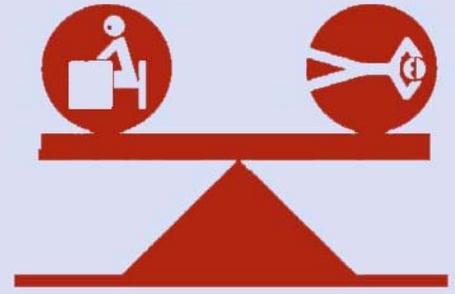


POST POLIO PACER

Conserving Strength and Energy through Pacing
July 2013— Madison, Wisconsin

Madison Area Post Polio Support Group Newsletter
MAPPSG formed in 1985 — This Is Our 28th Year!



Greetings from PHI

Polio survivor and ventilator user Gary Presley is an essayist, book reviewer, and author of "Seven Wheelchairs: A Life beyond Polio."

He blogs at www.garypresley.com. You may want to check his writings periodically. Here is a sample about a recent news item.

You Can't Always Blame Other People

Gary Presley

There's an interesting story in a recent New York Times about the treatment of people with disabilities by physicians here in the United States. Here's an interesting segment: The researchers then called more than 250 doctors' offices in four major cities across the country that offered care in areas like gynecology, urology, psychiatry, endocrinology and orthopedic surgery. The researchers presented themselves as the doctors that they were, and tried to make an appointment for the fictional patient.

One out of five offices refused to even book an appointment. Some explained that their buildings were inaccessible to people in wheelchairs, but most refused simply because they had no equipment like height-adjustable examining tables and chairs, specially designed weight scales or trained staff members to help move the patient out of the wheelchair.

But even the offices that agreed to see the patient were not necessarily offering appro-

priate care. When pressed, some acknowledged that they had no plans or equipment for moving the patient.

Others said that they would complete only the parts of the exam that they could — and forgo the rest. Fewer than 10 percent of these offices had appropriate equipment or employees trained to help patients with disabilities.

It's a shame, obviously. Every person should have access to decent medical care. That said, it's a naive "crip" who doesn't get this at the first visit with a new physician.

Doctors are trained to return the damaged to normal. And truth be told, there are few doctors who see disability as anything other than an impairment of normal. A physician can sometimes not understand that disability is normal.

Secondly, a person with a disability should be very wary if a physician's office does not have adequate equipment or staff—or staff with the wrong attitude toward disability. I have never met this sort of attitude, other than an odd response to a telephone call to an optical dispensary in another state. I requested an eye examination, and the response was "We don't do people in wheelchairs."

That's minor, but speaking personally as someone messed up by polio, that ugly old killer and maimer, I find most physicians younger than me are often entirely unfamiliar with the disease, its effects, and most especially with the subsequent effect called post-polio syndrome.

This is complicated by the fact that I am ventilator-dependent, and most physicians only encounter ventilators in a hospital setting. The combination of these factors means that too often I find myself part of the diagnostic team.

I accept that. I accept the situation because it gives me a greater sense of security. I began accepting that about two decades ago when I began occasionally encountering a physician who would argue with the fact that I am here, alive, a half-century after being inoculated by the Salk vaccine and ending up in an iron lung a week later.

"Oh, that's not possible," has been the response I've heard more than once.

The one thing that it has taught me—which is a lesson applicable to anyone who walks into a physician's office—is to never acquiesce automatically to every decision that a physician makes. Or a nurse, or medical technician, for that matter.

Ask "why?" Ask "how?" Ask about alternatives.

It's a shame that people with disabilities must do this, but then again it isn't. Everyone should do this. We are responsible for ourselves. Anyone who doesn't believe that may encounter far more problems in life than a visit to a physician's office that goes wrong.

However, the news story was about access, and an example was given of a man in a wheelchair who had diabetes.

In his 60s, overweight and in a wheelchair, the patient had been seeing doctors and nurses regularly for his diabetes. Only recently had they discovered a pressure sore after someone had finally, as he put it, "wanted to examine at my backside."

That's fine. I have no quarrel with criticism of the doctor or his facilities in this case.

