



The Polio Post

Ohio Polio Network Newsletter

*MERRY CHRISTMAS
&
HAPPY NEW YEAR*

Editor: Alice Sporar

Winter 2012 Issue



2012 OHIO POLIO NETWORK CONFERENCE

by *Judith Peascoe*

The 2012 Ohio Polio Network Conference was held at Tuscora Park in New Philadelphia, Ohio. We had approximately 60 attendees. Thanks goes to all the hardworking and generous people who made the conference possible. Winnie Walker and the HELPS Post-Polio Support Group arranged for the meeting room and food. Glo-decorations for McCort handled greeted every-arranged for the the program. work provided and pens. David scratch pads. Inc. who pre-food --the food everyone else making the con-educational

Several people, night before, for dinner and

Our first Marzano, Vice-Services of told us that until changed in from the type of lin Roosevelt.



**Ernest W. Johnson M.D.
2012 Bernice Krumhansl Advocacy Award
Recipient**

Photo by Aldeen "Monica" Wilford

ria Jones provided the the event. Ruth the registrations and one. Brenda Ferguson speakers and prepared The Ohio Polio Net- the Conference bags Long provided the Thanks to RTY pared and served the was great. And to who contributed to ference a happy and event.

who came up the gathered at Shoneys conversation.

speaker was Roger President of Clinical Yanke Bionics. He recently, little had brace technology brace used by Frank- (Continued on page 2)

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2012 Ohio Polio Network Conference (Continued from page 1)

He explained that feet grew roughly two sizes during adulthood and no one should try to wear the same shoe size that they did as high school students. He explained that few shoes have steel shanks so braces now have a foot plate that is worn inside the shoe. He showed various shoes that had elastic areas that relieve pressure on feet with bunions or hammer toes. He discussed the replacement of leather by thermo-plastics and kevlar-carbon fiber braces. Unfortunately, the new braces are made either in China or Scandinavia. He showed braces with various ways to lock and unlock the knee including prototypes with microchips. The braces that unlocked as pressure moved from the heel to the toe were very exciting.

He explained that he is a Medicare provider and cannot see people without prescriptions. He also explained that he sometimes is forced to sell braces below cost. Several members of the Mid-Ohio Valley Post-Polio Support Group are planning to get prescriptions to get either shoes or brace evaluations from him.

Dr. Ernest Johnson, Professor Emeritus, Department of Pain Management and Rehabilitation, Ohio State University first gave an overview of the history and treatment of polio. He suggested that people who are having breathing problems try using a respirator before they undergo a tracheotomy because of the risk of infection. He then discussed pain management. He pointed out that all pain medications have side affects. He then talked about alternate techniques like hypnosis, acupuncture and meditation. He ended his talk by using a manual wheelchair to demonstrate a “wheelie”. No one would take him up on his challenge to do a wheelie.

The Ohio Polio Network awarded Dr. Johnson the Bernie Krumhansl Award for his outstanding contributions to polio survivors.

Kathy Thomas outlined the work of the March of Dimes in the New Philadelphia area and her family’s involvement in the work. Her mother was a polio survivor.



Members of the Akron Post-Polio Support Group at the 2012 OPN Conference: Standing (L-R): Judy Minatodani, Judi Jacobs, Brenda Ferguson, Margie Ellison, Linda Straub, Jim Straub, Barb Schray Seated (L-R) Ruth McCort, Nelson Sommers, Jim Ellison, Bob Schray, Marian Evkovich

Photo by Aldeen “Monica Wilford

Members of Post-Polio Support Group Notify Legislators that People with Disabilities Vote

by *Warren and Judith Peascoe*

Post-Polio Health International decided to raise politicians' awareness of the needs of Post-Polio survivors and their numbers by posting a statement on PHI's website for Post-Polio survivors to sign and mail to office holders and candidates informing all of them of the voting power of Post-Polio survivors and their interests. There are more than 12 million polio survivors world wide. There are about 50 million people in the United States with disabilities.

