



The Polio Post

Ohio Polio Network Newsletter

Editor: Alice Sporar

Spring 2012 Issue

OPN mourns the passing of Board Member Chic Carlson

by *Brenda Ferguson*

It is with great sadness to inform you that our loving friend and long-standing member, Chic, passed away January 1st. Clarence F. Carlson is best described by lute, resourceful, generous, roic, and caring - someone dedicated member of our tion over 20 years ago.



Chic turned 85 this past family had a wonderful sur- brate. Chic's family was as cherished friends, and what a great friend he was to all of us. He brought so much life to our group, not to mention his wealth of knowledge and his great enthusiasm to help others.

He was a first generation Swedish American who only learned to speak English after entering kindergarten. He graduated from Akron Central High School in 1944 and enlisted in the Army where he attained the rank of first sergeant and served in the Pacific War before being struck with polio. He spent two years recovering at the Army-Naval Hospital in Hot Springs, Arkansas before returning to Akron. He met Juanita, his wife, on a blind date arranged by his friend and also a first cousin of Juanita. They married in 1948 and had three children, Mark, Elaine and Bruce. A 1950 graduate of the University of Akron, Chic worked briefly at Modern Motors before joining Babcock & Wilcox, from where he retired in 1981 as Sr. Accountant. While in college, he began acquiring residential rental property, a 300-unit apartment complex. There was another area in which Chic worked, however, from which he never retired. Beginning as a young man, he was committed to community service. He started as a Jaycee, which is where he acquired the nickname "Chic". He was a member of the Northeast Ohio Apartment Association, the Akron Post-Polio Support Group, a board member of the Ohio Polio Network, the Cleveland/Akron Vasa Order of America (a Swedish-American fraternal, cultural and education organization),

(Continued on page 2)

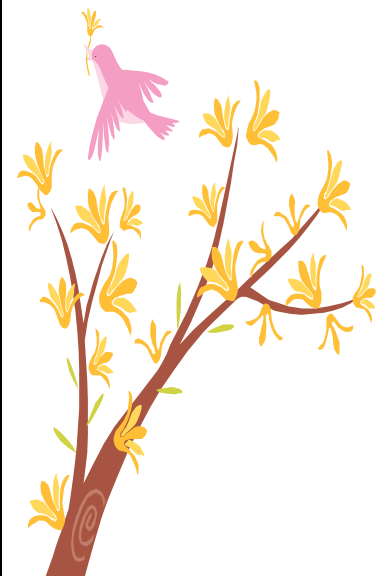
just after midnight on Sunday, "Chic" (as we all knew him) those who knew him as resogregarious, civic-minded, he- we will dearly miss, as he was a support group since its incep-

September and his very large prize party for him to cele- most important to him, as well as cherished friends, and what a great friend he was to all of us. He brought so much life to our group, not to mention his wealth of knowledge and his great enthusiasm to help others.



Inside this Issue

• PPS in under Two Minutes	3
• Marilyn Pressnell	4
• Making the Most of Time	5
• Losartan	6
• Sleep & Breathing Complications	7



Chic Carlson (Continued from page 1)

Weathervane Playhouse and, since 1971, the West Akron Kiwanis Club. . He served in various positions in all these organizations. Not just a joiner, Chic was a doer, devoting, time, talent, energy and financial support to the organizations he championed. Another very important part of Chic's life was his membership and involvement at the First Congregational Church of Akron.

Though Chic was deeply involved with organizations and charities, he was not all work and no play. He enjoyed golf for many years, loved a good bridge game and, most importantly, he loved to travel, both the world and to visit his family who are spread across the U.S. Last year, he and son, Bruce, made a trip to Sweden. He also loved to tinker and found quick and clever ways to overcome difficulties, many brought on in recent years by post-polio syndrome.

Fondly, we all remember a couple support group meetings in particular. Chic would bring bags of frozen strawberries (he was a very healthy minded person and loved to read "Prevention" magazine to keep current on the health scene). He believed a person should have 1-2 strawberries a day to help keep you at peak health, so he would pass these out at the meetings for everyone to sample. This is a memory we won't soon forget! Another very memorable meeting was when Chic gave a very interesting presentation on the "great and many uses of duct tape." He was knowledgeable about this subject and had umpteen (or more) creative ways to use it - it kept us smiling as he shared innovative ideas we never dreamed of!

