



The Polio Post

Ohio Polio Network Newsletter

*MERRY CHRISTMAS &
HAPPY NEW YEAR 2011*

On behalf of Pat Kelly, myself, and the members of the Ohio Polio Network Board, I would like to wish each of you and your families a very merry Christmas and the best of health in the New Year. Alice Sporar

Editor: Alice Sporar Winter 2010 Issue



Ohio Polio Network Conference: October 16, 2010

By Marie Smith

About 80 persons attended the one-day conference at beautiful Tuscora Park in New Philadelphia OH, some coming from as far away as Indiana and West Virginia. The featured morning speakers came from Johnstown Pa.

Dr. William DeMayo, the medical director of the Neuroscience Specialty Clinic at the JP Murtha Neuroscience & Pain Institute, spoke on "Best Practice Medical Care: Implications for Polio Survivors." He presented a holistic model of wellness which incorporates the mind, body and spirit, emphasizing that one could not be treated effectively without treating the others. Anyone wishing to be treated at the Johnstown Post-Polio Clinic must fill out an extensive medical history which is used to determine the specialists who will interview and treat the patient. The treatment is customized to the patient.

Dr. DeMayo stressed the importance of each patient taking responsibility for his/her own health. A person's attitude often determines how much improvement he/she will make: "What can I do . . .?" Instead of thinking "I can't," think "I don't know how to . . ." or "It's difficult for me to . . ." Instead of "I need to . . ." or "I have to . . ." or "I should . . .," which are disabling and stressful, try "I **want** to . . ." What are we willing to do in order to get what we want?

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By Jude King



TELL YOUR STORY

From Henry's Desk

For the last fifteen years I have attempted to write a column or essay on some subject related to Post Polio Syndrome (PPS) or a life with polio in almost every issue of the *Deja View*. On my computer hard drive I have stored eighty-three articles, which, if you divide that number by fifteen years, the answer is 5.5. The *Deja View* is published six times a year, and almost every issue has some missive by this author. Some of my articles originate as inspirations or I get a clue from something someone says or writes to me. In reviewing my articles, I have noticed that, on several occasions, I have encouraged polio survivors to write their stories. This article is an effort to get readers to begin that task. I have started writing my story, but I admit it is a laborious undertaking. Your story might be equally laborious, or maybe it will take less time. If you feel you cannot write it yourself, perhaps someone of the younger generation would be willing to listen to your story and write it down for you. I have learned that this method of getting an oral history can be most effective with other groups. It works very well for veterans of World War II and for Holocaust survivors. Compared to those two events, polio did not kill as many people, but polio did mark and distinguish us in a way that should not be forgotten. Below is a suggested outline to use, but you are certainly encouraged to write it with your emphasis and narrative style. I would encourage writing in the first person.

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Tentative Date for the next OPN Board Meeting
Saturday, April 16, 2011
Westerville, OH Library
Noon - 3 PM

OPN members are welcome to attend. OPN is always looking for members interested in becoming Board Members. If you are interested or have agenda items for the Board Meeting, please contact Patrick Kelly, pkelly03@sprynet.com

Tell Your Story continued from page 2...

Write about identifying data, such as birth date, sex, and place of birth.

When and where did you contract acute polio and how old were you?

Describe whether it was a city, rural, or small town.

Describe how you probably contracted polio.

Describe all the details of your acute polio illness, such as early symptoms, who made the diagnosis, and memories of being hospitalized in isolation and thereafter in a hospital.

Identify the hospital's name and location. If you remember, write about when you were admitted and memories related to admission, and when you were discharged. Also, describe when you learned that you had polio and who told you.

If you remember names of doctors, nurses, physical therapists or others, write about them, the good and the bad.

Describe in as much detail as you recall, about the damage to your body during acute polio.

Describe your condition when you left the hospital and whether you used any orthotic devices upon discharge.

Describe the makeup of your family at the time you had polio and what impact polio had on your family at that time and even later.

Following acute polio, describe the time period when you functioned at your maximum physical capacity after polio, even if you feel you had completely recovered. During this good time period, describe what you could do and not do. After maximum recovery, did you still need some assistive devices such as braces, special shoes, crutches, or even wheelchairs?

If you had visible signs of polio, describe them and how that made you feel.

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News & Notes

• **Post- Polio Information**

For information on post-polio Issues, join Post-Polio Health International. Memberships run from \$30 to \$150 per year, depending on what level you choose. For more information, contact Post-Polio Health International at 314-534-0475, 4207 Lindell Blvd. #110, St. Louis, MO 63108, or www.post-polio.org.

Educating ourselves about the effects of post-polio syndrome is important and may save our lives.