Members of the Mid-Ohio Valley Post-Polio Support Group prepare letters to remind legislators that "We're Still Here". The letter created by Post-Polio Health International requests the health, architectural, and transportation needs to be addressed to keep the mobility impaired active in their communities. In addition, it requests support for the original intent of the Americans with Disabilities Act and ratification the United Nations Convention on the Rights of Persons with Disabilities.

The statement we signed raised awareness in voting among our group of fourteen diners. So we contacted the County Clerk, right from the cafeteria, to confirm that one member was registered to vote and could access her polling place. We also got instructions to let another member register to vote just before the West Virginia deadline. The next meeting of the Support Group is the annual Thanksgiving and Xmas Party at the Golden Corral at 11:30 on Nov. 12. This will be a Dutch treat lunch and gab fest with some planning for next year. If you attended last years luncheon, please remember your Santa hats. If you want, bring a gift of \$5.00 or under for the "Gift Exchange" and a donation to ARC. Our Post-Polio Support Group Meetings will resume in February 2013. More information on this subject is available at <http://www.post-polio.org/adv/iss1.html#wsh>



Members of the Mid-Ohio Valley Post-Polio Support Group at the 2012 OPN Conference:
(L-R): Pat Kelly, Janice Kelly, Judy Peascoe, Pat Young, Larry Young, Patsy Johnson, Kay Eichmiller, Warren Peascoe, and Judy Hickman.

Photo by Aldeen "Monica" Wilford

Have You Learned Anything Today

by *William Stothers*,

San Diego, California, (wstothers@cox.net)

I don't mean, have you learned who ... won the gold medal in weightlifting (or whatever), or what so-and-so candidate said what on the campaign trail, or the latest and greatest achievement of your grandkids.

No, I am thinking about learning that engages and challenges your brain. Solving today's sudoku puzzle, or completing the crossword puzzle (in ink, of course), to suggest two easy examples.

We hear a lot about the need to exercise our bodies as we grow older in order to maintain good health. Eat nutritiously; keep your weight in check; exercise. And, increasingly, we're urged to exercise our gray matter.

I think all this advice goes double for those of us living with the late effects of polio.

A lot of study is devoted to memory these days. One thing seems clear: Our brains age but they retain plasticity. You can teach an old dog new tricks.

While neural connections can weaken, according to a 2009 *New York Times* article, researchers have found that the brain can get better "at recognizing the central idea, the big picture. If kept in good shape, the brain can continue to build pathways that help its owner recognize patterns and, as a consequence, see significance and even solutions much faster than a young person can. The trick is finding ways to keep brain connections in good condition and to grow more of them."

The *Times* quotes Kathleen Taylor, a professor at St. Mary's College of California, who says continued brain development and a richer form of learning may require that you "bump up against people and ideas" that are different.

"We need to... challenge our perception of the world," Taylor told the *Times*. "If you always hang around with those you agree with and read things that agree with what you already know, you're not going to wrestle with your established brain connections."

In other words, get outside your comfort zone. Learn a foreign language, how to play a musical instrument. Try, maybe, like me, to fathom sudoku.

I also think that to keep sharp we need to engage with other human beings. When you don't have to go to the office, or other "work" it is too tempting to stay home and putter or just watch TV. It's easy to drift into a state of not bothering, and imperceptibly slip into isolation from others and to miss healthy "bumping" into different and challenging people and ideas.

And then it's hard not to dwell on physical issues: weakness, fatigue, pain – is it polio, or just getting old?

Does it matter? The question is, what, if anything, can we – and are we – doing about it?

Personally, I get a lot of daily exercise just getting up and going in the morning. In my other daily routines I regularly use the same sets of muscles, day in, day out. I've learned, however, that some routines that I have stopped have cost me.

(Continued on page 5)

Have You Learned Anything Today (Continued from page 4)

For example, I used to wear a shirt and tie every day to work. Routine. For the past few years I have not needed to don those workplace symbols. Result? I need help to put on and knot one of my few remaining neckties.

I am learning that I must “use it or lose it.” So I am beginning to insert a few little “exercises” into my life.

I guess I am a slow learner. I am sure many of you are way ahead of me in knowing and using the incredibly extensive and valuable resources located on the [PHI](#) and [Polio Place](#) websites. Aging and Polio, and Exercise/Activity are two great sources of information, among many. They’re great places to nudge your brain and prod you into action. Take charge.