Even when Chic was diagnosed with esophageal cancer several months ago, his spirit never gave up - he fought the good fight and gave it his all to try and beat his illness. We admired his courage and strength throughout it all. Yes, Chic was a beacon of light wherever he went and he will be greatly missed in our support group. Let's remember him in regard to what he taught us about life and people, putting others before ourselves, working to make the world a better place, and spreading happiness wherever we go. Though it is a huge void for our group to face, Chic would want us to forge ahead and continue to promote helping those with post-polio. We are thankful for the blessing of having known this wonderful and kind soul.

Chic was predeceased by his wife Juanita. Survivors are his children, Mark Clarence Carlson (Dimitry Boll Carlson, PhD), Elaine Kerstin Wolf (Fred Wolf, PhD), Bruce Alton Carlson (Linda), twelve grandchildren, and three great grandchildren.

A memorial service honoring Chic's life was held on Sunday, January 15th at the First Congregational Church, 292 E. Market St., Akron. Memorial donations may be made to First Congregational Church of Akron, 292 E. Market St., Akron, OH 44304, or Weathervane Playhouse, 1301 Weathervane Ln., Akron, OH 44313.

OPN Board Meeting
Saturday, May 5, 2012
Westerville, OH Library
Board Meeting Noon - 2:00 PM
Meeting with the Central Ohio Post-Polio Support Group
2:00 - 3:00 PM

**If you are interested in being a member of the Board or have agenda items for the Board Meeting,
please contact Patrick Kelly, pkelly03@sprynet.com**

PPS IN UNDER TWO MINUTES

Have you tried to explain Post Polio Syndrome to a friend or relative?

Maybe half-way through you notice them nodding off?

Try this two minute drill.

Our brain communicates with our muscles through nerves.

Polio destroys those nerve cells causing our muscles to die or weaken.

The beautiful thing about nerves is that they help each other.

When one goes down, others help out, so a person can lose many nerve cells and not experience much dysfunction.

Most polio survivors have been living in this state of fewer nerve cells for years.

If they were very young when they contracted polio, they may have grown up thinking this was normal.

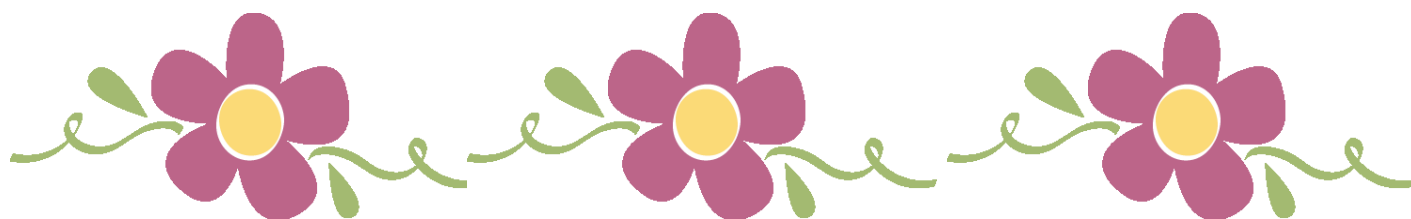
All people's nerve cells die off with age.

For the average person, having many nerve cells, this is not a problem.

For those of us that have been living with a reduced number of nerve cells, this can result in a variety of symptoms, including weakness, fatigue, and pain, to name just a few.

Reprinted in part from the publication of Post Polio Alliance of South Florida, Inc., April-August 2011.

Reprinted in part with permission from Constance Hanby Foel, a polio survivor. Original author unknown.



The Lorain County Post Polio Group is saddened by the passing of charter member Marilyn Pressnell

by
Joanne Sage, Al Thiery, Annette Will, and Busch Funeral Home

The passing of Marilyn Pressnell has left the Lorain County Post Polio group very saddened. It shocked us all very much to hear of her rapid decline. Many beautiful traits made up her character. The minds of those in the group are filled with very pleasant memories of her. She helped start our group over twenty years ago and was there to share her experiences as a beloved mentor.