Michigan Polio Network
Conference
August 20, 2011
More Details as they
become available.

Website:
[www.michigan
polionetwork.com](http://www.michigan
polionetwork.com)

Tell Your Story continued from page 3...

Write about your successes and failures in life that had anything to do with polio. For example, did polio help or hinder you in pursuing an education? Did it help or hinder you in getting a job or having a career? If you were a homemaker, did it cause problems for you in that activity? Did it have an impact on your life in other personal ways, such as marriage or having children?

Describe the challenges that you met and those that you were unable to accomplish.

Write about your religious faith, if it was a factor in living with polio past and present.

Of course, you should write about PPS and its impact on your life. You can follow some of the same factors in describing your life with PPS-- the onset, the progression, and the new limitations.

From your life with polio and PPS, what words of wisdom would you like to offer?

I strongly encourage all polio survivors to make an effort to write your story. The generations that will follow you should know of your unique experience. Let me know if I can be of any help.

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Reprinted from Second Time Around, Boca Area Post Polio Group, Boca Raton, FL, November 2010.

Reprinted from Polio Deja View, Central VA Post Polio Support Group, Richmond, VA, Oct/Nov 2009.

A REQUEST FOR PARTICIPATION IN A SURVEY

Big Island (Hawaii) polio survivor Jean Hartley has been commissioned by the national magazine, PN, published by the Paralyzed Veterans of America, to do an article on post polio syndrome. Although Jean will write the article through first person experiences, she is interested in different points of view, different personal stories.

Jean is asking members of the Network in their 50s, 60s, and 70s, who are experiencing PPS symptoms, to complete a simple questionnaire as background data for the article. The data will be anonymous and confidential unless you care to share your name.

The article will not be from the medical point of view, but an honest, realistic, account from men and women going through recent new physical pain, energy loss, or loss of strength - characteristics of PPS. The questionnaire can be completed by email or snail mail. Your participation is voluntary, without remuneration.

If you would like your voice to be heard in a national magazine for people with disabilities, please contact Jean Hartley at 808-769-4489 (Kailua Kona) or Jeanmhartley@yahoo.com. Please view her website disabledadventureshawaii.com and read her seven magazine and newspaper published articles about disability under "About Jean."

Jean is available to answer your questions by phone before you commit to responding to the questionnaire. She is grateful for your interest and participation.

Reprinted from Hawaii Post Polio Network, HI, June 2010.

Reprinted from Second Time Around, Boca Area Post Polio Group, Boca Raton, FL.

On Nov. 17, the Mid-Ohio Valley Post Polio Support Group had a successful Christmas and Thanksgiving Party at the Golden Corral in Parkersburg. Fourteen people attended. They played games and exchanged holiday gifts.

This fall the Group mourned the death of two long-time members, Edwin Dils and Wendel Littrell. We remembered them by making donations in their names to the Wood County Society.

From January to April, the Group will have Dutch treat luncheons on the third Monday of the month at 12:30 at the Golden Coral, weather permitting (cancelled if Wood County schools are closed or delayed). Everyone is welcome to attend but we appreciate prior notification so that we have a rough estimate of the number attending (email jagp@suddenlink.net). We rearrange the tables to enable people to talk to each other.

Regular meetings will resume for May and June at Health South in Parkersburg on the third Monday of the month at 5:00 p. m.



Highlights of the Ohio Polio Network Conference

By Warren and Judy Peascoe

On Friday, Oct. 15, a number of conference attendees, who were spending the night in New Philadelphia, met at Denny's for dinner and a gab session. Someone suggested that at the next conference, dinner the night before should be better publicized.

About 70 polio survivors and their supporters gathered at Tuscora Park in New Philadelphia, OH on October 16, 2010 for a one day conference on post-polio care and a reunion of friends. These included four polio survivors from the nearby Amish community and a number of their family members.

During registration, breakfast rolls and beverages were served. Various handouts were available for conferees to select.

Winnie Walker from New Philadelphia and Pat Kelly, President of OPN gave welcoming remarks

William DeMayo M. D. Medical Director Neuroscience Specialty Clinic at JP Murtha Neuroscience and Pain Institute. gave the keynote talk on *Best Practices in Medical Care: Implications for Polio Survivors*.

Janet Goodard, RN, BSN, CCRC, CCAP and Research Nurse Coordinator at JP Murtha Neuroscience and Pain Institute gave a talk on past, present and future research being carried out on polio survivors at the Institute.

A three course meal was then served.

Lee Owen, Mobility Consultant for the Rascal Company gave a short talk and a demonstration of wheelchairs and scooters.

