Is It Post-Polio – Or Something Else?
Bruce Lambert, Hempstead, New York

Post-Polio Syndrome – oh, that devilish master of disguises and confusion!

As a polio survivor, I have been fooled more than once. My doctors, too, even the good ones.

When I first developed post-polio syndrome, I erroneously suspected other causes for my problems. Even a neurologist scoffed at post-polio as unlikely.

But eventually post-polio was diagnosed. Then I made the opposite mistake, blaming post-polio as the root of every new problem. Wrong, again.

Take the example of my right groin, which I injured four years ago. Ever since, it was sore and stiff with limited flexibility. The nagging discomfort drastically worsened last summer as my entire leg weakened. I limped and needed a cane, then two canes. I was alarmed.

From the start, my doctors (an excellent primary physician, two locally prominent neurologists and a pioneering post-polio expert) had assumed my groin symptoms were just another part of my late-effects polio. I accepted their assessment.

They were all wrong, and so was I.

By chance, an entirely different diagnosis emerged. A neurologist had sent me to a physical therapist to strengthen my back, after multiple MRIs and x-rays had uncovered spinal arthritis. The doctor’s referral didn’t even mention my underlying post-polio.

In a 20-minute exam, the therapist could not find enough back pain, weakness or stiffness to warrant treatment. I told him what I thought my real problems were: post-polio, groin injury and lame leg.

“Have you had a hip x-ray – has anyone ever suggested it?” the therapist inquired. Puzzled, I replied: “No. Why are you asking?” He said: “Your symptoms could be from a bad hip.”

How right he proved to be. X-rays and two orthopedic surgeons confirmed severe hip arthritis. A cortisone injection magically banished the pain for weeks, my leg rebounded, and I put my canes aside. The shot did not repair the hip, of course, and the cortisone relief gradually wore off. So later this year I plan to get joint-replacement surgery.

“I may be your first patient who is glad he needs a hip operation,” I told the surgeon. “If my problems were caused by post-polio, they can’t do much about that.”

There’s a moral to my hip episode. Correct diagnosis is essential to health care, and polio survivors face a recurring challenge. Whenever a new problem arises, we must grapple with whether it’s post-polio syndrome or something else.

We are susceptible to automatically blaming polio. Many of us were ignorant of post-polio or in denial about developing it. But once confirmed, it can bias us to see everything through that lens. Military experts talk about the mistake of “fighting the last war” – misapplying old tactical lessons to new and different situations.

For me – and my doctors – diagnosing polio was tricky from the very beginning.

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The Long View: Remembering Dr. Ernie Johnson

Dr. Ernest W. Johnson passed away, Tuesday, November 18, 2014, spending his final hours in the rehabilitation center he helped establish, Ohio State University’s Dodd Hall. His association with the university lasted 57 years and is considered the longest in the history of The Ohio State University (OSU). He was 90 years old.

In *Acute polio and its evolution: reminiscences of a ‘polio fellow,’* Ernie, as he often requested to be called, wrote in the 1970s,

“My pivotal encounter with rehabilitation medicine began as I assumed my required service in the emergency room. One of the first patients I saw was a 19-year-old painter who had fallen from a scaffold and fractured his neck at C-6 (spared complete spinal cord injury.) I quickly referred the patient to OSU, which had just initiated a rehabilitation program.

“Seven months later (yes, you could keep a tetraplegic person for that long) I was asked to join the discharge conference. During that visit, I met Dr. Ralph Worden, the founding director of the physical medicine and rehabilitation program at OSU. He suggested that I apply for a National Foundation of Infantile Paralysis fellowship.

“Many of the original leaders in rehabilitation were ‘polio fellows.’ I spent my last month of the residency at the Mayo Clinic with Dr. Edward Lambert, the acknowledged ‘father’ of electromyography in this country. I copied all of his instrumentation and brought it back to the Columbus Children’s Hospital. My next step was to study the acute illness of polio and record the initial electromyographic findings in addition to those findings later in the disease. There was controversy about whether the motor conduction velocity was reduced in polio. Dr. John Guyton and I dispelled this notion.”

Dr. Johnson became the world’s foremost authority on the use of electromyography (EMG), a tool used in the diagnosis of nerve and muscle conditions. Additionally, he instructed more than 300 physical medicine residents instilling in them his “patient-first” philosophy.

