number of stations airing it now. It is also now available throughout Canada, on cable and satellite!

I fully endorse and encourage all readers to tune in to A Wider World. In my opinion, there is no greater resource for the diversity, availability and practical directions on how to get involved with programs that service individuals with special needs.

For detailed information, consult your PBS Directory for weekly show times and channels and/or call Elizabeth Kelly, director, producer and director of Marketing, at (248) 689-2610. Or, send an e-mail to ekelly@awiderworld.com. You will not be sorry that you did!

Len McCulloch of Farmington Hills is a Diplomat of The American Psychotherapy Association. He is credentialed in Mental Health, Brain Injury, Traumatic Stress, Addictions, and Social Work. He has published 150 articles in these various fields. He can be reached about his writing at (248) 474-2763, Ext. 22. This article is devoted to the memory of Roger Joseph McCarvilleo

# 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

-----

LAURELHAY@SBCGLOBAL.NET - Laurel

Escanaba, MI

BTOleksa@aol.com - Bernie

Rochester Hills, MI

vallen2@comcast.net-Velma

Muskegon, MI

hnjutzi2@ejourney.com- Jean

Harrison, MI

grossjjr@voyager.net - Janice

Lansing, MI

rick\_kugel@hotmail.com - Rick

Rochester Hills, MI

sharon kugel@hotmail.com - Sharon

Rochester Hills, MI

gramma44@hotmail.com - Linda

Farwell, MI

jpasich@sbcglobal.net - Judy

Ann Arbor, MI

vandar@sbcglobal.net- Darlene

Middleville, MI

pigger 38@yahoo.com - Bonnie

**Grosse Pointe, MI** 

Patsyanne@aol.com - Pat

Allen Park, MI

PhyllisPanozzo@comcast.net. -Phyllis

Niles, MI

ronmagnuson@comcast.net - Ron

Warren, MI

rileyjlb@comcast.net - Judy

Dearborn Heights, MI

Cairnview@comcast.net - Ean

Dearborn Heights, MI

j.boothe@comcast.net -John C. Boot

Grand Rapids, MI

lindagrimsley@sbcglobal.net Linda

Jackson, MI

ineer9298@wowway.com - Lawrence

Sterling Heights, MI

virginiahenry@ameritech.net-Virginia

St. Clair Shores, MI

wwmesseroll@aol.com - William

Lansing, MI

JPO6295@aol.com - John

Kalamazoo, MI

mleveemiller@verizon.net - Marilyn

St. Johns, MI

**Tmartin458 - Theron** 

Battle Creek, MI

leberghoef@sbcglobal.net -Leonard

Jenison, MI

v1ctorious@sbcglobal.net - Vicki

Waterford, MI

GLacagoo@aol.com - Laura

Fraser, MI

LindaLRobb@aol.com - Linda

Kalamazoo, MI

jodell@netonecom.net - Jim

Marion, MI

besachs@sbcglobal.net- Bruce

Livonia, MI

BarbBasirico@cs.com - Barbara

Macomb, MI

turtles@voyager.net - Sue (TurtleLady)

