

POLIO PERSPECTIVES

VOLUME 30 NO 1 SPRING 2015

Promoting Understanding Through the Michigan Polio Network, Inc. Since 1986

MICHIGAN POLIO NETWORK COLLABORATES WITH OAKLAND UNIVERSITY WILLIAM BEAUMONT SCHOOL OF MEDICINE

When questioned about post-polio difficulties and experiences, one very common complaint from polio survivors concerns their doctors or medical service providers having no knowledge of polio or post-polio issues. With this primarily in mind, your Michigan Polio Network focused its attention on this problem to see if anything might be done.

Three people representing the Michigan Polio Network, Inc. and the general interest of polio survivors, met with officials from the newly instituted Oakland University William Beaumont School of Medicine (OUWB) on March 11. They were Tim Brown, Bonnie Levitan and Mike Davis. The purpose of the meeting was to explore the possibility of introducing the issue of polio to medical students, and to raise the student's awareness of both Post-Polio Syndrome and concerns of polio survivors. The OUWB is striving to bring a unique teaching experience to the medical school, which includes such things as kindness, awareness and the human experience, rather than just viewing the patient as a bundle of facts! They have introduced innovative teaching techniques aimed at achieving their unique goal. Therein is where they are considering introducing the topic of polio to the students.

Those present at the March 11th meeting representing the medical school, were the decision makers of the program, and included the Associate Dean for Medical Education, the Senior Director of Service Learning, the Senior Director of Devel-

opment for the School of Medicine, the Associate Dean for Academic and Faculty Affairs, and the Assistant Dean for Community Integration and Outreach. Several of these people were also Professors of Biomedical Science. It was an impressive group who responded very positively to what the three polio survivors presented to them. They were more than receptive to working with polio survivors in the future and appeared very excited to be able to add the issues surrounding polio to their program. They were also impressed that survivors are an underserved group and that polio epidemics are a global concern! Polio remains a real and present danger and they agreed!

It was exciting to contemplate that the concerns of polio survivors may finally be brought to the attention of young doctors. And if the interest generated at the March 11th meeting is any indication, we will most likely see aspects of polio being introduced to the curriculum at the Oakland University William Beaumont School of Medicine as early as this fall! We are waiting for a suggested plan of action from the University. And we are very excited at this rare opportunity.♦♦

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:

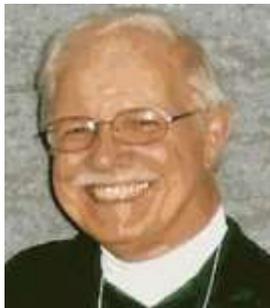
Vera Hazel, Editor
15235 Ackerson Dr
Battle Creek, MI 49014

FROM THE CHAIR

Bruce Sachs, Chairman

Spring 2015

Hopefully by the time you receive this, you will have said good bye to your snow banks and hello to Spring.



In my last article I mentioned that we were in communication with the Oakland University William Beaumont School of Medicine. At this point we can state that both sides have now indeed agreed to (at least slowly) join forces with the purpose of increasing awareness of polio and post-polio in the minds of medical students. We expect to launch our first efforts with OUWB in this fall's curriculum.

Although there are numerous details yet to be completed, it appears that we will have some input on Post-Polio in their curriculum. We will share the details as they become available. I thank Tim Brown, Mike Davis and Bonnie Levitan for their outstanding effort that made this possible. Recently Carol Cain wrote two articles for the Detroit Free Press/ Detroit News on disability.[3-8 & 3-15] Bonnie Levitan was quoted in the second article. This would be a good time to contact Ms Cain and thank her for the articles. Carol Cain can be reached at 313-222-6732 or lcain@cbs.com. There are some new books with a polio theme that will be reviewed before they are purchased. Check the Library Corner for library information.

On our annual Caribbean cruise we met with the leader of the only Post-Polio support group in Hawaii, and other polio survivors from Oklahoma, New Jersey, Kansas, Virginia, Canada, Florida, and Michigan. This gave us a chance to see how other polio survivors are living with PPS.

Although Amigo closed their Wixom store, they continue to sell and service mobility scooters at their Grand Rapids store and the factory in Bridgeport.

For information call 1-800-692-6446

Think warm weather.

Bruce

Michigan Polio Network Board of Directors 2015 meetings:

May 16

July 18

September 19

November 21

Meetings begin promptly at NOON.