In spite of continual physical difficulties, she never lost faith that God was and sweet spirit always remained. She



was an inspiration. Marilyn is survived by her husband who was with her at every meeting. Our hearts go out to him, her four sons, twenty-four grandchildren, and six great-grandchildren.

and sweet spirit always remained. She

band, Howard, of fifty-six years. Howard was her greatest supporter. sons, twenty-four grandchildren, and

Marilyn volunteered with the Board of Elections and was an ombudsman at Avon Oaks Nursing Home. She loved spending time with her family and friends and was very active in her church. She was a remarkable lady proving, "you can't keep an old polio down, because we are going to be strong and overcome."

We know Marilyn is in a better place, dancing to the German music that she loved, and her brace is being used as a memorial arrangement. She will be missed.

TRAVEL NEWS

by *Alice Sporar*

The American Drivers Alliance or ADA Nationwide offers emergency road services to members with disabilities. Some of the services are: Road Service, such as, lift service; wheelchair or scooter assistance; emergency towing; battery jump start, repair or replacement; mechanical adjustments; tire change, repair, or replacement; extrication/winch service; lockout service; fluid delivery; passenger transport. There is also Concierge Service, such as, prescription delivery; Emergency Travel Assistance, such as lost baggage search or lost travel document assistance; Emergency Medical Assistance, such as, medical evacuation assistance, prescription replacement, dispatch of doctor to hotel.

I have more peace of mind now that I'm a member, because when using the usual emergency road service companies, like AAA, there is no way to transport an individual who uses a power wheelchair. We can't climb into the truck and there's no place to stow a wheelchair. This road service provides us with the transportation we can use. For more information go to adaautoclub.com or call 800-720-3132.

Making the Most of Time

By William Stothers, San Diego, CA
(wstothers@cox.net)

It all depends on your disability, of course, but most of us probably pay out more money, and most likely more time and energy, to manage our daily routines than non-disabled people.

For example, even with health insurance, I shell out a steady flow of funds for wheelchair repairs, other orthopedic equipment and ventilator supplies. All those costs are only the beginning. I spend a lot of energy (my tank seems to empty faster these days) and time on my own disability to shore up my independence. For instance, it takes me two to three hours to get up and moving in the morning.

The alarm rings at 6:30 a.m. usually, and I begin my routine. Fortunately, with the assistance of my wife, also a polio person, I am able during this time to drink a cup of coffee, read my local newspaper and listen to NPR. After unhooking my BiPAP machine, I haul myself on to my bedside commode for an extended period – this is essential for me because once I get into my power chair and dress myself only the direst emergency can get me back to bed before nighttime. It's just too hard to do. Before I retired from a job that required me to be at my desk by 9 a.m., I got up even earlier and was much more focused, urgent and stressed in my routine; nowadays I am more leisurely and gladly spend – and even relish – this time.

We try as much as possible to keep up our house ourselves. Cooking, doing dishes, policing the clutter that inevitably accumulates; all get done even if we spend more time and energy doing these jobs than other people.

Some jobs, though, are beyond us. Changing light bulbs in ceiling lights, batteries in beeping smoke detectors, doing laundry, cleaning the bathroom, cutting the grass are some of the chores for which we have enlisted help.

Sometimes that takes more time (*time, again!*) than expected. We have eaten dinner by candlelight on several occasions when the bulb blew as the mac and cheese floated in from the kitchen. If only we could time it so that the bulb would go out when we have dinner guests, guests that is, who were able to change the bulb, not always the case in the circles we roll in.

Happily, we have neighbors willing to help take care of many of these often annoying little household crises. And we are able to pay a housekeeper once a week and a garden man twice a month. But, we have often felt in the past that our neighborly help tasted like charity. People helped us, and we were truly grateful. However, it was a one-way relationship and that bothered us. Over time we have developed an exchange system, largely unstated, that opens the way for us to help our neighbors, too.

We have writing, advocacy, office and computer skills that we have used to help our non-computer using neighbors (yes, there are people like that out there) find information they need.

We have a van that we help car-less neighbors go shopping or to appointments, and rescue friends with disabilities whose wheelchair vans have broken down.

(Continued on page 6)

Making the Most of Time (Continued from page 5)

Lately, we have become aware of a movement called “time banking,” wherein people donate an hour or more of time to assist another person, and in return, they can claim an equal amount of time for help from someone else.