He was one of that generation’s leaders who never forgot what he learned during the polio epidemics and put himself in a position to pass that knowledge on to other health professionals. Just as he remembered his mentors, many physical medicine and rehabilitation physicians (physiatrists) remember his influence on them.

As polio survivors and others with disabilities, we have been the beneficiaries. Thank you, Ernie.
As a polio survivor, you need to know that Social Security has special instructions for examiners who evaluate disability claims that involve postpolio sequelae.

Let’s quickly review the general rules. The Social Security Administration has a five-step evaluation process, known as the “sequential evaluation” process. The first question is whether the claimant is working at full-time employment; if yes, the claim is usually denied at this step. The second step is whether the impairment involved is considered “severe;” if it isn’t, the claim is generally denied. The third step is whether the impairment meets SSA’s criteria at Listing #11.11. If it does, the claim is awarded here. If not, the claim proceeds to step four. Here, the decision is made as to whether the individual can return to his or her former job. If not, the claim goes to step five to consider whether the claimant can perform other work on a full-time, competitive basis.

And now, let’s look at the special rules that Social Security applies to disability claims involving postpolio sequelae. The source is Social Security Ruling 03-1p. It states, “Disorders that may manifest late in the lives of polio survivors include postpolio syndrome (also known as the late effects of poliomyelitis), early advanced degenerative arthritis, sleep disorders, respiratory insufficiency and a variety of mental disorders. Any one or a combination of these disorders, appropriately documented, will constitute the presence of ‘postpolio sequelae’ for purposes of developing and evaluating claims for disability on the basis of postpolio sequelae under Social Security disability. Even though some polio survivors may have had previously undetected motor residuals following the acute polio infection, they may still report progressive muscle weakness later in life and manifest any of the disorders listed above.”

The diagnosis of postpolio sequelae is, by itself, not enough to qualify for Social Security disability benefits. The claims examiner is looking for the ways this condition limits your ability to do the kinds of activities that jobs demand. What kinds of “functional limitations” are often found?

Social Security Ruling 03-1p states, “Individuals experiencing postpolio sequelae may complain of the new onset of reduced physical and mental functional ability. Complaints of fatigue, weakness, intolerance to cold, joint and muscle pain, shortness of breath and sleep problems, mood changes, or decreased attention and concentration capacity may hallmark the onset of postpolio sequelae. Weakness, fatigue or muscle and joint pain may cause increasing problems in activities such as lifting, bending, prolonged standing, walking, climbing stairs, using a wheelchair, transferring from a wheelchair (e.g., from wheelchair to toilet), sleeping, dressing and any activity that requires repetition or endurance. Changes in attention, cognition or behavior may be manifested by reduced capacity to concentrate on tasks, memory deficits, mood changes, social withdrawal or inappropriate behavior.”

SSR 03-1p continues, “Many polio survivors who had been in a stable condition may begin to require new or additional assistive devices, such as

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Many polio patients fear anesthesia. Multiple surgeries in childhood were common for those who had polio, and anesthesia care then was not as sophisticated as it is today. Modern anesthesia is much improved since the time of polio epidemics! I have been asked, as a polio survivor and an anesthesiologist familiar with modern anesthesia practice, to answer recent, common questions asked by post-polio patients.

Do I really need to have a colonoscopy? It requires anesthesia, and I’m afraid of that.

Colon cancer is the third most commonly diagnosed cancer and the third leading cause of death from cancer in the United States. About 5% of Americans will be diagnosed with colon cancer in their life-time. Colonoscopy (looking at the lower part of the intestine with a flexible telescope, to identify early/possible colon cancer) is currently the most accepted way to identify early colon cancer; it has been well-documented to save lives because early lesions can be identified and removed.

Newer tests (virtual colonoscopy, stool DNA mutation tests and immunochemical Fecal Occult Blood Tests [FOBT]) have been developed recently, but only virtual colonoscopy has been compared with colonoscopy. It compares favorably, but it is not possible to treat lesions found. If lesions are found, you must still have a regular colonoscopy. There may also be problems with insurance payment for virtual colonoscopy.