Cassel's Restaurant
43003 W Seven Mile Rd,
Northville, MI 48167

INSIDE THIS ISSUE

MPN COLLABORATES WITH OUWB	pg 1
FROM THE CHAIR	pg 2
LIBRARY CORNER	pg 4
OUR SUPPORTERS . . .	pg 3,5
PP ROAD ALONG MEMORY LANE	PG 5
CONTACTS AND SUPPORT GROUPS	Pg 6
LACK OF VACCINE LIFE OF POLIO.....	Pg 7,8
MPN ELECTION BALLOT	pgs 9-11
UNFINISHED BUSINESS by Charlene Bozarth.....	pgs 12-16
SURVIVORS SHARING	pgs 17-19
MPN MEMBERSHIP FORM	Pg 19
BOARD OF DIRECTORS	pg 20



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-Cara and Joe



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LIBRARY CORNER

SPRING 2015

Greetings, Readers! I hope that winter was no worse than "necessary" to you and yours, and that spring, though rather reluctant to really get underway (at least in Southeast Michigan, where I live), will break into birds-singing, flowers-blooming, breezes-warming exuberance ASAP!!

A short column this quarter, as I'm in between books-being-returned and the newsletter deadline, but that cannot be helped. "Timing, timing, timing" is apparently just as important as "location, location, location!"

First off, MPN wants to thank former librarian Barbara Oniszcak, now residing in Nashville, TN, who donated her vast collection, three thick loose-leaf binders' worth, of material regarding polio and post-polio syndrome. Not only had Barb taken the time to collect all of this information, but she had very carefully placed everything into plastic sleeves to preserve it in the binders. A huge effort, to be sure, but those familiar with Barb don't find this to be unusual for a woman who never seemed to stop being curious about either subject. In fact, she is still on the job, sending articles and links every once in awhile.

Anyway, we're trying to figure out how to make this information available, whether to perhaps list each article and take requests from interested members for copies, or to display them on our MPN website. While this is still in discussion, a decision will be made soon, and I should be able to tell you more in the next issue of "Polio Perspectives."

Our book review this time comes from Paula Lemieux, whose fourth-grade grandson's class was assigned the reading of Peg Kehret's memoir



called **SMALL STEPS:THE YEAR I GOT POLIO**. Paula decided that reading the same story would be a good idea, so she borrowed it and got busy. In her review, Paula wrote: "Imagine my surprise & delight! This book is required reading in our grandson's 4th grade class! What an excellent book to educate the non-polio generations about our polio experiences: symptoms, diagnosis, isolation, paralysis, FEAR & vulnerability, rehab, Sister Kenny treatments, & about room-mates, even a smidge on post-polio. It is a great reminder of the powerful effect of love and positive encouragement. A great read."

If you'd like to borrow this or any other of our books, please let me know at 989-739-4065, or at 248-853-5465, or at denilaur@sbcglobal.net.

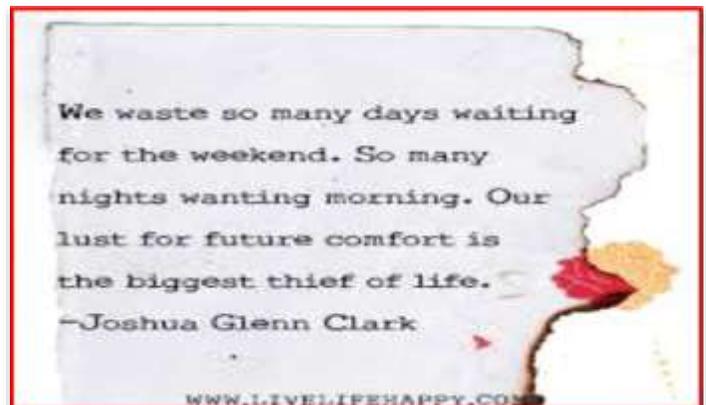
Finally, I had the pleasure of re-meeting Lorraine Sattelmeier, MPN member and author of her polio story, which has been published in a book entitled **ONCE UPON A VERY, VERY LONG TIME AGO**. Lorraine was invited to speak to those of us gathered at the Older Persons' Commission (aka Senior Center) in Rochester for the February Women's Luncheon. Her audience was quite interested in her life story, including the part about her contracting polio.

Since Lorraine's appearance coincided with her birthday, several family members were in the audience, too, making a pleasant afternoon's lunch-and-lecture a more festive occasion.

Well done, Lorraine!!

That's all for now. Please take care!

Laura Barbour, Librarian



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POLIO PERSPECTIVES

“Road Along Memory Lane”

By Vera Hazel, Editor

Awhile back the MPN Board of Directors was considering putting Polio Perspectives on their web page, <http://www.michiganpolionetwork.com/>, to make it available to anyone visiting our site.

I was very excited about this idea because I have a complete set of Polio Perspectives from the very first issue in 1986 to the present on file.

I had been a little concerned that they would be lost if I couldn't put them somewhere for safe keeping. So I started to scan the 1986 First Edition into my computer and sent it to Mike Scharl, our IT Consultant, to place into an Archive in the MPN WEBPAGE.

From then on I spent many hours to scan page by page all the back issues of Polio Perspectives and sent them to Mike. With Mike's expertise in the technical side of sending the issues, I was able to finish the project quickly.