Time banks are a kind of intentional community, which can be its own social reward. Time banks can be centered in a local area, or spread more widely if mobility is not a critical issue.

Have you had experience with time banking or other ways of exchanging, saving or stretching time – on the deficit or surplus side?

I would like to hear about it. Let’s share, and we can all get more high quality time and help others as well. That’s time well spent.

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)



Losartan - A commonly used Blood Pressure Drug may have another use

Newswise --- Using geriatric mice, a Johns Hopkins research team has shown that losartan, a commonly used blood pressure drug, not only improves regeneration of injured muscle, but also protects against its wasting away from inactivity.

A report on the old drug's new role, which is prompting preparations for a clinical trial of losartan in older adults, appears online May 11 in the journal, Science Translational Medicine.

"The goal of the investigation was to find a way to prevent a bad situation from getting worse in the case of old muscle that's injured or not used," says Ronald Cohn, MD, an assistant professor of pediatrics and neurology in the McKusick-Nathans Institute of Genetic Medicine, Johns Hopkins University School of Medicine. "As pleased as we were to see that losartan therapy in mice had a positive affect on muscle regeneration, we were most surprised and excited by its striking prevention of disuse atrophy."

Previous studies by other groups have shown that aging in humans causes activity of a protein secreted by cells called transforming growth factor beta (TGF-b) to increase, and that more TGF-b translates into less muscle repair.

Also studies in mouse models of Marfan Syndrome and muscular dystrophy - both of which involve disorders of muscle and connective tissue revealed that losartan promotes muscle regeneration by blocking a particular protein receptor (angiotensin II type 1) and ultimately tamping down activity of TGF-b.

To investigate losartan's role in muscle injury regeneration in the context of aging, the Hopkins team worked with 40 mice which, at 21 months old, were considered geriatric.

(Continued on page 7)

Losartan (Continued from page 6)

After treating half of those animals for a week to water laced with losartan, they injected a chemical toxin into all the animals' shin muscles. The researchers examined the stained muscle tissue under a microscope at four days and again at nineteen days, looking for signs of regeneration: small fibers with larger-than-usual nuclei. After four days, they saw no difference in the number of regeneration fibers between losartan treated mice and those not treated. However, after nineteen days, the losartan treated mice had about 10 to 15 percent of scar tissue formation compared with 30 to 40 percent of scar tissue formation in those not treated.

Next, the researchers conducted disuse experiments to find out if losartan, in addition to improving muscle regeneration, might have even broader clinical applications in the protection against immobilization atrophy. Again, using 21 month old mice, half treated with losartan and half not, the team this time clipped the hind right foot of the mice to their knees, immobilizing just the shin muscles; otherwise the mice were normally active.

After twenty-one days, the animals' shin muscles were weighed and compared under a microscope. The animals not treated with losartan lost 20 percent of the mass of their immobilized shin muscles. However, the losartan treated animals lost virtually no mass, according to Tyesha Burks a graduate student of Human Genetics, Johns Hopkins University School of Medicine.

"When we saw that the loss of muscle fibers was completely prevented by losartan therapy, it was quite mind-blowing," Cohn says.

Reprinted from the April-August 2011 Publication of Post Polio Alliance of South Florida, Inc.

Dr. Bach discusses prevention of Sleep and Breathing Complications in PPS

By Joan Swain in the New Jersey Network Newsletter, Summer 2003

From 3% to 10% of the general population develop sleep-disordered breathing as they get older, said John R. Bach, MD at the New Jersey Polio Network Conference on Post-Polio Syndrome in April. In his keynote speech, Dr. Bach, who is professor of physical medicine and rehabilitation at UMDNJ--New Jersey Medical School and a pulmonary specialist, researcher, and clinician explored the type of breathing difficulties that those who had polio might experience, how polios differ from other patients, and how this impacts therapy.

There are three potential problems in terms of breathing, according to Dr. Bach. The brain may not tell you to breathe, the throat may close and make it difficult to breathe, or the muscles may be too weak to breathe. Underventilation always begins during sleep, and symptoms of sleep-disordered breathing include excessive daytime sleepiness, fatigue, morning headache, irritability, depression, loss of libido, nightmares, and learning disorders.

