Getting The Most From Your Doctor

Excerpted from the November, 1986, newsletter of the Post-polio Support Group of Traverse City.

Dr. Thomas Auer, M.D., Traverse City internist, pointed out that new advances in medicines, surgical techniques, and specialization in various areas have changed the complexion of medicine. New diseases or complicated strains of diseases (including Post-Polio Sequelae) surface everyday. Dr. Auer believes doctors can learn from their patients about these new and unexpected conditions.

Dr. Auer explained that when seeing a doctor for the first time, you should define your situation as clearly as possible, give your history, present him with a list of medications you may be on (over-the-counter drugs, as well as prescriptions), mention any allergies or special circumstances, and state the reason for your visit. As a patient you also need to define for the doctor what you expect from him/her. Have your questions ready and written out, making sure you get all the answers you want. Dr. Auer says he’s a strong believer in designating a primary care doctor, choosing a doctor as a repository source for all your records: Medications, copies of any emergency room situations, x-rays, etc.

If you have a specialized concern that needs an “independent opinion”, whether it be visiting a specialist or consulting others via telephone, discuss this with your doctor. Tell him that you think you need to see a specialist, but “would it be all right to have findings sent back to him as your primary care doctor, your coordinating doctor?” Or tell him you have heard of some experts at a University Hospital and “would he please confer with them?”, that you would be happy to pay for the phone charges, etc. Let him know that you respect him, you want to retain him as your primary care doctor, but that you like everyone to work together to solve this special problem.

Dr. Auer says you should ask your doctor how long you should take a particular medication, and that you should then take the medication AS DIRECTED. He says studies show that four out of ten prescriptions are not filled, and that half of those filled are not being taken correctly. He warns us not to mix drugs without consulting a doctor or pharmacist, and says this holds true for the over-the-counter drugs, too, as many combinations can be harmful. Ask when you need to return to be seen again by the physician!

Also discussed was the provision of a list of doctors conversant with our particular concern, Post-Polio Sequelae, to our primary care doctors. You may wish to have a sticker attached to your file with the name and phone number of the doctor of your choice to be contacted should an emergency arise pertaining to your post polio condition. You may also wish to carry on your person this information and/or a letter from your doctor.♦♦♦
FROM THE CHAIR

Although we are past the Holiday Season and spring seems a long way off, we need to check out the new and improved MPN website.

[www.michiganpolionetwork.com]

Through a donation from polio survivor Rick Schwendenmann we were able to hire a person to redesign our website. It is much more user friendly and very informative. The home page features the announcement of our up coming Post-Polio Educational Conference on Saturday October 5, 2013. For those who are not connected to the internet, see page 18 for conference information. Conference registration information will be on the website and published in the Spring edition of The Polio Perspectives. We are looking forward to seeing you at the conference.

Easter Seals of Michigan has constructed a “Walkway of Champions” with each brick engraved with a person’s name and their achievement. With a generous donation from polio survivor Dan Matakas, The Michigan Polio Network purchased 2 paver bricks, one to honor Don Pixley and the other to honor Jerry Hazel. Easter Seals of Michigan is in the process of completing the walkway. It can be seen at the Easter Seals Headquarters at the Roger & Doris Mc Carville Family Center 2387 E. Walton Blvd., Auburn Hills, MI 48326.

Susan Burton and Vijayalakshmi Nagappan MD, both polio survivors, each donated a box of “Managing Post-Polio” by Lauro S. Halstead. A copy of this book is given to polio survivors on their first visit to the St. John Health System Post-Polio Clinic.

I came across the following thought that seemed fitting to all of us.

“This is for all the strong people who have been through a lot in life, and survived!!

Say this out loud, I am strong because I know weakness. I am compassionate because I have experienced suffering. I am alive because I am a fighter. I am wise because I have been foolish. I can laugh because I have known sadness. I can love because I have known loss.”

Trudy Barineau.

As we winter in Florida, we will be meeting with polio survivors on our cruise and at the Boca Area PPS Group and looking for information on how to improve the Michigan Polio Network.

Bruce Sachs, Chairman

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BAY CLIFF REVISITED

Once again in October Dianne & I journeyed to Bay Cliff Health Camp in Big Bay, MI. to join about 30 other polio survivors and spouses in a 3 day reunion.

We gathered for an informal supper on Monday and spent the evening renewing friendships.

Tuesday noon was the official start of the reunion. Tuesday and Wednesday were filled with activities including a session with Dr. Maynard, crafts, fishing, and for several of us we had a chance to meet with some former nurses from St. Lukes Hospital in Marquette. That is where we were when we had polio in the 1940’s.

We ended our reunion with breakfast on Thursday and were given a pasty to go.

As we age these reunions become more important. Since last year we lost 2 fellow campers with one a member of the “UP polio epidemic of 1940.”
WIN BY LOSING
By Rick Van Der Linden

I’ve had many challenges in my PPS career. New problems pop up on a regular basis, and each must be faced with the initial question, “Is this something I must calmly accept, or can it be fixed?” Each winter gets harder for me, so it’s no surprise that, even though it was comparatively mild, this past winter was a rough one. But there were a few details that had me scratching my head.

For example: it was getting much more difficult to get up the 3 steps into the house, my legs ache just going from room to room, scooter batteries had to be charged more often, my back brace (which wears like a girdle) is too small, shortness of breath is on the rise, I have to come up for air twice to get one shoe tied. Wait a minute? I’m fat!!!

Now, I’m not just writing this to talk about myself, I know that weight gain is a problem for a lot of PPS folks because we can’t exercise enough to burn off the calories, and it’s hard to avoid calories when there’s little else to do for fun other than eat tasty stuff while watching TV or reading or whatever non-active activities occupy our time. We have to find our pleasures where we can, and ice cream can come high on the list.