As I was scanning, I was reminded of the many wonderful conferences the MPN held. I especially enjoyed the EXTRA*EXTRA*EXTRA issue of our 11th Annual Conference, “Healthier Health Hiway Two” held in Battle Creek, Michigan. This was a “hands-on” conference in pictures issue. Also, remembering all the great speakers we had and vendors, and all the good and informative articles. In the first and earlier issues you can read about the beginning of the Polio Network and the search for polio survivors at the time when they were experiencing what later became known as the post-polio syndrome.

It has been a very wonderful and informative “Road Along Memory Lane”♦♦♦

Michigan Polio Network, Inc. newsletters, POLIO PERSPECTIVES are now archived in MPN Web <http://www.michiganpolionetwork.com/>.

If you do not have a computer go to your friends or to your local library to access the webpage.

CONTACT AND SUPPORT GROUPS

ANN ARBOR (PPSG)

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

CLIO AREA POLIO SURVIVORS SUPPORT-GROUP

The New Clio Area Polio Support Group is held at the Clio Area Senior Center
2136 W. Vienna Rd. Clio, MI 48420
On the third Friday each month at 9:00-10:30am.
Facilitator is Dennis Hoose phone: (810) 686-0292
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 POST POLIO SUPPORT GROUP

Meets at 1:30pm on the second Monday of spring, summer, and fall months - April through November.
Held in the lounge of Plymouth Congregational Church, 2001 East Grand River Avenue, Lansing, Michigan.
Margaret Nielsen Williams (517) 336-5921
Email: 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
Email: Lysue3@gmail.com
Chuck Bond Rockford (616) 866-1037

INFORMATION CONTACTS

MICHIGAN POLIO COLLECTION LIBRARY

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

MPN WEB SITE

<http://www.michiganpolionetwork.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

FOR LACK OF A VACCINE A LIFETIME OF POLIO



By Marney Rich Keenan
mkeenana@detroitnews.com
In Detroit News 2/13/2015

With almost daily reports of new measles outbreaks across the country, the vaccine debate rages on, more impassioned than ever.

Vaccine opponents cite a host of objections, stemming from religious and philosophical “all natural” views to fears of health risks. All the while, an abundance of studies say those risks are greatly outweighed by the dangers of catching previously eradicated diseases, not to mention spreading them to others.

Last week in this column, a local mother of four explained why she chose not to inoculate her two younger children. This week, a local mother and grandmother explains why she supports vaccines.

Bobbi Stevens, 60, of Royal

Oak was exposed as a baby to polio, a historically devastating disease that was eliminated in the United States by 1979 thanks to widespread vaccination.

While the vaccine was introduced in April 1955, children under a year were thought to be too young to receive the inoculation. Stevens was 5 months old in 1955 when she contracted paralytic polio. “I have lived with the consequences of being exposed to that disease every day of my life,” she says. “I never walk. I will never dance. I will spend my whole life in a wheelchair. I was too young for the vaccine, but perhaps, if the person who inadvertently exposed me to the polio virus had been vaccinated, my life story would have been much different.”

Completely paralyzed from her lower back down, Stevens, 60, has been wheelchair bound for the last 20 years. Until she was 40 years old, she was able to



Family photo
Bobbi Stevens contracted
polio at 5 months old.

walk with braces and crutches. But doctors said the cumulative pressure on her arms was the stress equivalent of a major league pitcher. About 20 years ago, “the doctors said if I want to retain the use of my arms I was told to sit down and not get up.”

Stevens is especially concerned about vaccinations because the highly contagious nature of these once-conquered diseases. She notes that measles, which can be fatal, is more contagious than almost any other disease. According to the University of Michigan School of Public Health, the reproduction rate with measles —the likely number of people to be infected from a single infectious case, is 12 to 18 people.

Measles is spread when an infected person sneezes, coughs or talks. The virus can stay in the air for up to two hours. Also, people with measles can spread the disease starting four days before the rash begins until four days after it appears.

Stevens says her parents were not able to determine how she contracted polio. “They didn’t know anyone who had an active case of polio at the time. But people can get mild cases and not even know they have it. And, if you are out in society, you are going to be shedding the virus whether or not you have any symptoms.”

Stevens says she knows personally people who still believe there is a link between autism and vaccines, even in the face of more than a dozen scientific studies discrediting British physician Andrew Wakefield, who originally posited the connection. “They still believe it,” Stevens says. “Without any medical training or any credentials that would qualify them to make such judgments.”

As far as other perceived risks, Stevens is unequivocal. “I’ve been a patient all of my life. Everything in medicine is a risk versus benefit proposition. Any doctor will tell you anytime you have any medical procedure or even get a prescription for an infection, there is a risk for complication.

Continued next page...

The Question:

DO YOU LIKE GETTING OLDER???

I can hit the golf ball any way I can and laugh if it goes in the lake. Them's the breaks. I'm just happy I can still hit that golf ball.