- Colonoscopy is recommended for everyone over age 50 years, earlier if you have a family history of colon cancer or other risk factors. You must have a bowel prep, to remove stool so the endoscopist can see lesions, and anesthesia (sedation) is usually given for patient comfort – bowel inflation with gas, to distend the colon, is needed, and is uncomfortable.
- You need to commit to getting screened somehow for colon cancer. Which screening is best depends on you and your MD’s experience. Colonoscopy should be done by an experienced Board Certified gastroenterologist, in a certified outpatient facility. The risk of anesthesia is small compared to the risk of colon cancer.

Why is it so hard to link up ahead of time with the anesthesiologist who will handle my case?

Daily anesthesia staffing is a complex equation. It is extremely difficult to know ahead of time who will be doing which case on a particular day. There is a constant flux of anesthesia staff (people get sick), other needed staff such as techs, incoming emergency cases, obstetric anesthesia cases, cases may move from one operating room to another for equipment or staffing problems, and so on. And, anesthesia group size is increasing; it is not unusual to have groups of over 100 anesthesiologists.

So, what can you do, given these problems? Two helpful possibilities follow:

If at all possible, try to have your operation at a major university hospital.

This gives the best chance of getting quality care (not only anesthesia care). Check its accreditation data on the Joint Commission for the Accreditation of Health Care Organization’s website. Many states also have hospital quality data on the web. Most academic hospitals also have pre-operative clinics in which patients are screened ahead of time. These are extremely helpful in identifying and preparing for difficult patients. They also have an array of expert physicians.
in many areas. Especially important here is ICU care and MDs capable of handling respiratory failure postoperatively.

**Use your surgeon to lead the way to the anesthesia department.**

Surgeons and anesthesiologists work together daily and often become “teams,” making it easier for them to work together on a difficult patient. When an operation is being planned, explain your post-polio issues (scoliosis, pulmonary failure and a history of iron lung use are red flags here) and ask that they be noted during scheduling and also if the surgeon could speak with the anesthesia department ahead of time, to warn anesthesia staff you’re coming and what the issues are.

**What’s new in anesthesia that I need to know?**

This is a brief listing:

- Better measurement of quality of care in anesthesia and better recognition of where problems are and how they could be improved.
- Increasingly sophisticated knowledge of ventilation problems and better management of respiratory problems post-op.
- Recognition that many patients are left with residual neuromuscular block and the possible complications.
- The desirability of using both regional anesthesia and general anesthesia together, for improved outcome.
- Shortages of standard anesthesia medications are happening, due to changes in the pharmaceutical industry. This has caused many problems.
- Does the medical literature document anesthesia problems for post-polio patients? A 2013 review found no unusual problems and that regional anesthesia was not reported to cause worsening of PPS.

**What are the issues in bariatric (intestinal surgery that can facilitate weight loss) surgery for post-polio patients?**

This sounds like a “quick fix” for obesity but is an area full of possible problems. There are no reports of post-polio patients having bariatric surgery.

Possible problems relate to the disease obesity (diabetes, presence of sleep apnea, presence of a fatty liver, the increased difficulty of anesthetizing obese people), where the procedure is done (outpatient facility/in a hospital), the procedure done (lap band or gastric bypass) and who does the operation. Lap band (placing a flexible plastic band with an injection port around the upper stomach and inflating the band as needed) sounds simple and quick, but the bands can have complications and may need to be removed.

Best results come from dedicated teams, including a dietitian, at academic medical centers. Long-term follow-up is essential!

*A Spanish translation of this story is available online at www.post-polio.org/edu/AnesthesiaUpdateSp2014.pdf.*
Choosing the Best Mobility Device for Your Needs
Kate Hofmann, Marketing Manager, Amigo Mobility International, Inc., Bridgeport, Michigan

When searching for a mobility device to help you stay active, it’s easy to become overwhelmed by all the options available. Finding a home medical equipment (HME) dealer who listens to your needs is important, but it helps to learn as much as you can and be a well-informed consumer. The following questions will help you become your own mobility expert and determine which type of device will help you stay comfortable, active and independent:

What type of device is right for you?
It is important to meet with your doctor to discuss your abilities and needs before you even start shopping for a device. With most conditions, doctors want you to remain as active as possible. The Medicare algorithm (see diagram on page 7) provides a guide for prescribing mobility equipment for different levels of disability. As people’s disability or age progresses, they may need to move further down the algorithm to a more advanced device.