Should Be.

At 6’ 2”, I should probably weigh around 180. As the spring of 2012 sprung I clocked in at over 220 lbs. That’s 40 pounds! Think about it – 5-gallon water bottle weighs 40 pounds and I’m trying to carry it around with me.

I’m thinking about getting a bigger back brace, a bigger scooter, can’t use my leg braces because I can’t tie my shoes, the doctor is bugging me to take statins, most physical activities are out of reach because of shortness of breath, I can barely scratch my own back, and why??? Because I’m fat.

Change

This revelation came about 3 months ago and I did make some changes. Not major, but effective. A few basic things made a difference.

First, I exchanged green tea for coffee. I don’t know why or how, but 2 cups of green tea instead of my usual 4 cups of coffee made my abdominal muscle seem to tighten without input from my brain. Seems weird, but there it is. Fat burns when muscles flex.

Second: there are two kinds of hungry: stomach growling hungry and brain hungry. I can live with an empty stomach, but brain hungry makes me feel like I’m losing consciousness. I need steady protein intake throughout the day to keep from getting brain hungry, so a good breakfast (egg whites are high on that list, and even a serving of oatmeal has almost as much protein as an egg) and then protein snacks throughout the day such as Greek yogurt, peanuts, baked chicken, tuna.

Third: I have two meals a day. Breakfast around 8 AM, and dinner after my mid-day nap, around 3 or 4 PM. The rest are small protein snacks (adding up to about 50 grams per day) except for the final meal of the day, which is usually high fiber cold cereal with soy milk, 2 hours before bed. Sometimes dried fruit, or fruit cookies with peanut butter are good.

I cut out bread (mostly), ice cream and desert in general, milk (soy milk instead), and salt. Increased: fruits and vegetables. Low sodium V8 juice is handy.

Oh, and there are a few tricks to eating out.

Fast food: sandwich only with water.
Restaurant: Split a dinner or take half home, no dessert. I have a general rule: it doesn’t have to be sweet, or salty, or fatty to taste good. And besides, you don’t want it to taste too good, or you’ll eat too much. These changes were easier to make than I thought they would be. The key was to cure brain hungry whenever it attacks. A swallow of V8 or an apple, or a handful of peanuts fixes the problem for an hour or two.

The Bottom Line

After just a week or two the new habits became normal procedure and weight began to slowly drop off. Now, after 3 months, I’ve lost 20 pounds and I feel much better. I’m starting to see myself as the thin, vital person I was 20 years ago – before PPS. I know I’ll never shed PPS, but now I can see that shedding the burden of all that dead weight improves health, activity level, mental function, and most of all, self image.

How about you?

Do you have a weight loss secret or other success story? Please share it with all the PPS folks here in your PPS NEWSLETTER.

From the California PPS Manager Newsletter
July/August 2012
Personal Memoir from the 1944 Kentucky Polio Epidemic

Adapted from an essay in Polio, U. of Rochester Press, 1997
By Mike Davis

From what I have read and heard from my fellow members of the Michigan and Southeast Michigan Post-polio support groups, my experiences with the disease aren’t much different, except I had just turned 13 a few weeks before infection, whereas many “polios” I have met lately were infants when they were hit. And my affliction has not included impaired breathing or mobility. Further, unlike infant onsets, teenagers remember what happened as well as what didn’t happen.

My Account

About 4 a.m. on a mid-July Thursday I was struck with a violent upset stomach, rushing to throw up in the bathroom. The vomiting, retching and nausea was accompanied for days with intense, throbbing headaches. My mother, an Army nurse in the First World War, tried to relieve my headaches with the traditional pre-chemical remedy: cold washcloths repeatedly applied.

I was moved into my parents’ first floor bedroom with the downstairs bathroom just behind, and the kitchen around the corner, altogether a convenient arrangement for the hot-pack months to come.

As reconstructed more than five decades later, the intense muscular spasms and pain must have started on the second day, Friday afternoon. They ran all over my torso, arms, legs, neck.

By the time those racking pains hit so long ago, my 13-year-old mind had already concluded I probably had contracted the disease that so terrified everyone. Louisville was in the throes of a polio epidemic. The newspapers printed stories every day reporting on the disease's progress, which I read even in my sick-bed. Locations of new victims were identified on a map of the county. Despite my pain and nausea, I recognized the symptoms listed in the newspaper — "stomach upset, vomiting, fever, headache and stiff neck" — and compared them to my experience.

Early Sunday morning the fourth day after onset, I struggled out of bed to the toilet in the adjoining bathroom. My left arm seemed loose, uncontrolled, wobbly. By afternoon, I couldn't lift it. That was July 16, 1944, and I've never had full use of it since.

That surely confirmed the diagnosis of my disease, if it had been uncertain before. Reconstructing from old newspaper clippings, I calculated that I became the 75th polio victim in Jefferson County out of 264 registered that year, the worst such epidemic in Kentucky history up to that time. The number of victims jumped from 71 on Friday, July 14, to 88 on Monday, July 17 — 17 new cases in three days.

If any other boys from the YMCA camp or the adjoining YMHA (Hebrew) camp came down with polio that summer, I never heard of them. Nor did any other person with whom I had personal contact in the days or weeks preceding my illness.

The terrible muscular pains must have continued for several days, but there is no clear memory of how long or how intensely. By that Monday evening, however, I was experiencing an entirely different and terribly discomforting pain in my belly. Dr. Buttorff was again summoned and quickly determined the problem: unable to void the bladder. Of course this was another sign of muscular paralysis. The ensuing catheterization — there were no numbing local anesthetics to apply in those days — was even worse than the racks of the muscular spasms and headaches.