As I've aged, I've become kinder to myself, and less critical of myself. I've become my own friend.

I have seen too many dear friends leave this world, too soon; before they understood the great freedom that comes with aging.

Whose business is it, if I choose to read, or play, on the computer, until 4 AM, or sleep until noon? I will dance with myself to those wonderful tunes of the 50, 60 & 70's, and if I, at the same time, wish to weep over a lost love, I will.

I will walk the beach, in a swim suit that is stretched over a bulging body, and will dive into the waves, with abandon, if I choose to, despite the pitying glances from the jet set. They, too, will get old.

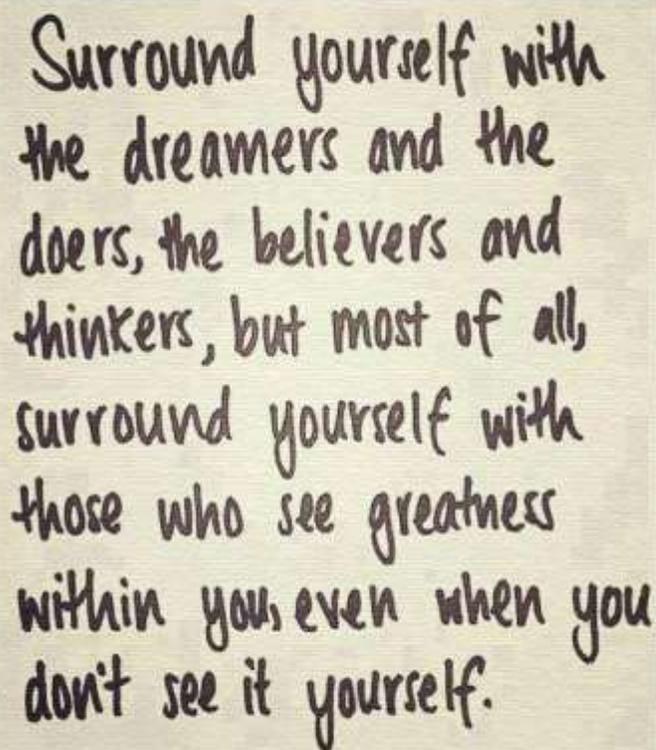
I know I am sometimes forgetful. But there again, some of life is just as well forgotten. And, I eventually remember the important things.

Sure, over the years, my heart has been broken. How can your heart not break, when you lose a loved one, or when a child suffers, or even when somebody's beloved pet gets hit by a car? But, broken hearts are what give us strength, and understanding, and compassion. A heart never broken, is pristine, and sterile, and will never know the joy of being imperfect.

I am so blessed to have lived long enough to have my hair turning gray, and to have my youthful laughs be forever etched into deep grooves on my face.

So many have never laughed, and so many have died before their hair could turn silver. As you get older, it is easier to be positive. You care less about what other people think. I don't question myself anymore. I've even earned the right to be wrong.

So, to answer your question, I like being old. It has set me free. I like the person I have become. I am not going to live forever, but while I am still here, I will not waste time lamenting what could have been, or worrying about what will be. And I shall eat dessert every single day (if I feel like it). ♦♦



Surround yourself with the dreamers and the doers, the believers and thinkers, but most of all, surround yourself with those who see greatness within you, even when you don't see it yourself.

FOR LACK OF A VACCINE,

CONTINUED...

There is always the possibility that something could go wrong; you weigh the benefits and risks accordingly.”

The point of immunizations, she says, is to not only protect your own child, but others as well.

“We have to think unselfishly as well as selfishly.

You’ve got a wonderfully healthy child who can be protected and you can also do so much good for others by having that child vaccinated.”

Above all, Stevens does not want anyone’s sympathy. She is neither martyr nor hero. “This is not a pity party,” she says. “I have a good life. I married a good man. We have two children and a granddaughter. I’ve had a wonderful life.

“But I know these parents would be grief-stricken if they saw their child come down with what I have and know that it could have been prevented.” ♦♦

-----FOLD-----

From:

PLACE A
FIRST CLASS
STRAMP HERE

Timothy P. Brown
1530 Fairholme Rd.
Grosse Pointe Woods, Michigan

-----FOLD-----

MICHIGAN POLIO NETWORK, INC. BOARD OF DIRECTORS

OFFICIAL ELECTION BALLOT TWO YEAR TERM 2015-17

You may vote for a total of eleven (11) persons, including any write-in which you may add below the ballot. Please provide the required information for any write-in candidates, as well as a brief biography stating your/his/her intentions and interest.

Write this on a separate sheet of paper and place it inside the ballot self-mailer (*you will need to tape the sides of the fold-up envelope*).

The Annual Meeting of the Michigan Polio Network, Inc., will be held on Saturday, May 16, 2015 at Cassel's Family Restaurant, 43003 7 Mile Rd., Northville, Michigan at 12:00pm. We encourage all interested in the future of the Network to attend.