Weak Diaphragm If you've had polio, your diaphragm may be weak, e.g., when you lie down, you become short of breath. If you go to the doctor with symptoms, the doctor may send you to a pulmonary functions lab where they take tests. You may be told that your breathing function is fine. The problem is that they don't ask how you sleep--the fact that you may use 8-9 pillows because of a weak diaphragm. Many doctors will send you to a sleep lab for tests.

(Continued on page 8)

Dr Bach discusses prevention of Sleep & Breathing Complications in PPS (Continued from page 7)

These tests are constructed to detect central (brain) or obstructive (throat) apnea (failure to breathe) problems, and are not designed to say the problem is muscle weakness, and they typically prescribe CPAP (continuous positive airway pressure) therapy. If the diaphragm is very weak, CPAP will not help the situation. It just keeps the airway open, but won't help very much to get air into your lungs. A modification of the CPAP is the BiPAP, which allows two different settings, one for inhaling and another for exhaling. This will help if you need an extra boost, but not if you have a weak diaphragm.

Daytime Breathing Problems "At the age of 40, we're all losing 1% of our anterior horn cells every year; and after 50, many of us lose up to 3%," Dr. Bach said. He explained that as people get weaker, those with breathing problems need help during the daytime. But often this is not recognized, and as a result, when they get a cold, they are unable to cough effectively, because of their weak muscles. They then develop pneumonia and respiratory failure and go into the emergency room, where they are given oxygen, which completely turns off their breathing. At this point, the patient becomes comatose, is intubated, and the doctor tells them they need a tracheostomy (tube in their neck).

"That's nonsense," Dr. Bach insisted. "There's never been a polio patient that I've seen in over 300 that I have treated, using help with breathing, that has ever needed a tracheostomy. None do. Anyone who can speak does not need a tracheostomy tube-whether spinal cord injury, muscular dystrophy, or polio. In fact, no one should suffer from respiratory complications of polio."

Hold the Oxygen The difficulty, he explained, is not that many people understand how to manage the problem. The reason they don't understand is because doctors are used to treating patients with lung disease. In these cases, they need oxygen. "However, in studies we have shown that treating people with muscle weakness with oxygen results in respiratory failure sooner than if you don't treat them at all.

"If you're symptomatic for sleep disordered breathing with a weak diaphragm, try nasal ventilation," Dr. Bach said. "We give air through the nose from a ventilator that delivers deep breaths." He then discussed the cases of people who have been successfully using ventilators since the time they had polio 50 years ago. He also described "frog breathing," the gulping in of air without using the diaphragm (frogs do not have diaphragms).

Treatment Goals In the event of a cold, it is important to keep the airway free of obstruction, according to Dr. Bach. "We teach people to do assisted coughing to free the airway of secretions." He also discussed a coughing machine that is used. And he has patients use an oxymeter to measure the level of oxygen in their blood. "As we get older, the cough ability goes down," Dr. Bach explained. "If you can't get a deep breath, you can't cough effectively. The leading cause of death in nursing homes is pneumonia, which develops because of weak coughs."

Dr. Bach's treatment goals are to achieve normal ventilation all the time; to maintain range of motion in the lungs and chest wall by air stacking and maintaining the mobility of the chest; and to maximize cough flows because mucus plugging is the primary cause of pneumonia.

Reprinted from the PPSSG Newsletter of Polio Heroes of Tennessee, Summer 2003.

Editor's note: Dr. Bach has, more recently, stated that people with pps breathing problems do not need a tracheostomy unless they can't speak, can't swallow, and saliva keeps the oxygen saturation less than 95. Also, some polio pulmonary specialists recommended oxygen at a very low level in addition to the ventilator, if the patient has pneumonia and the ventilator alone does not increase oxygen saturation levels.

