

### OPN and the Post-Polio Community Mourn the passing of Dr. Ernest (Ernie) W. Johnson 2012 OPN Bernice Krumhansl Award recipient

Editor: Alice Sporar



Dr. Ernest W. Johnson, MD, age 90, passed away Tuesday, November 18, 2014, surrounded by family and friends, spending his final hours in the rehab center he helped build, Ohio State University's Dodd Hall. He was born in New Jersey, on January 12, 1924 to parents Ernest and Harriet (Burgess) Johnson, who soon moved to Akron, Ohio, where he spent his youth. Preceding him in death are Joanne, his wife of 62 years, his daughter Jill, and son Walter. Left to mourn his passing are his daughter, Amy (Kevin) Scott of Pataskala, Ohio; wife, Susie Cull; niece, Beverly (Ron) Kristoff; nephew, Jeff (Glenda) Church of Taris, TN; and his many grandchildren and great-grandchildren.

Known to all as 'Ernie,' he was a longtime resident of Upper Arlington, devoted member of Riverside United Methodist Church, and servant to the Lord. After graduating from Akron Central High in 1941, Ernie earned distinction as the first draftee selected by the northern Ohio draft board and went on to serve his country as an Army captain in the south Pacific, returning home to Ohio upon war's end. Enrolling at The Ohio State University in 1946, Ernie began what became one of the University's most valuable and enduring relationships first as a student, then as a faculty member. Spanning 57 years, lasting until his retirement (his last of many), in 2012, his tenure is considered the longest in the history of the Ohio State University. After attaining his medical license, Ernie was awarded a fellowship from the National Polio Foundation in 1954. In 1957 he began working on what was then, the world's first medical-school program devoted to the study of physical medicine and rehabilitation, PM&R. Ernie devoted his life to the care of patients suffering from spinal cord injury, Parkinson's, brain injury, stroke, amputation, polio and post polio. He was instrumental in building Dodd Hall into the nationally recognized medical facility that it is today. Serving as PM&R chairman for 37 years beginning in 1963, Ernie is credited as Co-founder of the "creative living" apartment complex, designed to allow disabled adults in need of assistance to live independently. When it opened in 1974, Creative Living was the first complex of its kind in the nation. Additionally he was the world's foremost authority on the use of electromyography (EMG), a diagnostic tool used in diagnosis of nerve and muscle conditions. Author/Co-author of over 150 published articles, 40vear editor of the OSU medical journal and writer of the much beloved "Ernie's Editorials", Dr. Johnson is acknowledged internationally as a preeminent physician within the field of physical medicine and rehabilitation. His illustrious career

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includes a list of awards, accomplishments, titles and distinctions too numerous to list. Though well-deserved, he placed little importance on such accolades. His medical advice was sought by US presidents, world leaders, Coach Hayes, and tens of thousands of everyday people, all of whom he treated with the same respect and compassion. Above all else, Ernie considered himself a teacher. He instructed over 300 Physical Medicine residents, instilling in them his "patient-first" philosophy. To his residents he was the "Chief Wheelie" (see YouTube video "How to do a Wheelchair Wheelie"). To honor him, graduates of the residency program established the Dr. Ernest W. Johnson chair, in the department of PM&R. To his family he was husband, father, grandpa and hero. We loved him dearly, and his absence leaves us broken-hearted. Visitation will be held Friday, November 21, 2014 from 3-5 and 6-9 p.m. at SCHOEDINGER NORTHWEST CHAPEL, 1740 Zollinger Rd., Columbus, OH. A memorial service will be held at 2 p.m. Sunday, November 23, 2014 at Riverside United Methodist Church, 2701 Zollinger Rd., Columbus. In lieu of flowers, contributions may be made in Ernie's memory to <u>Creative Living</u>, 150 W. 10th Ave., Columbus, OH 43201-2093 or to OSU Wexner Medical Centers Ernest W. Johnson MD Residency Support Fund, checks made payable to OSU Foundation sent to OSU WMC Development, Kyle Sebastian 660 Ackerman Rd. Columbus, OH 43202. Visit <u>www.schoedinger.com</u> to share memories or condolences.