2015 NOMINEES ARE AS FOLLOWS: CIRCLE YES FOR EACH CHOICE

Laura Barbour (PS)* _____ YES

Dianne Dych-Sachs (PS)* _____ YES

Gwen Dyc –Schwendenmann* _____ YES

Vera Hazel* _____ YES

Daniel Matakas (PS)* _____ YES

William Thiedeman* _____ YES

**Incumbent (PS) Polio Survivor*

WRITE-IN CANDIDATES (PLEASE PROVIDE STREET & E-MAIL ADDRESS, AS WELL AS ABOVE-MENTIONED BIOGRAPHICAL INFORMATION ON A SEPARATE SHEET OF PAPER AND SEND ALONG WITH YOUR BALLOT):

1. NAME _____ (PS?) Y/N

2. NAME _____ (PS?) Y/N

3. NAME _____ (PS?) Y/N

Please mark your ballot and remove this page from your copy of Polio Perspectives.

Turn the page over, write your return address in the appropriate place, fold the page in thirds according to the lines, tape the newly-made “envelope” closed, put a stamp in the upper right corner, and mail the ballot.

It must be postmarked no later than April 30, 2015 in order to be counted.



LAURA BARBOUR LAURA HAS SERVED AS THE MICHIGAN POLIO NETWORK'S LIBRARIAN SINCE 2007. SHE HAS BEEN ON THE MPN BOARD OF DIRECTORS SINCE 2007. LAURA HAD NON-PARALYTIC POLIO WHEN HER BROTHER AND TWO COUSINS HAD THE PARALYTIC VIRUS. LAURA ENJOYS HER TWO MPN JOBS, AND HOPES TO CONTINUE SERVING NETWORK MEMBERS IN ANY WAY SHE CAN.



DIANNE DYCH-SACHS I HAVE BEEN A POLIO SURVIVOR SINCE 1952. I WORKED IN THE MEDICAL FIELD UNTIL POST-POLIO SHORTENED MY CAREER MORE THAN 10 YEARS AGO. IN 2005 I WAS ELECTED TO THE BOARD AND RE-ELECTED IN 2007, 2009, 2011, & 2013. I PRESENTLY SERVE AS SECRETARY. I ALSO AM ONE OF THE FACILITATORS AND TREASURER OF THE SOUTH-EAST MICHIGAN POST-POLIO SUPPORT GROUP. FOR THE PAST 7 YEARS I HAVE ALSO BEEN A GREETER AT THE ST. JOHN POST-POLIO CLINIC IN WARREN. WHILE ON THE BOARD I WORKED ON THE NETWORK CONFERENCE IN 2005, 2009, 2011, & 2013. AND WAS A MEMBER OF THE PLANNING COMMITTEE FOR THE 2007, 2009, & 2011 CONFERENCES. I ATTENDED THE 9TH POST-POLIO HEALTH INTERNATIONAL CONFERENCE IN ST. LOUIS IN 2005, THE POST-POLIO ASSOCIATION OF SOUTH FLORIDA'S INTERNATIONAL CONFERENCE IN MIAMI IN 2007 AND THE 10TH POST-POLIO HEALTH INTERNATIONAL CONFERENCE AT THE ROOSEVELT INSTITUTE FOR REHABILITATION, WARM SPRINGS, GEORGIA IN APRIL 2009.



GWEN DYE-SCHWENDENMANN IS NOT A POLIO SURVIVOR. SHE SERVED ON THE MPN BOARD FOR A YEAR. HER HUSBAND RICK IS A BOARD MEMBER AND POLIO SURVIVOR. SHE RETIRED FROM UNITED AIRLINES TEN YEARS AGO.



VERA L. HAZEL IS A NON-POLIO SURVIVOR, HAS BEEN ON THE MICHIGAN POLIO NETWORK, INC. BOARD OF DIRECTORS FOR NINETEEN YEARS. SHE IS THE EDITOR OF THE MPN NEWSLETTER, POLIO PERSPECTIVES.



DANIEL A. MATAKAS IS A POLIO SURVIVOR. DAN JOINED THE MPN BOARD OF DIRECTORS IN 2001 AND BECAME CHAIRMAN OF THE BOARD IN THE SUMMER OF 2002. HE WAS CHAIRMAN UNTIL THE FALL OF 2004.



WILLIAM THIEDEMAN JOINED THE MPN BOARD OF DIRECTORS IN 2003 BECAUSE HIS WIFE IS A POLIO SURVIVOR AND HE WANTED TO FIND OUT HOW HE COULD HELP HER WHILE HELPING TO SUPPORT THE BOARD.. HE IS A NON-POLIO SURVIVOR

UNFINISHED BUSINESS: Support Group Members Confront Feelings Surrounding The Late Effects of Polio

By Charlene Herndon Bozarth, O.T.R.