OPN BOARD AND ADVISORY BOARD

President

Patrick Kelly
 Marietta, OH
 (740) 374-0538
pkelly03@sprynet.com

Vice-President

Joan Prior
 Powell, OH
 (614) 888-5863

Secretary

Brenda Ferguson
 Tallmadge, OH
 (330) 633-8221

Treasurer

Ruth McCort
 Akron, OH
 (330) 724-8302

Support Group Liaison

Patricia L. Novak
 Oak Harbor, OH
 (419) 898-3130

OPN Board

Bud Boote
 Hudson, OH
 (330) 653-5395

OPN Board

Gretchen Estreicher
 Cincinnati, OH
 (513) 574-1192

OPN Board

Warren Peascoe
 Vienna, WV
 (304) 295-4233

OPN Advisory Board

Anthony Hayek, D.O.
 Edwin Shaw Rehab
 Akron, OH
 (330) 784-9306

OPN Advisory Board

Dave Livingston
 N. Ridgeville, OH
 (440) 420-2074

OPN Advisory Board

Greg Nemunaitis, MD
 MetroHealth
 Cleveland, OH
 (216) 778-3850

OPN Advisory Board

Robert W. Shields, Jr, MD
 Cleveland Clinic
 Cleveland, OH
 (800) 223-2273

OPN Advisory Board

Nikki Wingerson
 Stow, OH
 (330) 686-1071



POST POLIO SUPPORT GROUPS

Akron

Ruth McCort
 (330) 724-8302
 Brenda Ferguson
 (330) 633-8221

Central Ohio

Monica Wilford
 (614) 337-0990
 Susan Cull
 (614) 263-3339

Coal Grove

Carolyn Melvin
 (740) 532-7572

Defiance Area

John Schatz
 (419) 782-4699

Greater Cleveland

Alice Sporar
 (440) 942-1557

HELPS

New Philadelphia
 Winnie Walker
 (330) 339-6910

Lorain County

Joanne Sage
 (440) 327-9971

**Miami Valley
Greater Dayton**

Ed Baker
 (937) 325-8384

**Mid-Ohio Valley
Parkersburg WV**

Becky White
 (304) 295-5879
yellowrosebud_05@yahoo.com

**Polio Connection
Greater Cincinnati**

Chuck Humerickhouse
 (513) 777-3083

**Stark County
Canton Area**

Linda Conrad
 (330) 877-2632

**Toledo Post Polio
Connection**

Sandy Foss
 (419) 893-8110

Wooster & Wayne County

Vivian Gray
 (330) 264-2270
 Jim Straub



<p>The Polio Post is published quarterly. All articles are due according to the following schedule:</p> <table border="1"> <thead> <tr> <th><u>Issue</u></th> <th><u>Date Due</u></th> </tr> </thead> <tbody> <tr> <td>Spring</td> <td>March 1st</td> </tr> <tr> <td>Summer</td> <td>June 1st</td> </tr> <tr> <td>Fall</td> <td>September 1st</td> </tr> <tr> <td>Winter</td> <td>December 1st</td> </tr> </tbody> </table>	<u>Issue</u>	<u>Date Due</u>	Spring	March 1st	Summer	June 1st	Fall	September 1st	Winter	December 1st	<p>Membership Categories:</p> <ul style="list-style-type: none"> • Sponsor - \$50.00 • Basic - \$10.00 • Special Gifts <p>OPN is a non-profit & tax exempt organization under:</p>	<p>Make checks payable to:</p> <p>Ohio Polio Network c/o Ruth McCort 1048 Austin Avenue Akron, OH 44306-2956</p>
<u>Issue</u>	<u>Date Due</u>											
Spring	March 1st											
Summer	June 1st											
Fall	September 1st											
Winter	December 1st											
<p>Please forward letters and articles to the return address on the newsletter or e-mail to amsporar@worldnetoh.com</p>	<p>IRS 501(c)3 and Public Charity 509 (a) (2)</p>	<p>The newsletter is assembled, printed, and mailed by LEAP (Linking Employment, Abilities and Potential) 2545 Lorain Ave, Cleveland, OH 44113 www.leapinfo.org</p>										
<p>Disclaimer Notice: The thoughts, ideas, and suggestions contained in this publication are those of the writers and do not necessarily constitute an endorsement or approval of OPN. The articles are for information only. Consult your health care provider before beginning any new medications, nutritional plans or any other health related programs.</p>	<p>_____New Membership _____ Renewal _____ Change of Address</p> <p>Name: _____</p> <p>Address: _____</p> <p>City: _____</p> <p>State: _____ Zip Code: _____</p>											

The Polio Post
c/o Alice Sporar
7251 Olde Farm Lane
Mentor, OH 44060-3995



www.ohiopolionetwork.org