Because of the intensity and rapidly rising rate of infection, the only two polio-treatment facilities, Kosair Crippled Children's Hospital and the city General Hospital, were swamped. The city-county health director had declared a state of epidemic on the previous Tuesday. Kosair had only 100 beds for all crippled children, and those patients who weren't new polio cases now were moved to other hospitals to make room for the critical new paralytic victims.

Continued next page
Likewise, both hospitals a couple of years before had adopted the then still controversial Sister Kenny treatment for polio, but there was a shortage of technicians and aides who knew how to work with it. Repeated appeals went out for local volunteers to help, and the Red Cross and National Foundation sent in professionals from out of town. Only a month before, the American Medical Association had proclaimed it did not support the Kenny treatment, saying there was no evidence it prevented paralysis — an incredible non-sequitur since the treatment was aimed at alleviating the effects, not prevention.

The Kenny treatment was usually thought of as "hot packs," cocoons of boiled wool blankets wrapped around paralyzed limbs and torsos. Actually this was just the first, although often lengthy, phase. Subsequent stages included physical therapy to stretch shriveled muscles and educating a patient to learn how to use atrophied muscles or alternative techniques for performing normal functions.

The ideal treatment called for starting the Kenny hot pack applications as soon as possible after onset — both to relieve pain and to relax paralyzed muscles — but with the peak of the epidemic at hand, there was no bed available for me at either Louisville hospital. Even though my mother hadn't practiced as a nurse for some 20 years, and doubtless was exhausted by the round-the-clock care my illness had demanded for several days, there seemed to be no alternative but to start home treatments. Counseled by the Crippled Children people over the telephone, she went to a second-hand store to buy surplus army blankets, a rubber sheet and large wash boilers to heat on the gas burners of the kitchen range.

Then came the visit of a true miracle worker, a man who was to change my life and those of countless others, never letting us become discouraged, always encouraging, always optimistic. His name was John Untereker, a strapping 32-year-old Swede from Minneapolis, trained at the University of Minnesota and the Kenny Institute, and head of the Kenny treatment department at Kosair in 1944. (In 1953, Untereker obtained his M.D. from University of Louisville and with that credential became a noted physical medicine and rehab specialist in New York City.) He bounded cheerily — his trademark — into my sickroom with a tape measure and a huge pair of shears, and proceeded to cut up the ingredients for a Kenny "sandwich," custom-fitted for me. He showed my mother how to build the layers of cotton sheet for my fair skin, doubled blankets, rubber sheet, and outer cotton blanket for each of my body and limb parts, and how to fasten them around me every hour with huge, diaper-like safety pins. Fortunately for my parents, almost immediately a bed opened for me at the Kosair facility.

The hassle then was finding an ambulance, because none of the commercial outfits would transport a contagious polio patient. But the American Legion would. Two volunteers, World War I veterans like my parents, and wearing Legion overseas caps, came in a 1939 Cadillac ambulance to cart me away. On the way to the hospital with my father hunched down beside me in the back of the ambulance, the Legionnaire at the wheel asked if I'd like to have the siren on — it wasn't necessary, he said, but they'd be glad to, for me — and I nodded yes.

Kosair's isolation ward for new polio "admits" was on the second floor of the Tudor-styled, three-story facility, and I was placed in the middle of three beds in a room on the sun-hot west side. The interior walls had glass panels above the waist level so that attendants could see into the rooms from the hallway and from room to room. Weak and lying flat on my back in an iron bedstead with thin mattress over thick board, all I could see — until I gained enough strength to sit up — were the white-masked faces of attendants moving back and forth, and the ceiling. One's feet were firmly placed against an upright board across the foot of the bed to keep foot muscles and hamstrings from shriveling.

Continued next page...
As to sounds, for my whole two weeks in isolation there was the continuous wheezing and clanking of the iron lungs, the mechanical breathing machines, in a room across the hall. These stainless-steel cylinders on wheeled legs maintained — by air suction and pressure — the breathing motions of their torso-paralyzed patients, who were entirely encased in the machines except for their heads, lying even more helplessly prone than the rest of the polio patients. Only once did any of the machines cease their wheezing, during my third night in the ward when we were aroused by a flurry of activity by doctors and nurses across the hall. Subsequently we were told a twelve-year-old girl had died in the lung.

This experience, along with the relative conditions of my two roommates, taught me the greatest lesson of my life. To my right was a fifteen-year-old boy from one of Louisville's poorer areas near the stockyards, where the epidemic fell heaviest. His throat and facial muscles were paralyzed so that he had to be fed with a tube and could not talk except for mumbles. To my left was Donald, a boy a year younger, whom I knew slightly from the ballroom dancing classes customary for 6th and 7th graders of our set. Donald had no obvious paralysis at all, nor was he as weak. Initially I seethed with envy. And then I came to realize the essence of that lifelong lesson: There is always someone worse off, and someone better off.

Because Donald could move about a bit, he was able to scramble to the foot of his bed and bring up the clipboard that gave our diagnosis and condition. "Poliomyelitis," he spelled out for me. We discussed whether this was the same as "polio" and "infantile paralysis." Finally we asked a nurse and had it confirmed. That was the first time I knew for sure that the dread disease had indeed got me.

Besides pain, sight and sound, the other vivid sense is smell, and for me the Kenny treatment indelibly associated polio with the smell of warm wet wool.
Personal Memoir continued…

neck to my toes — which allowed me, as I regained strength, to read the 25-cent paperback books (called "pocket books" in those days) my parents sent up to me. I accomplished this by holding a book overhead with my unparalyzed right arm locked upright, lowering it to turn each page with my right-hand fingers. It was tedious, but I was far, far better off than those patients who couldn't even do that. Being able to read was a huge relief from the endless boredom of lying helplessly flat on your back day after day.