April 1987

“Before people can reach for new dreams, they need to grieve the loss of old ones.”

To the estimated 300,000 polio survivors in the United States today, polio is not a thing of the past. Although the disease itself was virtually eliminated in the mid-1950's, those of us who contracted polio prior to that time are now facing new medical problems, commonly know as the late effects of polio, which have taken us by surprise. The most frequently reported symptoms are extreme fatigue, new muscle weakness, new muscle and joint pain, sensitivity to cold, and respiratory problems. Neither we nor the medical community know why this is happening or what we can expect in the future. These new physical problems are affecting many other aspects of our lives. In response, publications, conferences, clinics, statewide networks and support groups are being organized across the country.

Shortly after the Polio Survivors' Support Group in Lansing, Michigan was formed, in the winter of 1985, two licensed psychotherapists, Martha Aldenbrand, Ph.D., and Marilny Sylvan Thompson, Ed. S., who were each seeing a polio survivor in their private practice, decided to offer a 10-week psychotherapy group for polio survivors, meeting once a week for an hour and a half. Rather than announcing this at a support group meeting, written notices were sent out to each post-polio on the support group mailing list. This was so people could think it over, make a decision and sign up, all privately. Otherwise, the social stigma still attached to being “in Therapy” might have prevented some needy individuals from joining the group.

At that time there were 60 post-polios on the support group mailing list—of those, seven registered for the therapy group, five women and two men. After one or two sessions, the men dropped out—one was preparing to move out of state and the other was asked to work overtime on his job. Two curious factors emerged: 1) Everyone was primarily concerned about coping with the late effects of polio when they came, yet the main topic as the weeks went by was the past. A great deal of troublesome old emotional damage surfaced, centering around rage, grief, shame, fear, hurt and loneliness. 2) Those who registered for the group had non-severe disabilities—either a slight to moderate impairment of the lower extremities or no physical impairment at all! The benefits of the group prompted the addition of another eight sessions, a total of eighteen.

The advantages of working on our problems in a group setting were many. Various topics and feelings could be shared with others who had been through the same experience. A camaraderie developed as we realized, with relief, we are not alone, not so different after all. It helped us break through our awful isolation. We felt “normal” for a change. The courage to be honest, rather than nice, often came forth. There was the opportunity to practice confronting our feelings in a safe environment, rather than avoiding them. During all of this, the therapists acted as guides with their skills of listening, analyzing and giving feed-back on what was taking place. And they offered helpful new ways for us to think about particular points. The therapists emphasized the importance of resolving the past because people tend to deal with what is happening to them in the present the same way they dealt with things in the past. In other words, if one's previous response to loss was denial and depression, one is likely to repeat that pattern when facing another loss.

John Schneider, Professor of Psychiatry at Michigan State University, internationally known grief

Continued next page...

UNFINISHED BUSINESS *continued...*

and loss authority, and author of **Stress, Loss and Grief**, says that since all significant losses result in a grief response, it is important that we examine our losses and understand the grieving process so we can move through and beyond our grief, grow from it, and have an easier time with future losses. He also says that a new loss can trigger the unresolved feelings around old loss, and that “unresolved loss may be one of the most significant factors in health and disease.”!

The polio experience is initially an experience of loss, both at the time of the original illness and again at the onset of the late effects. It seems safe to say that many, or maybe most, polio survivors did not grieve at the time of their first bout with polio because the mental health field was not as advanced 50, 40, even 30 years ago, as it is today. Consequently, medical professionals, our parents and friends, society in general, did not approach loss and grief with much understanding. We were blocked in our initial grief because we were not part of an accepting, encouraging community. In fact, we were actively discouraged from acknowledging and grieving that which had happened to us. With the best of intentions, we were advised to be thankful we had lived and had come through as well as we had, to get on with our lives and put the past behind us.

The potential for the loss of trust in a safe and fair world, in the power of our parents, doctors and prayers, was there for everyone, when those who had complete recoveries and those who were mistakenly thought to be too young to know what was happening. Clark Moustakas states in **Loneliness**, “The possibility of being abandoned or left alone is the most serious threat to the child’s whole existence. Of the many kinds of temporary abandonment, no experience is more desolating to a child than having to be in a hospital alone...terrifying fears, anxiety, and traumas...survive long after the physical defect has been rectified.”

John Schneider tells us that when a serious loss

happens to a young child, it is more devastating than for an adult because a child hasn’t yet formed an adequate world-view and is therefore apt to assume things she/he cannot check out. These assumptions are then turned into self-fulfilling prophecies such as, “When I really need someone, I’ll be abandoned.” Our therapists added that this is true for teenagers as well. Since most of us contracted polio as infants, children or teenagers, our losses were sustained during a most vulnerable time.

Being suddenly whisked away from everyone and everything familiar for an extended period of time with little, if any, preparation or support isolated and shunned for having a contagious disease, and in a situation where others had all the control—this while in a state of extreme pain, paralysis and fear of dying, left its mark. Our members reported evidence of resulting emotional states which are still with us today affecting our actions in very real ways.