Where will you use the equipment?
A good mobility consultant will ask if you plan to use the device primarily in your home, outdoors or both. This decision will help determine what type of tires and motor you will need, as well as what size will work best in your home or your vehicle.

Do you need customized seating?
Especially if you will use your device for more than four hours a day, seating is very important. Inadequate or improper seating can lead to pressure sores, poor posture and other injuries. Depending on your disability, you may need specialized seating to help with certain tasks. Specialized seating may include cushions, angled seating, swivel seats or a power seat lift to raise and lower as needed. If you are unable to stand or walk, consider how you will transfer to and from your mobility device to help you determine what seating options may be helpful.

Do the controls on the device provide comfortable and safe driving?
The type of controls you require will depend on your abilities and upper body strength. If you maintain some or all of your upper body strength, consider a manual wheelchair, which is self-propelled, or a power-operated vehicle (POV)/scooter with handle controls. People with very limited upper body or hand strength should consider a power wheelchair with a joystick for easy operating.

What size device is best?
Many devices have larger handles, bigger wheels and longer platforms. In most cases, the ideal device shouldn’t be much larger than your body. Before purchasing, ask your dealer to bring the device to your home so you can try it and make sure it fits in your vehicle. Sometimes a few inches can make a huge difference when fitting through doorways or closing your trunk.

Are treaded tires better?
The choice of tires often depends on where the device will be used. Treaded tires are ideal for outdoor use, but may bring dirt and stones into your home if the device is also used indoors. Ask your dealer about different tire options for the device you choose.
How will you transport the device?
If you plan to use the device outside your home, it’s crucial to consider how you will transport it. The device may be able to fit in your current vehicle using a compatible lift, or you may need a specialized van. Some devices can be taken apart for transporting, so ask your dealer or the manufacturer for a recommendation on how best to transport your chosen device.

Are products advertised as “FREE” too good to be true?
Each type of mobility device is reimbursed differently through Medicare. Before making your decision, talk with your doctor to determine the best equipment for your needs and abilities. Many people who have received a device for free later find it does not suit their needs, doesn’t work in their home or they can’t transport it, and in most cases the person is unable to return the device. Use your Medicare dollars wisely to buy equipment that fits you, your home and your lifestyle. Once you decide which equipment is the right fit, ask what your financial responsibility will be so you can plan ahead.

How much will the device cost?
Though devices are priced differently, low prices aren’t always a “bargain.” Be sure to estimate the life cycle costs of the product, especially if you will use it every day. Ask your dealer about service replacement costs of key components and how often batteries generally need to be replaced. It is also helpful to understand exactly who to call for service repairs before buying and how quickly repairs can be completed.

At the end of the day, you know your needs and abilities better than anyone else. Asking the tough questions in advance will help you find a device to best suit your needs and lifestyle. For a recommendation on an HME dealer near you, contact Amigo Mobility at 800-MY-AMIGO or info@myamigo.com.

Clinical Criteria Algorithm for Wheelchair Prescribing

About Amigo Mobility International
Amigo Mobility manufactures a complete line of innovative mobility products including power-operated vehicles/scooters, trunk and van lifts and motorized shopping carts. Designed to bring comfort and freedom to customers, Amigo’s quality, made in Michigan products have been Improving Lives Through Mobility® since 1968.

Source: Centers for Medicare and Medicaid Services
While on a family trip at age 8, I started feeling sick. My mother, a registered nurse, feared polio. A local doctor dismissed my symptoms as “probably just a virus.” (Some virus it turned out to be!) Still worried, Mom cut our trip short. Back home, our family doctor was reassuring, saying that many parents were needlessly panicking about polio.

Then one morning, I awakened and swung my legs over the side of the bed to get up – only to crumble to the floor. “Mommy, Mommy,” I cried out. “I can’t walk.” So much for those oblivious doctors.

I was taken from our small Ohio town to Children’s Hospital in Columbus. A spinal tap confirmed polio, consigning me to the polio ward for the next few months. At my worst, I was paralyzed from the neck down. Doctors predicted I would never walk again.

Fortunately, they were wrong again. I learned to stand and walk again and led a generally normal life, though I was never athletic, strong or coordinated.