Monroe, MI

maryk1660@aol.com - Mary

Muskegon, MI

Anniefred2001@yahoo.com - Pat

Okemos, MI

sithast@voyager.net - Saundra

Hastings, MI

bstevens1975@yahoo.com - Bobbi

Royal Oak, MI

SURVIVORS SHARI	N( ÷	continued
-----------------	------	-----------

SURVIVORS SHARING commueu		
KRBWAY@aol.com - Ken	cndchurch@lakeshore.net (summer)	
Hart, MI	cndchurch@gls3c.com (winter) - Charles	
sharonf@btc-bci.com - Sharon	Pentwater, MI	
South Haven, MI	gpjay@toast.net - Pat	
•	Six Lakes, MI	
fabo48@hotmail.com -Fran		
Quincy, MI	jhuck@att.net - Jerry	
LLBUTLER149@MSN.COM -Linda Butler	Selby Twp,MI	
Dearborn Heights MI	jandj316@aol.com - Jennifer	
thadandshei@juno.com - Ted	Livonia, MI	
Auburn Hills MI	wini@manoian.net -Wini	
frances43@juno.com Lorraine	Livonia, MI	
	rconnectus45@yahoo.com - Richard	
Fraser, MI		
jmc65@ncats.net - Michael	Manistee, MI	
Fremont MI	PRISCSMTH@aol.com - PAT	
mrsrogers@chartermi.net - Sharon	Livonia, MI	
Fenton, MI	Kathi644D@aol.com -Kathe	
boborsarah@juno.com - Bob	Shelby Township, MI	
Clarkson, MI	suzee5@juno.com -Ellen	
virginiafinkbeiner@yahoo.com - Virginia	Ortonville,MI	
	kwoodbeck@twmi.rr.com -Kaye	
North Branch, MI	•	
itopor@aol.com - Iris	Redford, MI	
Farmington Hills, MI	rktheloveline@aol.com Ruth	
jackofwb@juno.com - Jack	Rockford, MI	
W. Bloomfield, MI	ehbucsek46@yahoo.com Elizabeth	
jeanniew@provide.net - Jeannie	Romeo, MI	
Hartford, MI	RLloreJ@aol.com -Ramón	
· · · · · · · · · · · · · · · · · · ·	South Haven, MI	
r1obin@localnet.com	tryry@comcast.net -Mary C Riley	
Clare MI		
dmrydzon@aol.com - Debbie	Waterford, MI	
Chelsea MI	steve@vear.com -Stephen	
abufflogal@yahoo.com- Barbara	Hillsdale, MI	
Rochester Hills, MI	hrkolde@comcast.net - Rowena	
dausterberry@sbcglobal.net- Doris	Bloomfield Hills, MI	
Farmington Hills, MI	cheryl obannion@hotmail.com - Cheryl	
_	Phoenix, AZ	
AlanLoisS@aol.com - Alan		
Plymouth, MI	dworthy@usamedia.tv- Douglas	
gdr1237@hotmail.com - Gordon	Grass Valley, CA	
Decatur, MI	lkfrisco@msn.com - Lee	
JoanMcCarthy@sbcglobal.net - Joan	Santa Maria, CA	
Grand Haven, MI	daaog@home.com - Anne	
jackofwb@juno.com - Jack	Southern California	
	decopainter1998@yahoo.com - Jeannie	
W. Bloomfield, MI	Roseville, CA	
denny@power-net.net - Dennis	· · · · · · · · · · · · · · · · · · ·	
Chesaning, MI	Continued next page	

#### SURVIVORS SHARING continued...

eddyc7@peoplepc.com - Edward

tpbrown@frontiernet.net - Tim
Grosse Pointe Woods, MI
jjscg123@adelphia.net - Jane
Chickasaw, Ohio

bashley1@cfl.rr.com - Burnett

Bushnell, FL

cmerrill@cfl.rr.com - Chuck

St. Cloud, FL

deniswahl@comcast.net - Dennis

Sanibel Island, FL

charlesgruner@att.net -Charles

Coldwater, MI and Pharr, TX

JSGrady@aol.com - Jerry

Fort Wayne, IN

beckie44@juno.com - Beckie

Indianapolis, IN

JohnandKeriG@yahoo.com - Keri

**TENN** 

wctubandt@aol.com - Walter

Woodinville, WA

Bobuschi@msn.com -Ursula

Olympia, WA

ppseng@aol.com - Dr Richard Bruno

Englewood, NJ

susanvrm@clear.net.nz - Susan Kerr

New Zealand

The Post-Polio Clinic Center for Physical Medicine and Rehabilitation 13850 East 12 mile Road Warren, MI 48088 Phone (586) 778-4505

# MICHIGAN POLIO NETWORKM, INC. NEW WEB PAGE

http://www.michiganpolionetwork.com

# MICHIGAN POLIO NETWORK, INC. MEMBERSHIP FORM

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

PRINT:
Name
Address
City
State: Zip:
Are you a Polio survivor? ( ) Yes ( ) No
E-mail Address
MEMBERSHIP FEE ONE YEAR \$15.00
MEMBERSHIP FEE FIVE YEARS \$65.00
LIFE MEMBERSHIP FEE\$150.00
I wish to make a contribution to support the
work of the Michigan Polio Network, Inc.
\$
Make check payable to:
MICHIGAN POLIO NETWORK, INC.
AND mail to:

MICHIGAN POLIO NETWORK, INC.