A short OPN meeting followed at which Board Members suggested by the nominating committee were elected. Joan Prior presented Pat Kelly with the Bernice Krumhansl Award for years of service to OPN.

Door prizes were then drawn. Thanks to Winnie's hard work there were enough prizes that almost every family attending got a prize.

Many thanks to the people who worked hard to organize the conference especially Pat Kelly as OPN president, Winnie Walker who obtained the site and organized the food, and Brenda Ferguson who arranged the program.

*Warren and Judy Peascoe
Mid-Ohio Valley Post Polio Support Group*

Second Best

By Jude King

Don't be second Best!
'Though I am a little smarter
That's not a fair request
I wish that I could tell them
How I long for them to know
I'm behind before I've started
'cause I had polio!

Just try a little harder
For me life's rules are different
Why, I still don't know
I'm not allowed self pity
And challenge makes me go
And most of the time I've pulled it off
So well you'd hardly know
There's any handicap at all
'cause I had polio

The problem is I'm wearing out
From years of trying hard
It's like I've run a marathon
And missed the finish by one yard
Now, I must learn to take life easier
For reasons that don't show
And my good seems not good enough
'cause I had polio

I'm not asking for excuses
Or even sympathy
All I'm really claiming
Is permission to be me
Yes, I must strive for excellence
I just want someone to know
Mine may not be
The same as yours
'cause I had polio

Originally written after 1st Polio Evaluation

NRH 1987

Jude King

Jude: 24-25

As part of his presentation, Dr. William DeMayo read the poem, "Second Best" written by Jude King. In response to many requests, we have provided the poem here. Our thanks to Jude King for allowing us to share this wonderful poem with you.

Ohio Polio Network Conference continued from page 1...

Dr. DeMayo also stressed the importance of exercise for Post-Polio people. The trick is to figure out how much one is able to do without doing harm to oneself. He shared a continuum with no exercise at one end and too much at the other end, with the right amount somewhere in between. When a person does too much exercise and experiences negative results such as pain and fatigue, he/she must start over somewhere less than their "right amount" and again work toward their goal. It is up to the individual to determine what is right for him/her.

Janet Goodard, RN, BSN, CCRC, CCAP & Research Nurse Coordinator at JP Murtha Neuroscience & Pain Institute, told us about the variety of research which has been done and which is presently in progress at the institute.

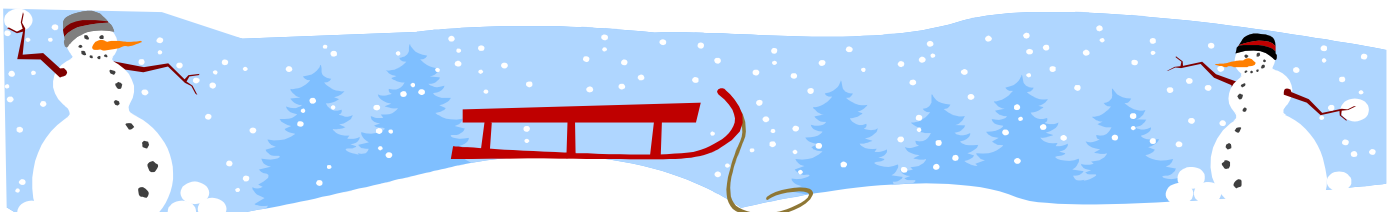
The small Cognitive Fatigue study, completed in 2009, showed that "the PPS group has no greater tendency toward cognitive fatigue than the non-PPS group." A Non-fatiguing, Isometric Exercise intervention was designed to teach stress management, non-fatiguing exercise strategies, and self-management skills; it was completed in 2003. A Polio Survivor Registry has been established "to provide a description of polio survivors based on demographics, to identify trends in polio history, PPS, and interventions, and to develop future clinical research." Presently an ongoing study of Obstructive Sleep Apnea could use some more participants. If interested you may call Jan (814) 269-5288 or Wendi (814) 269-5202.

After a satisfying lunch, Lee Owen, a mobility consultant with the Rascal Company, demonstrated the various features of several scooters. Prices ranged from affordable to extremely expensive. Many of our group enjoyed trying them out. Mr. Owen also discussed the trends to expect from Medicare in the near future---the criteria Medicare would use when it comes to paying for a scooter.

At the end of the day the Bernice Krumhansl Advocacy Award was presented to Patrick Kelly for his hard work and leadership of Ohio Polio Network. He has been instrumental in getting the word out that "We're Still Here!"

The day ended for most persons with a door prize, lots of information, new acquaintances, and a sunny drive home.

*Marie Smith
Akron Post-Polio Support Group
Polio Survivors of Stark County*



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