### 10 Things You May Not Know about the ADA

1. A New Perspective on Disability Facts and Figures. In preparation for the anniversary of the Americans with Disabilities Act (ADA) in July, the U.S. Census Bureau released its collection of the most recent data pertaining to Americans with disabilities. The numbers are striking. Approximately *57 million* Americans have a disability. Since this figure may be difficult to comprehend, let's take a look at some facts for comparison: There are more people with disabilities living in America than the entire population of Canada or the Caribbean. The number of Americans with vision impairments is comparable to the entire population of Switzerland, and there are more Americans with hearing impairments than in all of Denmark, Paraguay or Hong Kong. If you take the population of Ireland and cut it in half, that's roughly the number of Americans living with Alzheimer's or other neurocognitive disorders. Additionally, more Americans with disabilities require the assistance of others to perform basic activities of daily living than the entire population of Greece.

**2. Breaking Down the ADA.** <u>The ADA</u> of 1990, including its <u>Amendments Act of 2008 (ADAAA)</u>, covers five different areas:

<u>Title I</u> requires employers with 15 or more employees to treat qualified individuals with disabilities equally in all stages of employment. From the hiring process to full employment, this includes compensation, benefits, trainings, promotions and other aspects, such as offering reasonable accommodations to workers with disabilities. This section also restricts hiring managers from asking certain questions about an applicant's disability during the hiring process or retaliating against someone for opposing discriminatory employment practices.

<u>Title II</u> prohibits public entities like state or local government agencies from discriminating against individuals with disabilities. All programs and services, such as public transportation, recreational activities, courts and town meetings, should be available to people with disabilities. In addition, state and local government buildings must be accessible, and accommodations should be available to communicate effectively with those who have vision, speech or hearing disabilities.

<u>Title III</u> requires public accommodations and commercial facilities to offer equal access and treatment, effective communication and removal of existing barriers for people with disabilities. Examples of such facilities include restaurants, retail stores, hotels, movie theaters, private schools, convention centers, doctors' offices, homeless shelters and recreational facilities. Any altered or newly constructed buildings must follow architec-

tural and design standards to ensure accessibility. Additionally, classes and examinations for professional, educational or trade-related purposes, licensing and certifications should be accessible to people with disabilities or alternative arrangements must be offered.

Under <u>Title IV</u>, telecommunications companies must establish telecommunications relay services for callers with hearing and speech disabilities.

<u>Title V</u> includes various provisions that are not necessarily covered by other titles, but have been used to clarify the application of the law. For example, this section notes that the ADA does not invalidate or override any other federal, state or local laws that provide equal or greater protections for people with disabilities. It also defines conditions that are not covered under the term "disability," as defined by the ADA.

**3. Preserving Our History**. "Those who cannot remember the past are condemned to repeat it." This quote, spoken by philosopher George Santayana, reflects the missions of both the <u>ADA Legacy Project</u> and the <u>Disability Visibility Project</u>. The ADA Legacy Project has a threefold mission: to preserve the history of the disability rights movement, celebrate the impact of legislation like the ADA and educate the public on improving inclusion and equal rights for those with disabilities. In partnership with <u>StoryCorps</u>, the aim of the Disability Visibility Project is to record the stories of those in the disability community. You can <u>participate in the project</u> until July 2015 by attending a recording session in the San Francisco Bay area, Chicago, Atlanta or one of the <u>Mobile Tour locations</u>. All stories will be archived by <u>The American Folklife Center</u> at the Library of Congress. You can also visit <u>adalegacy.com</u> to <u>find ADA events or programs near you</u> and prepare for the <u>25<sup>th</sup>anniversary of the ADA</u> next year. There's even a countdown calendar!