After the quarantine period ended, patients were moved from the isolation ward to recovery rooms on the first floor. From my new place in the east wing at Kosair, I still couldn't see anything but treetops through the window to the south because I was closest to the hallway and still bedridden. Hot-pack treatments were reduced so that one could sleep through the night, and I began to get stronger. Most of all, it was great to see my parents again!

Because my mother and a family friend were both nurses and took special Kenny training to care for me, in mid-August I was released early from Kosair after only a month of hospitalization, in order to free my bed for a more recent victim of the epidemic.

I'll never forget being wheel-chaired down a rear ramp of the hospital and spotting my Dad's 1941 Nash parked under a tree on the hospital driveway. It was Freedom, and with nurses and aides and parents trying to restrain me, I rose to my feet for the first time in more than four weeks and shakily made my way the two-dozen steps or so to the car. My legs, though far from perfect, seemed to be okay. From my point of view that was an important milestone of recovery. Soon after, the best thing about being able to walk and getting home was being able to use the bathroom toilet and not hated bedpans and urinals. Again, I was so very, very more fortunate than so many Polios patients, especially those in the iron lungs and those with shiveled legs.

My weight loss was so severe that I literally could hold water in the hollow between the bones of my good right forearm. I dropped from about 120 to 90 pounds, at an adolescent height perhaps two inches less than my present 5'11". With good home cooking, that part of my physique recovered fairly soon.

Kenny hot-pack treatments continued over the next nine or ten months in my parent's bedroom around the corner from the kitchen stove's wash boilers. My mother and our family friend nurse worked out a schedule so neither would get too tired changing the packs every hour from early morning to nine or ten at night. When not undergoing these treatments, I carried my left arm in a cotton sling for many months. Specifically, the biceps, triceps, deltoid and trapezius muscles were significantly paralyzed and shortly began to atrophy, or shrink away. In addition, many other muscles in my torso, neck and legs had to be relaxed, stretched, strengthened or re-educated.

At first once a day and then three times a week I was driven to the outpatient clinic in the basement of Kosair, where John Untereker started my muscle re-education process. For example, over several months, I had to learn how to breathe naturally, not with just my chest but also my abdomen. Indeed, there were all kinds of involuntary muscles, previously unknown or unnoticed, that had to be re-educated. I had to stretch the shrunken hamstring muscles that ran from my feet up the back of my legs to my back. I had to learn how to swing my left arm consciously as I walked so that it would not dangle uselessly. And even though I thought I could walk okay, even that process required months of therapy.

Except for the left arm, fortunately all my other afflicted areas recovered over time to just about normal. My left leg is a tad shorter than the right, a fact tailors catch every time I'm fitted for new trousers, but otherwise is scarcely noticeable.

Upon release from bed confinement in order to start the physical therapy, I was also able to start visiting with the neighborhood kids and do continued next page…
kid things, like sitting around talking or playing hide-and-seek. Without consulting anyone, a couple of weeks after coming home from the hospital I wheeled my bike out of the garage and rode it a block away for a gathering. I was determined from the very beginning not to let this disease whip me! And, what the heck, I'd learned how to ride one-handed with my broken arm a few months earlier. When "Dr. John," as the other polio kids called our Kenny therapist, heard about this escapade, he laughed but warned me not to overdo, as it might cause a muscular relapse and setback. I sure didn't want that to happen; my freedom was valued now.

In the meantime, we pondered what to do about school. I should have been entering the 8th Grade that September. Public school openings were delayed a couple of weeks because of the epidemic but my own outlook was uncertain. The solution was enrolling at a private school, Rugby, situated in a turn-of-the-century Greek Revival mansion about a mile from our home. The private school could be flexible about my lessons and class attendance. By October, morning hot-pack treatments were discontinued, permitting me to attend school for a half-day. After January, treatments were reduced to late afternoons after a full school-day and evenings.

This routine of smelling hot wet wool and being literally steamed out to relax the muscles went on for eight months or so with occasional relapses until I departed for college in the fall of 1949.

The outpatient physical therapy treatments continued three times a week for three or four years, then dropped back to once a week, then once every two weeks and finally monthly. After the initial attention to muscular re-education and strength, therapy concentrated on trying to reconstruct what could be done with the left arm and shoulder.

For two years, there seemed to be no improvement at all, and I became discouraged. My mother took me to the leading orthopedic surgeon who worked with polio patients, of which there were literally hundreds in Kentucky. "How long has it been since the paralysis?" he asked. "Two years." "There's never any improvement after that long," he bluntly pronounced. He then proposed an operation to install a steel pin fastening my upper arm bone to my shoulder blade, so that by hunching my shoulder, I could lift my arm perhaps 30° outward. Now I was really discouraged. I already felt like a freak and didn't want to look and act like one as well. Discouragement was soon displaced by anger and renewed determination.

We went back to see John, the lowly physical therapist and Kenny practitioner. He listened to our account of the surgeon's prescription, careful not to dispute a senior member of the medical profession, an M.D. "Well, let's just keep working on it," he said, flexing my arm and instructing me to concentrate on thinking of lifting, hoping to trigger some forgotten muscle strand to cooperate.

At John's prescription, my mother installed a sling with a pulley arrangement on my bedroom closet doorjamb. With this arrangement I could practice raising my left arm several times daily, helping the dormant muscles by pulling down on the rope around the pulley with my good arm while thinking "lift" to my left.

Miracles do happen, and under John's care, my paralyzed arm's function improved more in the next year and a half than it had in the previous two years. I actually regained some degree of use in the biceps and triceps.