The explanation for the fact that those who came to the group had non-severe disabilities may very well lie in some of the conclusions of a study of college handicappers for a doctoral dissertation done by Russell Scabbo, Ph.D., also at Michigan State University. He found that handicappers with non-severe disabilities suffer from particular stresses which have not before been recognized and are often caused by: 1) Capacity for denial, 2) High expectation of performance from others, and 3) Lack of “belongingness” in either the world of the able-bodied or that of the seriously handicapped.

Our group keenly identified with these sources of stress. Denial has been practiced in an accomplished way not only by us, but those around us. We find it so wearing to need to explain, day in and day out, year after year, that we cannot keep up with our able-bodied peers—explaining that we’re not lazy, not spoiled, and not kidding. There is the constant, exhausting striving to function as an able-bodied person which is imposed on us by

Continued next page...

UNFINISHED BUSINESS *continued...*

society and by ourselves. We agreed that not fitting into either group put us in a “twilight zone,” adding to the burden of being different, increasing the feelings of being the odd one and alone. Trying to function in the world of the able-bodied leaves us feeling very second-rate by comparison. We simply have not received support and assistance as have those with severe disabilities. As Dr. Scabbo has stated, we really do not have a place in the system. And those of us with non-severe handicaps often feel tremendous guilt over our psychological problems when we were indeed so “fortunate.” But as Ann Kaiser Stearns advises in Living Through Personal Crisis, “You... have to give up the idea that you aren’t entitled to mourn because others have greater sorrows. All of us have both the right and the responsibility to take our losses seriously.” In addition to that, psychic pain is subjective. It’s not possible to measure one person’s pain and compare it to the pain of another.

It soon became obvious in our group that a great deal of energy was still tied in to old issues, markedly reducing the energy we have available to cope with today’s problems, and not just with polio-related problems, but right “across the board.” A visible paralytic handicap affects every relationship, alters the attitudes of others, and challenges one’s self-esteem. It requires meticulous minute-by-minute monitoring and control to an extent quite unperceived and unimaginable by the able-bodied. This condition of being handicapped generates a range of emotions, whether expressed or not, that must be dealt with, not just at onset, but continuing through out the rest of the patient’s life,” writes Hugh Gregory Gallagher, a polio survivor and author of FDR’s Splendid Deception. Our group bears witness to the fact that these statements are true regardless of the degree of one’s impairment and to the fact that if this range of emotions isn’t dealt with directly, the feelings are likely to smolder, fester and color every aspect of one’s life. Several years ago Esquire Magazine carried an ar-

ticle entitled, “The Summer Before Salk,” which poignantly describes the emotional atmosphere of the epidemic years. In telling of the young patients’ reactions he said, “Some moaned. Some cried. Some nurtured cynicism. Some grew detached. Some were swept away by ungovernable cheerfulness. Rarely did anyone scream in rage, however common the feeling. All were overpowered, all were taught respect—for the unseen powers of nature, the smallness of human aspiration, the capacity for sudden and irrevocable change, the potential of chance.”

In keeping with this, we uncovered a number of common emotions. There was rage at what had been taken from us as children, at not receiving the support we needed; at having to be overly happy, kind and loving in order to make up for being disfigured and making so much work for those around us when we were ill; at having to cover up these feelings; and now at having to face another round with polio in the form of the late effects. Shame was a big issue—the humiliation and self-loathing that comes with being disfigured and the accompanying painful self-consciousness and rejection. We experienced fear of abandonment at the time of our hospitalization and again now as we face new limitations. We wonder if those close to us will decide they either can’t or won’t want to take it. We assume others will resent taking care of us. We felt despair at the possibility of becoming physically helpless. Old feelings of being overwhelmed and without control flood back in on us. We’re worried that we’re not as flexible now as we were when we were children. There was guilt for causing others inconvenience, for not having perfect bodies. And there was the hurt of knowing someone wishes we were different than we are. And, finally, the loneliness that has come from not being able to discuss these feelings openly. We found ourselves withdrawing, our worlds becoming smaller and smaller.

We identified a number of defense mechanisms, or

Continued next page...