**4. Job Accommodations** enable people with disabilities to perform essential job functions, be productive and accomplish work tasks with greater ease and independence. Examples include modifications such as ergonomic desk chairs, reserved parking, flexible schedules, telecommuting, alternate workstations and periodic rest, food or bathroom breaks. According to the Job Accommodation Network (JAN), a free source of expert one-on-one guidance on workplace accommodations and disability employment issues, nearly 60 percent of the accommodations needed by workers with disabilities cost absolutely nothing, and only 36 percent of employ-ers incurred a one-time cost of roughly \$500. JAN's publication, the *Employees' Practical Guide to Requesting and Negotiating Reasonable Accommodations under the Americans with Disabilities Act* (*ADA*) summarizes the provisions of the ADA, common accommodation issues and JAN's practical solutions for resolving them. For additional guidance on reasonable accommodations and enforcement, visit the Equal Employment Opportunity Commission (EEOC) website.

**5.** The Rights of Pregnant Workers are generally protected by three laws: the <u>ADA Amendments Act</u> (<u>ADAAA</u>), the <u>Family and Medical Leave Act (FMLA</u>) and the <u>Pregnancy Discrimination Act (PDA</u>). Although pregnancy is not considered a disability under the ADAAA, pregnancy-related impairments, such as gestational diabetes, severe nausea, sciatica or preeclampsia, may be recognized as a disability and could require an accommodation. Nursing mothers also have protections under the <u>Fair Labor Standards Act</u>. According to the <u>National Partnership for Women and Families</u>, 10 states and two cities have implemented laws requiring employers to provide reasonable accommodations for pregnancy. These include Alaska, California, Connecticut, Hawaii, Illinois, Louisiana, Maryland, New Jersey, Texas and West Virginia, in addition to New York City and Philadelphia. The Women's Legal Defense and Education Fund's <u>interactive map</u> details pregnancy discrimination laws, as well as breastfeeding and leave rights, in each state. An article from the Society for Human Resource Management (SHRM), "Accommodating Pregnant Employees," highlights real-life situations and offers helpful suggestions on reasonable accommodations for pregnant workers. If you feel you have been discriminated against, visit the EEOC's Pregnancy Discrimination page, which provides contact and other useful information about how to file a complaint.

6. Does Your School Pass with Flying Colors? Students with disabilities attending post-secondary schools are protected from discrimination by both the ADA and Section 504 of the Rehabilitation Act of 1973. In accordance with these laws, a school must make its programs, including its extracurricular activities, accessible to students with disabilities in an integrated setting. This includes providing accessible architecture, such as classrooms and housing, accessible transportation and <u>auxiliary aids and services</u>, if requested. Examples of auxiliary aids include interpreters, electronic readers and talking calculators. A student must disclose his or her disability to the school in order to receive these accommodations; however, if no accommodations are needed, then students are not required to disclose this information. When choosing a school, students with disabilities should consider factors such as the type of services already in place, accommodations they will require and the school's overall attitude and reputation towards providing accommodations. Students should talk to their school's ADA coordinator, Section 504 coordinator or Disability Services coordinator for more information or if problems arise.

7. Get the 5-Star Accessibility Treatment. The ADA (i.e., Title III) requires all hotels and motels in the U.S. to make their facilities equally accessible to people with disabilities. There are two types of accessible guest rooms: those with "mobility" features and others with "communication" features. For guests with mobility impairments, roll-in showers and grab bars, lower counters and closet bars are a few of the structural features that should be offered. For guests who are deaf or hard-of-hearing, hotels and motels are required to provide rooms equipped with visual notification devices, telephone amplifiers and TDDs (Telecommunication Devices for the Deaf). According to the <u>2010 ADA Standards for Accessible Design</u>, accessible guest rooms must be dispersed among different classes of guest rooms and provide choices in the type of guest rooms, number of beds and other amenities comparable to those offered to other guests. A fact sheet from the Northwest ADA Center, "<u>Accessibility for People with Disabilities at Hotels and Places of Lodging</u>," gives an overview of the different elements accessible hotels should include. For more tips on finding an accessible hotel room, read the post, "<u>Disability Travel...a Dream or a Reality?</u>," on Disability.Blog.