I have a greater quarrel with this patient's desire to place all of the blame on the physi-

cian. When was it time for him to say, "I need to be checked for pressure sores"?

Physicians generally have a god complex. And why not? A physician tinkers amid the blood and guts, bones and electro-chemical reactions that keep us functioning. That's enough to inflate anyone's ego and generate a sense of entitlement to a house on a golf course and a new Mercedes-Benz.

True enough, a good physician knows in a general sense he or she is smarter in the ways of the human body than the person being treated, but a good physician is also humble and open-minded.

Originally published on www.garypresley.com
Reprinted with permission of Gary Presley,
<www.garypresley.com>

Limping Through Life **By Jerry Apps**

Reviewer: Kathleen Blair
Pacer Columnist

I read *Limping Through Life* by Jerry Apps shortly after the memoir was published, but I certainly didn't "limp" through it. I couldn't put it down. Jerry's vivid description of the onset of polio in 1947 – the doctor called it *Infantile Paralysis* – when he was an eighth grader in a country school in Waushara County resonated with me and, I'm sure, many others who shared similar experiences.



Throughout the book I was awed by this young boy's resilience as he suffered the fear & pain of spending his days on the couch in his farm home while polio took its toll on his young body. His disease was diagnosed by the local doctor, but there was no room left in the hospital, no known cure & not much care information available. So Jerry's parents took him home & tried their best to care for him.

I understood the “no room in the hospital.” In September of 1955 I got the last room available in St. Joseph’s Hospital in Marshfield. Polio patients who came in after me were “isolated” in the halls. Reading *Limping Through Life* made me appreciate how much the care of polio patients had improved from 1947 to 1955. After the fever subsided I had daily hot baths – hydrotherapy – followed by a visit from the physical therapist who worked on my paralyzed right leg to stretch the muscles.

Jerry not only worked hard on his own making his paralyzed leg do what he wanted it to, but as soon as he was able to sit up, he diligently caught up with his eighth grade studies so he could pass the Waushara County exams in order to be eligible to attend high school the following school year.

When he was able to return to school to complete his eighth grade year his father drove him to school for the first two weeks. After that he was expected to walk the distance. What normally took him 20 minutes to walk now took an hour. So he had to leave home 40 minutes before his younger twin brothers in order to arrive at school on time.

When you read the book you will be delighted to read how he not only passed the county test for eighth graders, but did so with flying colors.

He describes in the book his frustration with feelings of inadequacy at not being able to play baseball or basketball with his school-mates. To compensate he delved into his studies and achieved success throughout high school. His skill with words and speaking were recognized by coaches and teachers, and he was asked to provide commentary over the loudspeaker during home basketball games which made games more meaningful and enjoyable for fans.

In this memoir, Jerry Apps provides a shining example of a young man who overcame his disability by honing his communication skills. He graduated from high school with honors, earned degrees at the University of Wisconsin in Madison and became a successful writer. His literary works include many stories about rural life, children’s books and fiction.

I hope that *Limping Through Life* will be read by many teens and young adults as well as “us wiser, older folks” because it’s filled with many important life lessons.

Many aspiring authors have enjoyed Jerry Apps’ creative writing workshops throughout the years. I have fond memories of one such workshop I attended at The Clearing in Door County the summer of 2004. *Jerry Apps is seated with his cane on the left-hand side of the photo titled “The Clearing – 2004.”*



FASCINATING LIVES

'HAPPINESS is a CHOICE'

Myra Goldick won't let post-polio syndrome define her. She believes in rising above her challenges — and helping others do so, too.

"I'm an expert at tomorrow," says the unsinkable Myra Goldick, for whom tomorrow hasn't ever been just another day. That the day after today will be better has been the hope that kept her going at age 10, when all she could move were her eyelids. It's been the promise that life still holds joy as her body today twists and bends in a slow, painful betrayal, a little-known, late-life legacy of a disease most Americans have forgotten. Polio. Sixty years after she fought her way out of her childhood's wheelchair, Goldick, 70, must rely on one again because of post-polio syndrome, which strikes some former polio patients 25 to 40 years after the initial infection.