Now, if I can only learn not to procrastinate....

Bill Stothers is a long time editor and consultant on media and disability policy. He edited Mainstream, a national advocacy and lifestyle magazine for people with disabilities and major newspapers in Toronto and San Diego. He is a member of the Board of Directors of Post-Polio Health International and currently serves as its Chair.

Source: Post-Polio Health International (www.post-polio.org)

The Dangers of Benzodiazepines

by Anneliese Feddersen

When I needed surgery in 2008, I contacted the German Polio Association for help. They referred me to a German physician who also has post-polio syndrome and is the advisor for the post-polio population and a published author about post-polio. He sent me a list of all the neuro-toxic medications for post-polio. Benzodiazepines are on this list. I was taking Temazepam (Restoril) for insomnia and had become immune to it. Even with this medication I could hardly sleep two hours toward morning. Through Divine Guidance I found Dr. Ashton's website. I printed out the withdrawal schedule for Temazepam and faxed it to my primary care physician.

Benzodiazepines are very dangerous medications and are more so for persons with post-polio issues. I have successfully followed the withdrawal schedule for Temazepam (Restoril) in 2010. Since October 15, 2012, I am free of this drug and back to my own self again.

In addition, I am free of medications for heartburn and high blood pressure. Endoscopy and colonoscopy are normal, no more inflammation or polyps. Respiration is normal again and shows no sign of polio. Muscle strength has increased. Blood pressure has dropped from 188/97 down to 140/80 with no medication. Eyesight has returned to normal, and on my new driver's license there is no restriction on glasses to drive. I sleep like a baby without sleep aids. My memory is intact, and I'm in a good mood. I no longer need knee braces, a walker, or a wheelchair. Miracles do happen!

For more information, go to benzo.org.uk/manual. There you will find a list of benzodiazepine drugs and non benzos that act like benzos. If you don't have access to the internet, you can purchase a copy of the manual or get it from the library---Benzodiazepines: How They Work and How to Withdraw, by Prof. C. H. Ashton. Withdrawal must be slow and takes anywhere from six months to one year or more.

(Continued on page 6)



The Dangers of Benzodiazepines (Continued from page 5)

EDITOR'S NOTE: WITHDRAWAL MUST BE UNDER THE CARE OF A PHYSICIAN WHO UNDERSTANDS THE DANGERS, SUCH AS, SEIZURES. These drugs are recommended for very short term use only, meaning a few weeks. Someone close to me had an adverse reaction to a benzodiazepine after taking it for years. The reaction to both the drug and to the withdrawal was severe paranoia and secondary psychosis.

Benzodiazepines and Similar Drugs

Alprazolam (Xanax)
Bromazepam (Lexotan, Lexomil)
Chlordiazepoxide (Librium)
Clobazam (Frisium)
Clonazepam (Klonopin, Rivotril)
Clorazepate (Tranxene)
Diazepam (Valium)
Estrazolam (ProSom)
Flunitrazepam (Rohypnol)
Flurazepam (Dalmane)
Halazepam (Paxipam)
Ketazolam (Anxon)
Loprazolam (Dormonox)
Lorazepam (Ativan)
Lormetazepam (Noctamid)
Medazepam (Nobrium)
Nitrazepam (Mogadon)
Oxazepam (Serax, Serenid, Serepax)
Prazepam (Centrax)
Quazepam (Doral)
Temazepam (Restoril, Normison, Euhpnos)
Triazolam (Halcion)

Non-benzodiazepines with similar effects

Zalepon (Sonata)
Zolpidem (Ambien, Stilnoct)
Zopiclone (Zimovane, Imovane)
Eszopiclone (Lunesta)



**ENSURING ACCESS TO QUALITY COMPLEX REHABILITATION
TECHNOLOGY ACT OF
2012 - HR 4378
by *Alice Sporar***

This is a copy of my email to my Congressional Representative. Feel free to use the text of it to either email or send a printed letter to your own Congressional Representative. The information was obtained from the National Spinal Cord Injury Association/United Spinal Association.