8. Accessible Public Transportation, such as buses, trains, subway systems, paratransit and ferries, makes it possible for people with disabilities to get to work, medical appointments and social activities in their communities. According to the <u>U.S. Census 2009 American Community Survey</u>, six percent of workers with disabilities age 16 and older use public transportation to commute to work. Common accessibility features include accessible parking, elevators, raised lettering and Braille signage, automatic doors, wheelchair turnstiles and lifts, public address systems, curb cuts, elevator status announcements and TDDs. Air travel is regulated under the <u>Air Carrier Access Act</u>, which prohibits domestic and foreign passenger airlines from discriminating against people with mental or physical disabilities. For additional information on transportation, read the May 2014 *Disability Connection* newsletter, *(Continued on page 5)* 

## KNEE REPLACEMENT by Nick Polanski

I have polio in my left leg since 1951. For the last five years have been looking for a doctor that has knowledge of doing a knee replacement on a polio person. I had checked with several polio groups in state as well as out of state. Asked the national group in St. Louis only to be told we have no knowledge or recommendations to tell me. I could not be the only person in the USA with polio that needs a knee replacement. Finally after 5 years I ran across info that led me to Doctor Brendan Patterson.

Doctor Patterson has done over 14 polio knee replacements, written many papers on the procedure, helped with the invention of the knee replacement and has such vast Knowledge of polio and how it is different from a normal surgery. His secretary Emigda Gabriel has more knowledge of polio than most current doctors. I had the knee in my Polio leg replaced by Dr. Patterson and it was the best thing I ever did. I think we need to share info as polio survivors to help others.

(Continued from page 4)

"<u>10 Things You Need to Know about Planes, Trains and Automobiles</u>," or read Easter Seals Project AC-TION's <u>Glossary of Disability and Transit Terms</u>.

**9. Technology and the ADA**. Let's first discuss the difference between accessible technology and assistive technology. Accessible technology can be used by people with a wide range of abilities, whether they use assistive technology or not. Assistive technologyallows individuals with disabilities to perform tasks or functions they might otherwise be unable to do. For example, someone with low vision may not be able to read a book without a video camera magnifier. Under the ADA, governments and public entities must provide devices temporarily to help individuals with disabilities access their programs and services. For example, a movie theater should loan you an assistive listening device if you have a hearing disability. The <u>Assistive Technology</u>, <u>Accommodations and the Americans with Disabilities Act</u> brochure from the ILR School at Cornell University explains more fully how assistive technology is covered under the ADA. If you are interested in learning more, the <u>ADA Online Learning Center</u> offers webinars on a variety of technology-related topics.

**10. People You Should Know**. The enactment of the ADA would not have happened without the hard work of these advocates and many others:

<u>Justin Dart, Jr.</u>, who is known as the "father" of the ADA, held public forums across the U.S., Guam and Puerto Rico at his own expense to converse with people with disabilities and advocate for their civil rights. <u>Dr. Fred Fay</u>, who was a quadriplegic and prominent advocate for disability rights, won support for not only the ADA, but also the federal Architectural Barriers Act of 1968.

<u>Patrisha Wright</u>, who is known as "the General" of the ADA, was also a driving force behind the Handicapped Children's Protection Act of 1986 and amendments to the Fair Housing Act, which prevented landlords from discriminating against people with disabilities.

<u>Robert Burgdorf, Jr.</u>, a professor at the University of the District of Columbia, wrote the original version of the ADA that was introduced in Congress.

Lex Frieden, the former director of the National Council on the Handicapped (now the <u>National Council on</u> <u>Disability</u>), helped craft the language of the ADA. The concept of "reasonable accommodation" stemmed from his experience in college when his classes were moved to a building that could better accommodate his wheelchair.

<u>Tony Coelho</u>, a former Congressman, was the primary author and sponsor of the ADA. He stated the law was urgently needed to prevent the discrimination against individuals with disabilities that he experienced as a person with epilepsy.

<u>Senator Tom Harkin</u>, whose brother is deaf, authored, sponsored and introduced the ADA to the Senate. He considers it to be his signature legislative achievement and continues to advocate for the rights of people with disabilities.