She's endured years of increasing muscle weakness, atrophy, chronic spinal pain and complicated surgeries. For a time, she thought her spinal degeneration would render her a paraplegic.

The disease's progression forced her to leave a career she loved as a New York hat designer, after she suffered several severe falls in the company's warehouse. Yet, while her ability to move diminishes, her capacity for happiness has not. The key, she says, is never to ask, "Why me?" Instead, ponder this question: "Now what?"

One is the lament of a victim; the other the quiet courage of a survivor.

Raising money for book

The buoyant Lake Worth, FL resident is finishing a book she hopes will inspire others to reach beyond their own physical challenges. "The disabled are the fastest growing minority in the country," said Goldick. "At first, it can feel like you don't have a purpose anymore.

We have to reinvent ourselves and our dreams."

She's trying to raise \$7,000 for publication of *"Dancing on Our Disabilities: Never Say Impossible to Your Dreams,"* through the crowd-source funding site, Indiegogo.

The title came from an evening in a nightclub, where Goldick yearned to dance instead of being sidelined in a wheelchair. She watched a young, wheelchair-bound girl roll up to the dancers and joyfully join in. Goldick turned to her husband, Neil and said, "Now that's dancing with your disability."

Happiness, Goldick has come to believe, is an acquired skill, like learning a foreign language or memorizing physics theorems. "I realized," Goldick, said, "how many people are miserable, even without these challenges. I refuse to be. I believe happiness is a choice. If you can't do one thing, there's something else that will make you feel alive."

In her home west of Lake Worth, Goldick is driving her motorized wheelchair as if she's behind the wheel of a Ferrari. An adept three-point turn brings her to the dining table, then she buzzes down the hall, making a tight right turn into her office and studio.

She dazzles in a blue maxi-dress with matching shawl, her abundant dark hair pinned up and over one shoulder in a dramatic sweep. Her make-up is glamour girl perfection. If there was an ad campaign for aging with allure, Goldick could be its face, if not its body.

She's still the exotic dish who turned her husband, Neil, to jelly when he was a cab-driving student at New York University. "She got into my cab," said Neil, "and she was unbelievable." That part hasn't changed. So much else has.

Paralyzed except for her eyes

Goldick grew up poor and bi-racial in 1950s' New York City, one of two children of an often-absent, briefly-famous Calypso musician from Trinidad named Sam Manning. To es-

cape pre-war Vienna and move to London, her Austrian mother claimed she was Jewish. Eventually settling in New York, the family lived a hand-to-mouth existence in a welfare apartment with a shared kitchen and bath. "I was that strange half-breed of a kid, constantly being asked, 'What are you?'" Goldick remembers.

In the pre-vaccine days of the 1940s and '50s, summer ushered in terror as polio epidemics swept across the country like a virulent humidity, killing and paralyzing mainly children. There were 33,000 cases in 1950. A year later, cases had nearly doubled, to 59,000. Until the vaccine, there was little treatment and no cure.

Goldick was 10 the Labor Day weekend of 1953 when she contracted polio, spending 10 days in a coma. When she woke, she was paralyzed except for her eyes. It took three years for her to acquire enough strength to go back to school.

Not surprisingly, she has no patience for those who refuse to immunize their kids against polio. "Why would you refuse to do the one thing that can protect them against this?" she says, gesturing to her legs.

She learned to walk again, attended the Fashion Institute of Technology, married Neil and had two daughters. She had careers she loved, first as an executive with Flori Roberts, one of the first cosmetics company for women of color. In her 50s, she returned to FIT to earn a degree in millinery, and then began working for a major Seventh Avenue hat designer. If you wore a hat to the Kentucky Derby or Easter services in the 1980s, there's a good chance Goldick designed it. But by then, the weakness had begun. She couldn't control her legs.

'Happiness is a choice'

The cruel irony of post-polio syndrome is that it strikes at mid-life, just when former childhood polio patients have finally put the horrors of iron lungs and braces behind them.