I continued at-home exercises and, when I reached New Haven, a several-times-weekly routine at the Payne Whitney gymnasium. One day when I was doing my exercises at the Yale gym, one of the assistant football coaches, not really noticing what I was working on, came up and said, "Say, you've got sturdy legs. You play football?" I was flattered but this was one hurdle I knew I'd never be able to jump, if for no other reason than my left arm and shoulder were extremely sensitive to pain from impacts because there was little protective...
personal memoir continued...

muscular tissue over the bones. But I did manage
to cross some other barriers.

The ever-optimistic encouragement that
John imparted to me, the ethic of never giving up,
the determination not to become discouraged,
infect ed many others as well. Some polio victims
were able to buy into John's enthusiasm but, sadly,
not all.

From the beginning of my physical retrain-
ing, I learned to improvise. At the very simplest, I
learned to put on a shirt or coat by pulling the
sleeve awkwardly up over my left arm and up to
my shoulder with my right hand, not pushing my
left arm down into the sleeve. Rather than reaching
out to grasp objects with my left hand, I learned to
crawl with my left fingers across whatever surface
was available to put the object in range. Or fasten
my left hand onto my right, using the right to carry
the left into position. Today I do this routinely,
automatically, never thinking it odd or awkward.

More complex adaptations were required
for driving a car. As soon as gas rationing was dis-
continued at the end of World War II, many of my
peers were learning how to drive, though under-
age for licensing. After some difficult driving in-
struction from my very nervous father, I tried driv-
ing on my own when my parents were away on a
business trip, starting up the Plymouth that my
mother had inherited a few months before and,
on a couple of days, teaching myself the basic
skills. When my aunt, a retired teacher who was
staying with me, asked my parents if doing this had
been okay, my father was so relieved from not hav-
ing to teach me that there were no retributions.

Teaching myself to drive was especially
challenging in an era when cars had "three-on-the-
tree" manual transmissions, steering was not
power-assisted and manual left-arm signals pre-
dated electric turn-indicator lights. While shifting
gears with my right, I steered by holding my left
arm in my lap, fingers gripping the wheel, nudging
the arm up with my left knee as required; to get
leverage, I crawled my fingers up the circumfer-
ence of the wheel where gravity of the arm's dead
weight could be used to pull it right or left. For sig-
aling turns and impending stops — as required by
law — I would first reach across with my right arm
to crank the driver-side window down. (Power win-
dows were far off in the future.) Then I would
hunch my left forearm onto the window sill. For a
right turn, I would crawl my fingers up the front of
the window frame until I could catch the wind in
my palm and flip the forearm back to an upright
position where I could lock the elbow joint at a
right angle; for a left turn, I would let the wind
fling the arm straight out, locking the elbow
straight. Signaling a stop was easy, as all I had to
do was drop the arm down alongside the door.
These signals required a degree of planning be-
cause the car had to be moving to create the wind
pressure necessary for the motions.

My stubborn refusal to "give in" to polio
has continued for many decades. Although popular-
ly priced cars began to offer automatic trans-
missions in 1950, I didn't succumb for my personal
car until 1991 and still drive a "stick" as readily as
an automatic. However, as soon as electric, self-
canceling turn signals became available as accesso-
ries around 1950, I mounted one, and I compro-
mised in the late Seventies by finally ordering
power steering and power windows. Another op-
tion I readily accepted was the mechanism to ad-
just outside mirrors by remote control from the
instrument panel. Today, all these one-time op-
tions or accessories are standard equipment.

I still steer, unconsciously, one-handed
much as I learned over 60 years ago, with left arm
in my lap, fingers guiding the wheel from the bot-
tom of the rim. Curiously, my oldest daughter
steers the same way. I suppose she observed me
during her formative driver-learning years.

Nevertheless, drive-up ATM's, parking ga-
rage ticket-dispensers, curbside mailboxes and
such are still sources of frustration, requiring me to
reach across with my right arm to use them.

Further improvisation became necessary
when another psychological aspect of my recovery
manifested itself — a need to prove my manhood.

Continued next page...
Personal Memoir continued…

It is hard to explain how inadequate a teenager afflicted with polio feels. In the 9th grade I managed to earn a letter in soccer, a little known sport in those days in Kentucky, mainly because I was of a good size for my age, had regained full ability to run hard — and having only one good arm didn't matter.

Two years later a pair of miracle workers came my way. The school had hired two young war veterans to coach basketball. One day at recess, they came up to me and the hefty blond one said, "Why aren't you out for basketball? You're tall and fast on your feet, and we could use you." "Oh, I can't play basketball, I've only got one good arm," I replied. They looked at one another, and the slender dark-haired coach said, "Look here, I caught a German shell in my arm during the Battle of the Bulge. I have full disability." He took my sleeve and tugged me over to his new Pontiac sedanette. "See the special steering wheel and the Hydramatic transmission? The Government paid for those, for my disability. I learned how to play basketball again, and we can teach you, if you'll give it a try." I couldn't say no.

And they did teach me, how to shoot one-handed, how to move the ball around, how to use the plays and one-on-one tactics to my advantage. I wasn't the greatest player, but I did win my letter. I had the satisfaction of being a good ball-stealer because of my speed, height and ability to anticipate competitor's moves.

There were other barriers to be overcome: ROTC, National Guard, intramural softball, private pilot’s license. I imagine every Old Polio has his or her own list. My career as a journalist—author-lecturer has been unaffected by polio. Only in recent years—later than most Polios—have I become afflicted with Post-Polio syndrome symptoms like fatigue—or could it be the 80-plus years on the odometer? My main frustrations/annoyances are new-found difficulties in fastening shirt buttons and tying shoelaces or a necktie (therefore I mostly wear pullovers), holding a dish in only one hand at buffets, carrying a tray in cafeterias and placing carry-on luggage in airline overhead compartments.