1156 Avon Manor Rd

Rochester Hills, MI 48307-5415

#### MICHIGAN POLIO NETWORK

Board of Directors2010-2011 CHAIRMAN Bruce E. Sachs ps2010 1070 Balmoral St. Mt. Clemens, MI 48043 (586) 465-3104 besachs@sbcglobal.net

SECOND VICE CHAIR
Daniel A. Matakas ps2011
7569 Harrison
Westland, MI 48185 (734) 422-5659

SECRETARY
Dianne L. Dych-Sachs ps2011
1070 Balmoral
Mt Clemens, MI 48043
(586)465-3104
dldych@wowway.com

ASSISTANT SECRETARY
Judy Pasich ps2011
617 Revena Place
Ann Arbor, MI 48103-3639
(734) 623-1252 jpasich@sbcglobal.net

TREASURER Don Pixley 517 Oak St Rochester, MI 48307 (248) 651-0360

ASSISTANT TREASURER
Richard Kugel 2010
2715 Plymouth
Shelby Twp, MI 48316
(586)786-1029 Rick kugel@hotmail.com

LIBRARIAN
Laura Barbour ps2011
1156 Avon Manor Road
Rochester Hills, MI 48307-5415
989-739-4065 denilaur@sbcglobal.net

Susan Burton 2011 40547 Firwood Plymouth, MI 48170 (734) 765-8384 Lucyandbailysmom@aol.com Carl Fenner ps2010 1146 Kettering St Burton, MI 48509-2368 (810) 742-2709

POLIO PERSPECTIVES EDITOR, Vera Hazel 2011 15235 Ackerson Dr Battle Creek, MI 49014 (269) 964-8184 vlhazel38@comcast.net

Jeremy Jaworski 2010 21553 Indian St. Southfield, MI 48033 (248) 350-8948 jjorthotist@yahoo.com

Sharon Kugel ps2010 2715 Plymouth Shelby Twp, MI 48316 (586) 786-1029 Sharon kugel@hotmail.com

Paula Lemieux ps2010 21295 Whitlock Farmington Hills, MI 48336 (248) 474-1817 Plemu@sbcglobal.net

William Messeroll ps2011 13350 Chandler Rd. Bath, M 48808 (517) 641-6398 wwmesseroll@aol.com Barbara Oniszczak ps2011 52 N Plaza Blvd Apt. 428 Rochester Hills, MI 48307 (248) 260-7195 abufflogal@yahoo.com

Pam Spinella 2011 23304 Beverly St Clair Shores, MI 48082 (586) 294-3135 plspinella@sbcglobal.net

William Thiedeman 2011 6537 Ostrum Rd. Belding, MI 48809 (616) 794-9738 uscgbill@pathwaynet.com

MPN WEB SITE http://

SICIAN.

www.michiganpolionetwork.com/

DISCLAIMER!!
ALL MATERIAL IN THIS NEWSLETTER IS THAT OF THE INDIVIDUAL
WRITERS AND DOES NOT CONSTITUTE AN ENDORSEMENT OR APPROVAL BY THE MICHIGAN POLIO NETWORK, INC OR ANY OF ITS BOARD OF DIRECTORS OR POLIO PERSPECTIVES STAFF. IF YOU HAVE PERSONAL MEDICAL PROBLEMS CONSULT YOUR PHY-

Michigan Polio Network, Inc 1156 Avon Manor Road Rochester Hills, MI 48307-5415 Bulk Rate
CAR-RT-SORT
U.S. POSTAGE
PAID
Ithaca, MI 48847
Permit No. 29