<u>Evan Kemp, Jr.</u>, a former chairman of the EEOC, worked closely with President George H.W. Bush during the ADA deliberations. He even wrote several of the President's speeches for disability-related events. Don't forget to like <u>Disability.gov</u> on <u>Facebook</u>, follow us on <u>Twitter</u> and use #disabilityconnection to talk to us about this newsletter. the article is taken from Disability Connection.

## NEWSLETTER DELIVERY

How do you receive your newsletter? By "snail mail" or "e-mail?" It's easy to pick it up at the mailbox, but if you have a computer, you can view it more quickly and in color! If you don't receive it via e-mail presently, would you consider changing to this? With postage having just reached \$.49, we would be so appreciative if you would allow us to mail it to you in this manner. Email Alice Sporar @ amsporar@worldnetoh.com and/ or Ruth McCort @ igiveahoot8@aol.com and they would be happy to add you to the e-mail list. Thanks for helping our postage bill!

THE POLIO POST

## THE FIVE MINUTE MENTAL MARINADE

By: Kathryn Tristan - Washington University School of Medicine To quickly reset and rebalance both psychologically and physiologically, do the following exercise. It should take about five minutes or longer if you wish. It's a great "badbiochemistry" buster and something especially to do before bedtime!

- Cross your hands over your heart.

- Close your eyes and take five deep, slow breaths.
- Recall five positive things about your life.
- Focus on a beautiful scene, someone you love, or something you love to do.
- Take five deep, slow breaths.

- Relax and marinate in the feeling!

For more free tips, tools, and strategies, see whyworrybook.com

Reprinted as presented at PHI's 11th International Conference, St, Louis, MO, May/ June 2014.

Reprinted from Second Time Around, August, 2014, a publication of Boca Area Post Polio Group, Boca Raton, FL.

## Reflections on Living with Polio

by Warren Peascoe

While talking after dinner at the Polio Health International conference, one of my companions commented that I had said something that resonated with her. My first thought was that I might need a graceful way to extract my foot from my mouth. After some discussion we realized that it had been about the phrase polio survivor. In an earlier session, someone mentioned that he didn't like the term polio survivor. I suddenly had a wonderful "AH HA moment". I knew a better term for survivor and I had proceeded to tell them about it. My foot and mouth were safe!

Then she asked me where it came from. I thought about that all night and came up with three things that all came together. Of course I realized that I might be wrong and I could've have heard it elsewhere.

I had just finished The Man He Became a book about FDR. The author claimed that polio played a major part in FDR becoming president. Because of the paralysis, FDR had to learn new methods to do even the simplest daily tasks. Basic things were now major obstacles which he had to fight through both emotionally and physically. This is something all polio survivors learn to do. This experience of having to attack a problem without any idea of the answer is was what gave Roosevelt the confidence to try new programs to get the nation out of the depression.

Sunday night Dr. Maynard led the group in sharing positive polio experiences. I realized then what a marvelous group of people had gathered at the conference.

One chapter in a church book study was about not just living but thriving. Thrive has such wonderful connotations. When we thrive, we flourish, we broaden, we grow. One component of thriving is also helping others to thrive.

Now when someone says that I am a polio survivor, I will correct them and say, "I am not a polio survivor. I am a Polio Thriver". I find thinking of myself as thriver is much more empowering than thinking of myself as a survivor.

After we were home a few weeks, my wife mentioned that her Dragon Boat team members who had breast cancer referred to themselves as thrivers. We had also bought a book entitled "Thriving Through It - How they do it" by Joyce Ann Tepley. Obviously thriver did not originate with me.

I think everyone who has endured the effects of polio can be proud to call themselves a "Polio Thriver".

## WHY WORRY? STOP COPING AND START LIVING

By: Kathryn Tristan - Washington University School of Medicine

### Ten Instant Stressbusters

1. **Breathe, Breathe, Breathe.** The amazing power of feeling more relaxed begins with taking three deep breaths and slowly exhaling. Stop stressed-out shallow breathing.

2. Move, Wiggle, Stretch. To dissipate anxious feelings, loosen up taut muscles and move around.

3. Focus on Now. Although you have to plan for the future and take care of responsibilities, don't forget to enjoy the present moment.