Until recently I played a hacker's golf game, rarely breaking a hundred, but enjoying the exercise. I've never blamed my links mediocrity on polio; I think I'm simply not that well coordinated. I played for years with some colleagues who were surprised to learn I had a paralyzed left arm.

Indeed I've had acquaintances for decades who, noticing me pulling on my coat or perhaps not swinging my left arm fully when I walk, ask if I "just" hurt my arm. "Yeah, years ago," I tell them. When I explain, they more often than not will comment, "Well, you really came out all right, didn't you."

"There's always someone better off and someone worse off," I tell them.

MPN BOARD MEETING 2013 SCHEDULE

ALL MEETINGS WILL BE AT
BAKERS OF MILFORD
2025 S MILFORD RD
MILFORD TWP, MI
ALL MEETINGS WILL BEGIN AT NOON

JANUARY (meeting will be an e-mail up date)
APRIL 6, 2013 (This is actually the March Meeting)
MAY 18, 2013 (Annual meeting following the regular meeting)
JULY 20, 2013
SEPTEMBER 21, 2013
NOVEMBER 16, 2013
Greetings of the winter season, dear Readers. I hope that this January or, even, February day finds you as well as can be expected for a winter day. Writing into the future can be tricky, of course. Maybe the snow of Christmas week has continued to pile up (our little street is being plowed as I write), covering the landscape and insulating whatever is below, waiting to burst into growth as spring arrives...on time, this year?? Perhaps we're in the midst of signs of another early warm season, though, with worries about the frost to follow and how that will decimate the early bloomers. If it ain't one thing, it's another, right? Or even still, you may be reading this effort in one of the warmer-most-of-the-time places to which we send this newsletter, with thoughts of snow, ice, and out-of-kilter seasons low on your list of "interesting topics." Oh, well...wherever you find yourself, you have my best wishes for a healthy new year.

Books? I haven't ordered any lately. Quite honestly, there aren't very many new ones about at this time, at least not where I've been looking. I did find something awhile back, but it's price ($135-WHA ???) made me hesitate to even look further, fearing I'd press the wrong key and end up in a tangle of trying to cancel the order I didn't mean to make. A friend is coming over for a visit and a trip to the local computer store, though, and she's bringing information about chair exercise which may be of interest to some of our members. We shall see....

Borrowing books?? There haven't been many requests lately. I hope it wasn't something I said/wrote, but my Librarian's Hat is getting rather dusty. At least the one I wear when organizing book-borrowings and taking same to the Post Office for mailing to you is looking positively cobwebby, which is both a testament to my housekeeping and to the fact that I haven't had to wear the thing much lately (HINT! HINT!!). It would be a shame to have me replaced by a computer, so please consider contacting me about borrowing a book, video/DVD, whatever. The list of materials is on the new MPN website (www.michiganpolionetwork.com), which looks very good, from what I've been told. As always, if you have read/heard of a book or something else which doesn't appear to be in the collection, contact me (248-853-5465 or denilaur@sbcglobal.net) and I'll see what I can find out about ordering it for you and others to borrow.

Meanwhile, stay warm (or for those in other climes, cool), healthy, and contentedly reading. Take care!
Laura Barbour, Librarian

10 Commandments For Reducing Stress In Your Life

1. Thou Shalt Not Be Perfect, Or Even Try To Be
2. Thou Shalt Not Try To Be All Things To All People.
3. Thou Shalt Sometimes Leave Things Undone That Ought To Be Done.
4. Thou Shalt Not Spread Thyself Too Thinly.
5. Thou Shalt Learn To Say No.
6. Thou Shalt Schedule Time For Thyself And Thy Supportive Network.
7. Thou Shalt Switch Off And Do Nothing Regularly.
8. Thou Shalt Be Boring, Untidy, Inelegant, and Unattractive At Times.
9. Thou Shalt Not Even Feel Guilty.
10. Especially, Thou Shalt Not Be Thine Own Worst Enemy But Be Thine Own Best Friend.

From Harvest Center’s Post Polio posting
By Cindy Koshinski Bernstein
LIGHT - WHEN THE POWER IS OFF

I have a friend who used her solar lights inside at night when her current was off during the hurricane. She stuck them in a jar or bottle and said they gave off plenty of 'free light'. She put one in each room and would put them back outside in the daytime and bring them in at night as long as the current was off. They are safe to use and cheaper than batteries. Bring in a solar light one night and test it.

Due to a thunderstorm, we lost power for about 5 hours. We were scrambling around in the darkness, looking for matches, candles, flashlights, etc. We looked outside, and noticed our solar lights shining brightly all around our patio, stairs, dock, etc. They were beautiful. My wife walked outside, and brought several of the solar lights inside.

We stuck the solar light pipes into plastic drink bottles containers and they made the nicest, brightest, safest, lighting you could ever imagine. We put one in the bathroom, the kitchen, the living room, etc. There was plenty of light. There are all types of solar lights available. We bought ours at Harbor Freight. We put them all around our yard. They look nice and they do not attract flying bugs like the outdoor lights around our doorway.

The lights we have fit into the small (20 oz.) water bottles and they also fit into most of the larger liter bottles. If you need a weight in the plastic bottle to keep them from tipping over, you can put a few of the pretty colorful "flat marbles" that they put in aquariums, and vases. (you can also use sand, aquarium gravel, etc., whatever you have available).

The lights we have were perfect inside our home. They burn all night long if you need them. The next day, you just take your solar lights back outside and they will instantly recharge and be ready for you to use again any time you need them. Perfect for power outages, hurricanes, etc.

I never thought of it, and now you don't have to.

Contributed by Professor Mike.