"It's almost as if the polio wakes up again to remind patients that it's still there," said Dr. Tamar Ference, Assistant Professor of Rehabilitation Medicine at the University of Miami Leonard M. Miller School of Medicine. She directs the center's post-polio clinic, the only one in South Florida.

Falls become frequent. Decades after re-learning how to use their arms and legs, they're once again being fit with braces and often require canes and eventually, wheelchairs.

In Goldick's case, her spine has become so twisted she's lost more than 3 inches in height. She's had one complicated surgery to correct her spinal problems and is facing another. Her muscles are atrophying, leaving her too weak to walk more than a few steps. Her hands, with their shrunken muscles, are as delineated as birds' wings.

Pain has become a daily companion. But Goldick refuses to dwell on that.

Instead of ticking off a list of what she could no longer do, Goldick moved to Florida in 2003 and investigated what was still possible. Her wheelchair, she told herself, was just a more comfortable perch from which to work.

Always artistic, she took painting classes and built a reputation as a realist painter. Her portraits, often of glamorous women with perfect, nearly-nude bodies, are sold online.

She joined Toastmasters and gave inspirational talks. Slowly, she became a spokeswoman for disability issues, offering positive encouragement to people struggling with physical and emotional limitations. A thoroughly modern businesswoman, she has her own web site (myragoldick.com), a Face-book page and regularly sends out uplifting messages to her Twitter followers.

"I began to discover my value in terms of inspiring others," she says. "Learning that life isn't just about you takes the focus off what you may be feeling deprived of. Your purpose

begins to be more than serving only your personal needs."

More recently, she's begun taping a weekly internet radio show called "Never Say Impossible," to help people unlock their own creativity. It is possible, she says, to accept your disabilities — she wishes the world would call them challenges — with joy. She directs her message to anyone, but particularly South Florida retirees who are dealing with illness and depression. Happiness is a choice. Adjust your dreams to your circumstances. Never give up, she directs.

"That is my value, I've finally come to realize," she says. "I hope I can help people who feel abandoned, who feel alone by offering encouragement and support."

It was the lesson she learned while lying in a hospital bed, at age 10, too paralyzed to wipe away the tears streaming down her face. "It's impossible," she told her doctor. "I'll never walk again." "Young lady," he told her sternly. "Never say something is impossible."

It's been Goldick's mantra ever since. "Because once you say something is impossible," she says, "it is."

On-line Source:

The Harvest Center, Coffee House <<https://www.facebook.com/groups/148377278537482/>>

Article written by Barbara Marshall, Palm Beach Post Staff Writer and reprinted with permission of Myra Goldick.

Editor's note: Many thanks to Mary Parks for recommending this article for inclusion in the Pacer.

F.Y.I.

POST-POLIO: THE FACTS

- > Post-polio syndrome is not contagious. It affects only polio survivors.
- > The number of people with the condition is not known. In the mid-1990s, there were 1 million polio survivors in the US.
- > Researchers estimate that the syndrome affects 25 percent to 40 percent of polio survivors.

SOURCE: National Institute of Neurological Disorders and Stroke

"The Open Door", Access To Independence's newsletter is available in PDF, a text-only format & large print edition at <www.accesstoind.org> .

ATI, located at 3810 Milwaukee St, Madison, WI, provides services to Dane and Green counties.

Please remember to let the editor know when you change your street or e-mail address to ensure you will receive the Pacer in a timely fashion.

Golden Rule of Post Polio Syndrome

"If something you do causes you fatigue, weakness or pain, you shouldn't be doing it!"

EXECUTIVE PLANNING COMMITTEE

Kathleen Blair 608-838-8773
 Bonnie Haushalter 233-9617
 Fayth Kail 249-1671
 Gail Kempfer 608-846-3776
 Betty Leiser 222-8897
 Mary Parks 608-838-3072
 Nedeem Strand 222-4946

Do you have suggestions for speakers, topics, books to read and discuss, etc.? Call or e-mail (see e-mail list) one of the people listed above to suggest program topics or speakers, volunteer to organize one meeting program, share your knowledge (or find an expert) about becoming a non-profit organization or volunteer your talents (financial, organizing, etc.) as a committee member.