UNFINISHED BUSINESS *continued...*

methods of coping, that we have used. Denial was a major method. This may have been an instinctively wise choice since psychotherapy was not readily available at the time. Minimizing was used to make our losses more bearable. We took comfort in the fact that at least we could still do this or that. We often became super-independent and super-achievers to prove that we were as good or better than our able-bodied peers. We did this also to fortify ourselves against our fears of being weak and helpless. Dissociation helped us detach from our frightening situation, a kind of self-hypnosis to deaden the pain. We became overly pleasing and placating to others to make up for being defective and a burden. Often we felt we needed to apologize for just being! While defense mechanisms serve a useful purpose, up to a point, beyond that they become destructive. Often they don't work indefinitely. New ways of coping need to be adopted. As an all female group, we returned again and again to our concerns over our appearance. We were unanimous in our distaste of having to wear utilitarian-style shoes, of wanting to wear pants or high boots to hide our legs, of feeling dreadful in a bathing suit. Our self-worth, femininity and attractiveness seemed very much at stake even though we knew we ought to regard these matters as superficial, that the inner person is supposed to be what counts. These things have had a definite impact on our contacts with the opposite sex. Hospital care experience and attitudes was another topic which came out. During our polio illness and subsequent surgeries, we had often been subject to rigid, cold, and controlling (even sexually abusive, in one case) behavior on the part of the hospital staff who were medically, but not emotionally, correct. The medical treatments were often frightening and painful. This left us with a tendency to regress in our reactions to present hospitalizations and treatment, even when unrelated to our polio residual. It is not unusual for us to resort to child-like behavior, which, when not understood in the proper context,

seems inappropriate to others and embarrassing to us. Old memories are reawakened at such times. We discussed the aggravating folk remedies, or health hints, frequently offered by our well-meaning associates: "If you would only eat more bananas, you wouldn't be so depressed." Or, "If you would only get out and do more, you wouldn't be so tired." This makes us doubt our own judgment at times and raises our frustrations.

Long-standing symptoms were reported that seem typical of the Post Traumatic Stress Disorder, common today among Vietnam veterans. Among the symptoms of PTSD are chronic weepiness, nightmares, night sweats, flash-backs, hyper-vigilance, and emotional numbing.

We spoke often of our growing interest in the spiritual dimension—of the specific ways in which our personal understanding of the meaning of life, the universe, and our particular roles, has enlarged and deepened, putting things in a different perspective, giving us a more solid foundation on which to work through some of our pain and live with that which can't be eliminated. This topic became quite exciting! If this small group is typical, and apparently it is in a number of ways—based on hundreds of private conversations I have had in my work with polio survivors, both at the state and local level over the past several years—many of us have a lot of unfinished business in the emotional realm. Could this unfinished business be at least one factor in the cause of the late effects? Considering the intricate relationship now commonly recognized between the mind and body, and considering John Schneider's observation that unresolved loss plays a prominent part in health and disease, it seems quite reasonable. It certainly will be a factor in how well we handle the late effects.

The anguish of the past or present does not have to dominate our lives. We can have a more proactive, joyous, healthier way of being. We need to begin by identifying and mourning our losses. In this way, we can eventually let go of them. With the right

Continued next page...

UNFINISHED BUSINESS continued...
kind of assistance we can begin transcending. It's not too late. We can take advantage of some or all of the means available to us: going into therapy, group therapy or one-to-one, or both; joining a support group and participating in polio activities; reading related books and articles (spiritual as well as psychological materials); talking extensively with an understanding family member or close friend; thinking things through as thoroughly as possible; and allowing adequate time to assimilate it all. Problems that took time to develop will need time to be resolved. It will not always be a smooth, upward movement, but rather one of ups and downs, starts and stops along the way, nevertheless in an upward direction.

We need to remember that we have adult capabilities now for such things as creative problem solving, verbal expressiveness, humor, kindness, empathy, wisdom, etc. These are precious inner resources which will help us cope with the future. We need also to remember that the future always holds unforeseen pleasures and opportunities, as well as problems.

Our lives will probably not be what we had envisioned in the beginning, but they can still be good in a different way. While the pain may never go away completely, it can become significantly less. By constructively examining our pain we can grow and develop a depth, a strength and a sensitivity that is not likely in those who have not had many problems. So, in some very important respects our lives can be even better.◆◆◆

(Editors note. The above article was a speech made by Polio Network chair Charlene Bozarth in 1987 possibly at a support group workshop.)

**Give this PLENTY of thought,
Cover the Answer and don't
cheat!**

See if you can figure out what these words have in common.

This isn't a joke.

**Banana
Dresser
Grammar
Potato
Revive
Assess
Uneven**

Are you peeking or have you already given up? Give it another try... you'll kick yourself when you discover the answer. Go back and look at them again; think hard. OK... Here you go... hope you didn't cheat. This is so cool.



ANSWER

In all of the words listed, if you take the first letter, place it at the end of the word, and then spell the word backwards, it will be the same word.

The words 'racecar,' 'kayak' and 'level' are the same whether they are read left to right or right to left (palindromes). (Yep, I knew you were going to "do" this one.)

There are only four words in the English language which end in "dous": tremendous, horrendous, stupendous, and hazardous. (You're not doubting this, are you?)

There are two words in the English language that have all five vowels in order: "abstemious" and "facetious." (Yes, admit it, you are going to say, A E I O U)

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 Hazel3SGS@comcast.net to get on the list! Also include your city and state. Happy Sharing!! ☺

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