4. Say a Calming Phrase. Develop a phrase that helps you, such as, "All is well," or "This, too, shall pass." Keep repeating it.

5. Focus on Positive Possibilities. Stop terribilizing and assuming the worst may happen. Visualize things going the way you want and feeling happy about it...Possibilize!

6. **Embargo Junk Food.** What you eat affects your mood. Reduce sugary, caffeinated, or non-nutritious food. Try eating a banana, some turkey, or drink chamomile tea. All contain natural relaxants.

7. **Take a Hike.** Get out or connect with Mother Nature in some way. Touch your feet to the ground to literally, "get grounded."

8. **Do Something Enjoyable.** Whether it's gardening, organizing, or engaging in a special hobby, etc., build in some fun time.

9. Smile. Studies show whether you mean it or not, smiling releases mood-enhancing endorphins.

10. Take a Mental Health Day. Sometimes you just need a break to rebalance. You deserve it.

For more free tips, tools and strategies, see <u>whyworrybook.com</u>. Reprinted as presented at PHI's 11th International Conference, St. Louis, MO, May/June 2014.

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# THANK YOU!!

To retiring OPN Board member Gretchen Estreicher for her service to OPN for 14 years

We would like to say	KAREN SWAN	FRED GALLO
THANK YOU To the members and non-members	WILLIAM COLEMAN	BEVERLY SCHMITTGEN
Supporting OPN	HOLLY KING	<b>BRENDA FERGUSON</b>
Through their generous donations	IRMA STEPHAN	PATRICK KELLY

### TIPS FROM SEVERAL TALKS

by Warren Peascoe

Recommendations for aging were: call friends, travel, don't worry about being a burden, take a risk, figure out along the way. Staying connected with other people was super important.

If you're in a wheelchair put a breadboard on top of a drawer to get a lower work surface. Have an occupational therapist look at how you do things and make recommendations to improve them.

You need a network of people to help you, this can include professionals. Tap into what other people are good at and and ask them to help with what they like to do. Have a backup for everything like scooters and wheel-chairs.

It is necessary to stay in the positive. Avoid negative.

Transportation and independence are important. Use adaptive cars, vans, community transportation, area agencies on aging, and formal and informal networks.

We need to realize that we are role models for other people who are aging. We need to share the tricks and things we have learned.

Change, "I can't", which means there's no way to help, to, "I don't know how", which indicates there is a way to help. Change ,"I have to, I need to, or I should", which are bad and imply that you're stuck, to, "I want to". I want to is empowering. It means that it is a question of finding the cost and working out alternatives.

Go ahead and try anything that isn't going to do any permanent harm. Ice packs and Tens units (transcutaneous electrical nerve stimulation) are probably ok.

When getting a new orthotist or brace man; ask her for credentials, understand your own anatomy, ask what the device can do for you, ask about cost, insurance, and co-pay.

When asked to do something, wait 24 hours, before accepting.

Useful wording to decline a new responsibility. I usually give 100%, but I don't feel I can give at that level right now. Do you really want me to do that?

What we really want in marriage is someone who can read our mind 100% of the time. It is better to ask.

There is an emotional mode and a problem solving mode that we can slip between.We first need to validate the emotional mode before we switch to problem solving. If we don't we are likely to be rejected. Useful validation words - "I understand where you are..." "This is so frustrating....". Ask permission to make a suggestion.

Suggestions on the process of down sizing.

Save representative samples - not everything.

Donate stuff. Ask "Who will want it after I am gone?"

Recycle and let someone else enjoy.

Plan ahead whenever possible. When we have a more accelerated decline we move into crisis management. Factors that increase likely hood of falling with PPS:

older age

reduced mobility

loss of vision

## **2015 OHIO POLIO CONFERENCE**

## TO BE HELD

## SATURDAY SEPTEMBER 19, 2015

## IN NEW PHILADELPHIA OHIO MORE INFO TO COME

Post-Polio Health International 4307 Lindell Blvd. #110 St . Louis, MO 63108-2930 Phone:0314.534.0475 Fax: 314.534.5070 Post-polio.org Email: info@post-polio.org

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