Decades passed. Then in 1985 The New York Times reported that some polio survivors were developing renewed problems years after their original infection. Doctors named the condition Post-Polio Syndrome.

At the time I was 42. Concerned, I went to a support group. Other attendees had serious physical complaints. But I had no new symptoms, and my polio was a distant 34 years in the past. My conclusion: I was among the lucky ones dodging the post-polio bullet.

I was wrong. But ignorance can be bliss, and I enjoyed another quarter century of decent health before things went haywire.

At age 67, fatigue bowled me over and I drowsily drifted into long midday naps. I attributed this to changing springtime allergies. The fatigue forced me to stop my exercise routine of walking up and down 50 flights of stairs three times a week. Then I began to feel stiff and weak. Naturally, I blamed my inactivity. Or maybe this was just “old age.”

It all seemed quite logical, but events proved me wrong.

On my 68th birthday I treated myself to an Asian music concert. After settling into my center seat, I belatedly realized that I had misread my ticket and was in the wrong row. By now other people had filled the seats on my left and right, and I did not want to disturb them by squeezing past.

I only needed to go back two rows, which were still empty. So I clumsily climbed over the back of my seat to the next row, then again to the row behind that. No problem.

I thought that this exertion might make me a bit stiff or sore the next couple days. Instead, I was hunched over in pain and immobility for weeks, having a hard time getting up and down from a chair and in and out of my car.

As my symptoms piled up, I went to my doctor. We drafted a list of possibilities, including chronic fatigue, Epstein-Barr, fibromyalgia, low testosterone, hypothyroid, Lyme disease, cardiomyopathy, rheumatoid arthritis – and post-polio syndrome.

As tests eliminated other causes, post-polio loomed as the likely culprit. But a neurologist was highly skeptical, saying I was simply depressed and suffering psychosomatic symptoms. He was wrong. After electromyography and skin conduction tests, he grudgingly confirmed post-polio.

He was not much help, unaware of books on post-polio or support groups. I found both on my own. From Post-Polio Health International’s Post-Polio Directory, I contacted the excellent clinic at the MedStar National Rehabilitation Hospital in Washington. It assessed me, designed calibrated exercises and made other
recommendations. About the same time I also was diagnosed with sleep apnea, a common disorder in post-polio, and began using a breathing machine at night.

It all helped, and for a couple of years I was stabilized, albeit at a lower plateau of energy and strength.

But suddenly last summer, pronounced fatigue and napping returned. My right leg weakened drastically, requiring canes. It was obvious to me that this was a big new decline in the progression of post-polio.

Once again, I was wrong.

A sleep doctor found that I had neglected to change the silicone liner of the face mask for my breathing machine, so it weakened and leaked air, reducing the pressure needed to ease breathing. As soon as I changed the liner, the fatigue and long naps disappeared.

For my walking difficulties, I went to a second neurologist. She focused on my spine and diagnosed neck and lumbar arthritis. She sent me to the physical therapist whose fortuitous hunch about my hip joint – the one I had strained at the concert four years before – proved to be a real breakthrough.

Ironically, the groin injury that was the last straw prompting my original post-polio diagnosis apparently wasn’t caused by post-polio after all.

My doctors and I have been wrong many times. They thought I didn’t have polio to begin with. Once it was diagnosed, they predicted I would never walk. At middle age I believed I had escaped post-polio. Years later when I started getting symptoms, I blamed other causes, and a neurologist blamed depression.

And what appeared to be alarmingly worsened post-polio last summer turned out to be fatigue caused by a breathing mask defect, and a limp caused by hip arthritis that doctors and I had missed for four years.

An old medical adage advises: “When you hear hoofbeats, think of horses, not zebras.” In other words, in making a diagnosis first look for common illnesses, not exotic ones. By that metaphor, post-polio is exotic. And the maxim needs a corollary: “But if you have a zebra and hear new hoofbeats – don’t rule out horses.”

What I have learned is to take nothing for granted, neither medical expertise nor my own guesses and assumptions. Keep an open mind, explore possibilities, question everything, get more tests and second and third opinions, keep searching and welcome serendipitous insights like my physical therapist’s hunch.

Bruce Lambert is a PHI member and retired New York Times reporter and union advocate in Hempstead, N.Y.