Alice Sporar
7251 Olde Farm Lane
Mentor, OH 44060-3995

November 9, 2012

[recipient address was inserted here]

Dear [recipient name was inserted here],

People with disabilities require the right wheelchair systems.

Individuals with disabilities need access to customized wheelchair systems to achieve and maintain independence and mobility.

Please support HR 4378, Ensuring Access to Quality Complex Rehabilitation Technology Act of 2012.

Sincerely,

Alice Sporar
440-942-1557

DISABILITY GAS COALITION

A common complaint that is heard from people with disabilities is that when they pull into a gas station, it is difficult to get the attention of someone to come out and pump gas for them. Some aren't aware that The Americans with Disabilities Act requires them to pump our gas if there is more than one person working at that particular station and others just don't care.

Since this problem affects so many of us, a few people formed the Disability Gas Coalition in order to improve the situation. If you are interested in being involved in improving the situation, go to www.disabilitygas.org for more information.

BACKYARD GRANNY PODS

by *Fredrick Kunkle*

America's booming elderly population may soon live happily next to loved ones.

The Reverend Kenneth Dupin, who leads a small Wesleyan church in Salem, Virginia, has a vision: As America grows older, its aging adults could avoid a jarring move to a nursing home by living in small, specially equipped, temporary shelters close to relatives. So he invented the MEDcottage, a portable high-tech dwelling that could be trucked to a family's backyard and used to shelter a loved one in need of special care.

Skeptics have a product: the granny pod. some local officials warn ready authorized by the will spring up in subdividing not-in-my-backyard perhaps being misused. people into a storage backyard? asked one granny pod. What's pod?"



different name for Dupin's Protective of zoning laws, that Dupin's dwellings – al-Virginia state government – sions all over the state, creat-tensions with neighbors and "Is it a good idea to throw container and put them in your local official. "This is the next? The college-dropout

The idea, Dupin said, came to him after years of leading humanitarian missions to developing countries, and it was encouraged by a growing sense of his own mortality. But he also said it just might make a lot of money, since the nation's elderly population is set to double in about 20 years as more and more baby boomers hit retirement age. Surveys by AARP and others also show that large majorities prefer to live in their own homes or with loved ones rather than in retirement communities.

So Dupin hit on the idea of the remote-care pod. The MEDcottage would be equipped with the latest technology to monitor vital signs, filter the air for contaminants, and communicate with the outside world via high-tech video. Sensors could alert caregivers to an occupant's fall, and a computer could remind the occupant to take medications. A video system would monitor the floor at ankle level, so the patient would have privacy, but a caregiver would know if there was a problem.

A lift attached to a built-in track in the ceiling would help a caregiver move a patient from bed to bathroom if necessary. Knee-high lighting would illuminate the floor and help occupants avoid tripping – the most common cause of falls. Technology could also provide entertainment, offering a selection of music, reading material, and movies.

The dwelling would take up about as much room as a large shed and, like an RV, could connect to the electrical and water supplies of a single-family house. The cottage could be leased for about \$2,000 a month, a cost Dupin hopes will be borne by health-care insurers.

Source : Boca PPS Group Aug. 2012 Newsletter/Washington Post, July 20, 2012 / Reprinted fr/Readers Digest, 12/10 - 01/11.

2013 Mid-Ohio Valley Post-Polio Support Group 25 Year Anniversary

Celebration in June! More Information in the next issue and on the OPN Website!

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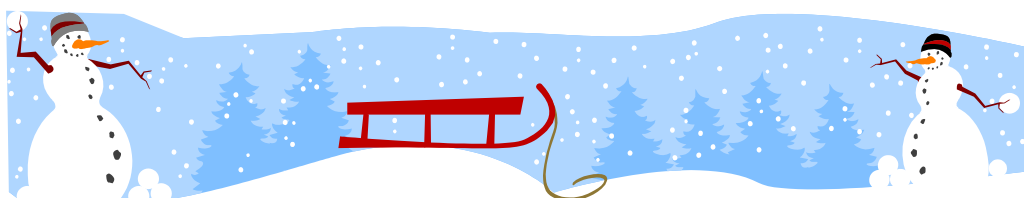
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