Odd Shoe Exchange

By John Kippe

Some years back there was an Odd shoe Exchange offered in the Polio Perspectives and later on the Internet. I took part in it and found a person to exchange our odd shoes. Sadly the person has passed away and I am left with the odd shoes we shared.

So now I wish to advertise my odd shoe sizes.

I have shoes and boots available in sizes:

    Size 7 right foot
    Size 10 1/2 left foot

If you can use any of these size shoes please

call me at 810-655-4927

Email me at jandjkippe@aol.com

John Kippe
6205 Anavista Dr.
Flint, Michigan 48507
STABILIZING VACCINES AND ANTIBIOTICS WITH SILK

Researchers developed a way to use silk to store and distribute vaccines and antibiotics without having to keep them cold. By eliminating the need for refrigeration, the technique can lower costs and help expand the use of these lifesaving medical tools around the world.

Most vaccines and antibiotics need to be refrigerated to remain effective. Their chemical structures break down when they’re exposed to heat or humidity, making them less potent. These compounds are currently handled by “cold chain” distribution networks, which keep temperatures down during transport, storage and handling. The process is expensive, accounting for up to 80% of the cost of vaccines.

The cold chain system severely limits the availability of vaccines and medicines in developing nations. Billions of dollars worth of drugs and nearly half of all global vaccines are lost annually due to high temperatures and humid conditions.

A research team led by Dr. David L. Kaplan at Tufts University investigated whether silk protein could increase the shelf life of vaccines and antibiotics at higher temperatures. Silk fibers purified from silkworm cocoons are highly resistant to changes in moisture and temperature. Previous studies have found that the fibers can form a mesh-like environment that helps to immobilize molecules and stabilize their structures.

The team developed a new silk-based film and tested it with the live measles, mumps and rubella (MMR) vaccine as well as the antibiotics penicillin and tetracycline. The MMR vaccine quickly loses potency above the recommended storage temperature of 2 to 8 °C (about 35 to 46 °F). Penicillin and tetracycline also break down quickly when unrefrigerated. The study was funded by NIH’s National Institute of Biomedical Imaging and Bioengineering (NIBIB), National Eye Institute (NEI) and National Institute of Dental and Craniofacial Research (NIDCR). It appeared on July 9, 2012, in the online edition of Proceedings of the National Academy of Sciences.

The researchers found that immobilizing the MMR vaccine in the silk film greatly enhanced its stability.

Even after storage at 45 °C (113 °F) for 6 months, the vaccine retained more than 80% of its potency. Typically, the MMR vaccine would rapidly lose all its potency under those conditions.

Immobilizing antibiotics in silk greatly increased their stability, too. Tetracycline lost only 20% of its activity when stored in silk at temperatures as high as 60 °C (140 °F) for 4 weeks. These conditions would normally eliminate all its activity. Penicillin lost no detectable activity when stored in silk at 60 °C for 30 days. Typical storage of the drug under those conditions would bring a 20% loss of activity.

The ability to store vaccines and medications at high temperatures for long periods of time would enable much more effective distribution. This technique could have a significant impact on the health of people in developing nations.

“We have already begun trying to broaden the impact of what we’re doing to apply to all vaccines,” says Kaplan. “This could potentially eliminate the need for the cold-chain system, greatly decreasing costs and enabling more widespread availability of these life-saving drugs.”

U.S. Department of Health & Human Services
NATIONAL INSTITUTES OF HEALTH
July 23, 2012

A truly happy person is one who can enjoy the scenery on a detour.
POST-POLIO SYNDROME NOT SECOND VIRUS ATTACK

PAUL DONOHUE To Your Health

Dear Dr. Donohue:

My wife’s father is 91 and was in excellent health until a month ago. He began to experience pain. He barely could rise from the sitting position. Many blood tests were run, and he was referred to an orthopedic clinic. He underwent a physical exam from an internal medicine specialist. He was referred to a neurologist, who performed an EMG (electromyogram, used to detect nerve-muscle problems). Since he had polio at age 34, the neurologist diagnosed post-polio syndrome. Will you comment on it? Since the polio generation is reaching older ages, I thought it would be helpful to make others aware of this illness. -G.S.

Dear G.S.: Thanks to the polio vaccine, many people know little about polio or the fear it used to provoke in people of all ages. The polio virus destroys nerve cells that activate muscles. The infection causes varying degrees of paralysis and, in some instances, death.

Now a percentage of people who were victims of polio in the bad old days are having to deal with a second blow from that old infection—post-polio syndrome. It’s not a resurrection of the polio virus. What happens is this: Nerves adjacent to the ones destroyed by the polio virus took over some of the duties of the killed nerves. That allowed many polio patients to carry on their lives effectively. At older ages, those neighbor nerves are dying from the strain of having to do double duty. That results in a resumption of pain and weakness in the affected muscles. There’s no medicine that rids the burden of post-polio syndrome. But pain relief is achievable. Pacing oneself improves muscle weakness.

Your father-in-law and his family can obtain timely information on this syndrome from the Post-Polio Health International. Phone (314) 534-0475, and at www.postpolio.org.

Write to Dr. Donohue at P.O. Box 536475, Orlando, FL 32853-6475.

The U.S. Centers for Disease Control Suggests you Make These Preparations

EMERGENCY CONTACTS.
Make a list of emergency phone numbers. Keep it in a plastic bag. [Your local police and fire departments should know you are handicapped and need help if you have to evacuate your home]

WATER.
At least one gallon per person per day for three days.

FOOD AND OTHER PROVISIONS.
A three-day supply of non-perishable (canned or dried) food per person. Baby and pet supplies as needed.

FLASHLIGHTS AND EXTRA BATTERIES.
A first-aid kit and a seven-day supply of medications and medical items such as glasses, contact lenses, syringes, cane, etc.