Social Security Disability Benefits

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braces, canes, crutches, walkers, wheelchairs or pulmonary support. The reduced ability to sustain customary activities, including work, may result. A previously stable functional capacity may be further diminished. Many individuals with medically severe polio residuals have worked despite their limitations. The new onset of further physical or mental impairments (even though they may appear to be relatively minor) in polio survivors may result in further functional problems that can limit or prevent their ability to continue work activity. Postpolio sequelae may effectively alter the ability of these individuals to continue functioning at the same level they maintained for years following their initial polio infection.

You can find these rules on Social Security’s website: www.ssa.gov. Look for Social Security Ruling 03-1p: “Policy Interpretation Ruling Titles II and XVI: Development and Evaluation of Disability Claims Involving Postpolio Sequelae.” If you are interested in hiring a lawyer for representation with your initial application or with any level of appeal following that, NOSSCR’s referral service can provide contact information to an attorney in your area.

Nancy G. Shor is Senior Policy Advisor at the National Organization of Social Security Claimants’ Representatives (NOSSCR). NOSSCR maintains a national referral service for claimants seeking Social Security lawyers; the toll-free telephone number is 800-431-2804. Visit NOSSCR’s website at www.nosscr.org.
Question: I would like your take on using drugs such as gabapentin for use in treating PPS pain. With the new drug laws, my doctor has prescribed this drug for pain instead of the hydrocodone I was taking. (Editor’s Note: Under a final rule issued by the U.S. Drug Enforcement Administration, hydrocodone combination products are now in a more restrictive category of controlled substances, along with other opioid drugs for pain like morphine and oxycodone. See more at: http://blogs.fda.gov/fdavoice/?s=oxycodone&submit=Search#sthash.e7bJpWM6.dpuf) I can usually manage the pain during the day but have problems sleeping. Some nights it feels like someone is trying to peel my muscles from my bones. I am asking because gabapentin is used to treat seizures, but I do not have seizures. When I looked up the usage, it is also given for treatment of pain for the shingles for a period of three to four months. Whatever I decide to take for pain, I will possibly use for the rest of my life. Has anyone done a study of the long-term usage of gabapentin for post-polio pain? I do not want to take this medication and find out it was not good for managing post-polio syndrome.

Answer: Gabapentin and pregabalin are only approved for control of seizures and fibromyalgia (in the case of pregabalin). There are no studies supporting their effectiveness for leg cramps in the survivors of polio. Gabapentin is the most widely prescribed drug and used “off-label” for chronic pain syndromes of all sort. If these drugs are used for leg cramps, they should be evaluated carefully on an individual basis relative to their effectiveness and the optimal minimally effective dose.

For survivors with leg cramps, a thorough history and exam should be done regarding the most likely cause(s) of the cramps. Tight muscles are the most common contributing factor, but they can be treated with stretching. The next most common cause is overuse/ misuse of the leg muscles. Metabolic imbalances of calcium and magnesium are also common. None of these common causes are likely to respond to treatment with gabapentin/pregabalin.

In regard to your specific concerns about trying it: gabapentin appears to be safe from the standpoint of serious side effects from long-term use. There are many non-serious side-effects in the short-term for many people who take it, particularly sleepiness, fatigue, mental slowness, nausea. They stop when the drug is not taken.

In your question, you mention problematic pain, particularly at night, and for this problem I would encourage you to try gabapentin at a small dose (100 mg) taken about one hour before going to bed. If it is helpful and your night-time problem is not every night, you can take it “as needed” at night, but it may take an hour or more to be helpful.

Don’t be too concerned about it being listed as an anti-seizure medicine or a helpful treatment for shingles-related pain. It does help these conditions and because they have been studied sufficiently, it is legal and appropriate to say that it helps some with these conditions.

I know from my own practice and from speaking with other physicians that it can be prescribed safely and is sometimes helpful as an adjunct to effective pain management for polio survivors. It is probably a better choice for chronic pain than regular use of hydrocodone. Nevertheless, it should be considered as a “pain modulator” for chronic musculoskeletal pain and certainly not a true analgesic or a primary treatment for PPS pain.
For recognizing your friends and loved ones with contributions to support the unique mission of PHI and IVUN. PHI strives to publish an accurate list. Please contact us if we made an error.

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Having your most current email is important! The newsletter will not be available in print. Note: The newsletter will be sent from info@ventusers.org.

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