POST POLIO PACER STAFF

Marcia C. Holman, Editor
 3629 Alpine Rd.
 Madison, WI 53704-2201
 e-mail: wghmch@chorus.net
 Phone: 608-249-2233

Kathleen Blair, Columnist
 5404 Wellington Circle
 McFarland, WI
 e-mail: knlblr@yahoo.com
 Phone: 608-838-8773



Madison Post Polio Support Group e-mail list:

Arnold, Arthur—UncleBunks@aol.com
 Beckwith, Gail—dbgb1973@sbcglobal.net
 Blair, Kathleen—knlblr@yahoo.com
 Casper, Mary—mhcspr@ticon.net
 duRocher, Carl—carld@gmail.com
 Fisk, Julie—jkfisk@hotmail.com
 Gratke, Katherine—kat3gratke@att.net
 Jordan, Buffy—newacademy@comcast.net
 Kail, Fayth & Bob—bandffab50sltr@yahoo.com
 Kempfer, Gail—WP6838@windsorparkside.com
 Klotzbach, Jennifer—maywoodteach@aol.com
 Klotzbach, Marilyn—marilynkcgw@yahoo.com
 Leiser, Betty—bileiser@att.net
 Marsolek, Betty—bmarsolek@tcc.coop
 Miller, Diane—welcomehome@hnet.net
 Montgomery, Robert & Joyce—jmrm@tds.net
 Murphy, Dorothy—ddm4hymn@msn.com
 Mylrea, Marian & Earl—mamylrea@aol.com
 Newman, Leanne R.—roonie@charter.net
 Onsum, Chuck—charles_wm@onsum.net
 Palzkill, Marge—margepal@hotmail.com
 Parks, Mary—mparks3072@charter.net
 Paszkiewicz, Mary—mpasskey@yahoo.com
 Post, Theresa—tjpost@charter.net
 Purdy, Elizabeth—epurdy1@verizon.net
 Schaffer, Sheryl—sheryls@gioffice.com
 Schubring, Kathy Sue—kathysue@gmail.com
 Smith, Joy—handswow7@hotmail.com
 Strand, Nedeem—tstrand@charter.net
 Tomter, Linda—tomter@discover-net.net
 Torti, Geri—gatorti@wisc.edu
 Wieland, Dennis—boxdodger@yahoo.com

To get your Pacer in color on line, set your email program to always accept messages from wghmch@chorus.net

Names in bold are new to the list or have an address change. To add your name and/or up-date your e-mail address to this list, notify Marcia Holman at: wghmch@chorus.net

POST POLIO PACER is a quarterly newsletter published in January, April, July & October for polio survivors, the Madison Area Post Polio Support Group, health care professionals and interested persons to share information and to promote friendships. Articles in this newsletter are for information; medical advice is always necessary.

Please request permission from the editor to reprint articles from the Post Polio Pacer.

Disclaimer: The opinions expressed in this publication are those of the individual writers and do not imply endorsement by Easter Seals Wisconsin or the Madison Area Post Polio Support Group.



Easter Seals Wisconsin
101 Nob Hill Rd., Suite 301
Madison, WI 53713

Address Service Requested

Non-profit
Org.
U.S. Postage
PAID
Permit No. 136
Madison, WI

A NEWSLETTER FROM THE MADISON-AREA POST POLIO SUPPORT GROUP

Mark your calendars!

LOCATION:

Monona Garden Family Restaurant
6501 Bridge Rd., Monona
Noon to 2:30

Printing and postage
is provided by:

EASTER SEALS WISCONSIN

608-277-8288 voice
608 -277-8031 tty
608-277-8333 fax
<http://www.EasterSealsWisconsin.com/>



Saturday, July 13, 2013

Jean Lynch and Janet Bollig will talk about Home Health United Meals on Wheels program and outreach services—referral sources, physicians, discharge planners & others in the medical field. Printed materials will be distributed.

Saturday, September 14, 2013

To Be Announced