PERSONAL DOCUMENTS.
Medication list and medical information, proof of address, deed/lease to home, passports, birth certificates, insurance policies and contact information for your home insurance agent. Keep in a plastic bag.

EXTRA CASH.
Charged cell phone, plus a charger and extra battery. [Although this was not on the list, if you have a cell phone charger that works in your car, you can charge your cell phone in your car. OnStar should also work.]

EXTRA BLANKETS.
These are needed since polio survivors have cold intolerance and difficulty regulating our body temperature. If the power goes out, that often means your furnace goes out as well. Therefore, I advise gathering several blankets and having them in easy reach.

*****
ANN ARBOR (PPSG)
Liina Paasuke (734) 332-1715
Sunny Roller (734) 971-1335
Meetings 3rd Tues. of August and December.

CLIO AREA POLIO SURVIVORS SUPPORT GROUP
The New Clio Area Polio Support Group is held at the Clio Area Senior Center 2136 W. Vienna Rd. Clio, MI 48420
On the third Friday each month at 9:00-10:30am.
Facilitator is Dennis Hoose.
To join our group call (810) 687-7260

HARTFORD, MICHIGAN - PPSG
Jeannie Wessendorf
Support group meetings at Hartford Federated Church, Hartford Michigan for meeting times please call Jeannie at 269-621-2059 or email jeanniew@provide.net

LANSING AREA SUPPORT GROUP
Meet April thru December (except for July)
Margaret Nielsen Williams (517) 336-5921
nielsenwilliams@yahoo.com

MID-MICHIGAN (PPSG)
Jean Iutzi, Harrison, MI (989) 539-3781
Group info. 1-800-999-3199
Meeting twice a year. June and Nov.

SOUTHEAST MICHIGAN (PPSG)
Bonnie Levitan (313) 885-7855
co-facilitated by Bruce Sachs (586) 465-3104
Dianne Dych-Sachs (586) 465-3104
Bobbi Stevens (248) 549-2149
Meets 4th Sat. of the month
March thru October 10am-Noon

THUMB AREA PP SUPPORT GROUP
Rita Wall (989) 673-3678
Blue Water Center for Independent Living
1184 Cleaver Rd Suite 1000
Caro, MI
Meets last Tuesday of each month 2:30pm

WEST MICHIGAN PPSG
Scheduled Meetings:
April, June, Sept, Nov
Linda Walthom Grand Rapid (616) 363-7625
Lynette Hooker Grand Rapids (616) 455-5748
Email: lysue@inbox.com
Chuck Bond Rockford (616) 866-1037

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info@post-polio.org www.post-polio.org
POLIO SURVIVORS SHARING

This is a one-on-one e-mail list so you can mail only to the selected name; an e-mail list of Polio Survivors who wish to communicate with other Polio Survivors and discuss your concerns, ideas, fun, jokes, as well as sharing information of what is happening to each other. I would like your permission to add you on this list. Please email to vlhazel38@comcast.net to get on the list! Also include your city and state.

Happy Sharing!! ☺  Vera Hazel, Editor

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MICHIGAN POLIO NETWORK INC
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EDUCATIONAL POST-POLIO CONFERENCE
AT THE
GENESYS CONFERENCE & BANQUET CENTER
GRAND BLANC, MI 48439
SATURDAY OCTOBER 5, 2013
8:45 AM TO 3:00 PM

SPEAKERS

PROFESSOR MIKE KOSSOVE
MICROBIOLOGIST
TOURO COLLEGE NEW YORK, NEW YORK

VIJAYALAKSHMI NAGAPPAN MD
INTERNAL MEDICINE, INFECTIOUS DISEASE
OAKWOOD HOSPITAL

DEVINDER MAHAJAN MD
INTERNAL MEDICINE, PULMONARY MEDICINE, SLEEP MEDICINE
OAKWOOD HOSPITAL

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THE SPRING POLIO PERSPECTIVES NEWSLETTER

AND AT

www.michiganpolionetwork.com
Request to all membership

Please check the mailing label on the back of this Polio Perspectives for the expiration date of your membership. If membership renewal is due, your check should be sent along with the completed Membership Form found in this issue.

Please direct all MPN MEMBERSHIP and ADDRESS CHANGES to one of the following Board Members:

Tim Brown at 313-886-6081
(tpbrown47@gmail.com)

or

Laura Barbour at 248-853-5465
(denilaur@sbcglobal.net)

Two Post-Polio Clinics in the Southeast Michigan Area

St. John Post-Polio Clinic
Center for Physical Medicine & Rehabilitation, P.C.
13850 Twelve mile Road
Warren, MI 48088
Phone: 586-778-4505
Fax: 586-552-4878

University of Michigan
Post-Polio Clinic
Eisenhower Park West
2850 South Industrial Highway Suite 400
Ann Arbor, MI 48104-0758
Phone: 734-936-7175
Fax: 734-975-4726

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The Michigan Polio Network, Inc. is a tax Exempt non-profit organization with 501 (c) (3) status. Your contribution is tax deductible as allowed by law.

Membership includes our quarterly newsletter Polio Perspectives, use of our library, voting privileges as well as the networking and support from our membership.

To join it is not necessary to be a resident of Michigan or be a Polio Survivor.

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Name ________________________________
Address _____________________________________
City ____________________________
State:___________ Zip: _____________
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E-mail _________________________________
Are you a Polio survivor? ( ) Yes ( ) No

MEMBERSHIP FEE ONE YEAR .......... $15.00
MEMBERSHIP FEE FIVE YEARS ..... $65.00
LIFE MEMBERSHIP FEE ............. $150.00

I wish to make a contribution to support the work of the Michigan Polio Network, Inc.

$________________________
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