

June-July 2009
Southern Arizona
Post-Polio
Support Group
Est. 1985
P.O. Box 17556
Tucson, AZ 85731-
7556
(520) 750-8608 (msg)
www.polioepic.org

General
Membership
Meetings
every
Second Saturday
of the Month
10:00A.M. - 12:00N
Education Room
HealthSouth
Rehabilitation
Hospital
2650 N. Wyatt Road
Tucson, AZ

June 13th
Fun and games with our
own Karla's Polio
Jeopardy, and yearly
elections
July – August
Summer Vacationing
September 12th
Presentations from the
Warm Springs PHI
convention attendees.
Come learn what is new
or better for
Post Polio's.

In August, we have a
board meeting, and all
are welcome!

POLIOEPIC, INC.

Are we really the only support groups, that support Ourselves?

I was amazed to watch an interview with Dr. Bruno, where he stated how difficult it was to keep support groups working. His reasoning was that it was the only type of support group, where the leaders and organizers are all survivors of that condition. His theory is that the leaders are suffering more and more from their post polio, and able to do less and less. His example were the 15-20 support groups in New Jersey, that now are down to 2, in the space of less than 10 years. Because I fear that he might be correct, we have to think “outside of the box”, we have to work smarter and not harder. We have to find ways to make our lives easier, while providing the same support and education that we WANT to provide. There are so many things happening in the medical world right now, and we don't want to get caught “power napping”. At our last board meeting, we were discussing ways to change our organization to provide the same support, and not wear out the same people year after year. As a member of Polio Epic, please help us think of things and ways that can help ALL of us.

Nobody cares if your idea is totally different, or unusual. Nobody is more or less qualified than anyone else. I know for a fact that many of us on the board would MORE than welcome more voices, thoughts, and ideas. Your's might be the one that really truly works for everyone! If you decide that you want to have a regular voice in our FUNCTIONAL board; become a member! Easy to do, just show up, work with us, attend the meetings, and SPEAK UP!

Remember, there is nothing sacred. Our support group can be changed in any way that we want. Call me, write me, e-mail me, visit me or whatever you can do, if you want to speak up, and don't know where to start!

Micki Minner

The few who look forward, while always knocking on new doors, no matter how futile it may seem or how insignificant their progress, will carry the many who just keep waiting for things to get better.

The opinions expressed in this publication are those of the individual writers and do not necessarily constitute an endorsement or approval by POLIO EPIC, INC. If you have personal medical problems, please consult your own physician.

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Popular Science – June 2009 How it Works – Inside the first government-sanctioned clinical trial to heal injured spinal cords with stem cells. A blunt blow or disease can cause paralysis by destroying nerve fibers, or axons, in the spinal cord that carry signals to and from the brain. When these signals are disrupted, the protective insulation surrounding the axons, known as myelin, erodes, leaving permanent damage. Starting next month, scientists at Geron Corporation will begin injective myelin precursor cells derived from embryonic stem cells into patients with newly injured spines. The hope is that the new cells will create myelin and restore the flow of nerve impulses traveling along the axons.

The information listed below is important to show the first longstanding study involving re-innervation, and the possibility for Post Polio Syndrome, not just Parkinson's. As a matter of fact, this study showed, that the new connections succumbed to Parkinson's again after 12 years.

PPSrs don't have to worry about that!

Summary - Published in Journal Watch Neurology May 5, 2009

Long-Term Outcome in Fetal Cell Transplants for Parkinson Disease. Human fetal tissue transplantation for Parkinson disease (PD) was a procedure of great interest in the 1990s. Two NIH-funded, randomized clinical trials demonstrated that dopamine cells transplanted into the striatum remained viable, but the clinical benefits of the procedure were inconsistent (*N Engl J Med* 2001; 344:710). Now, researchers report on neuro-pathologic findings in a patient who had received bilateral human fetal grafts at age 63. The patient had longstanding PD; his symptoms improved for 12 years after the procedure but worsened in the last 2 years of life.

Comment: This report confirms similar findings from two prior studies (*Nat Med* 2008; 14:501 and 504). **The good news is that the grafted cells in the patient reported here survived more than a decade, made connections, and were able to reinnervate large swaths of the striatum into which they were implanted.** The bad news is that the transplanted cells appear to have acquired neuro-pathologic features of Parkinson disease over time, presumably because of PD-related changes in the host. In a time of renewed interest in cell therapies for neurological disease, these and other recent observations provide two cautionary notes: First, the neuropathology of PD is not restricted to the substantia nigra, but is more widespread, particularly after 10 to 15 years (*Neurology* 2008; 70:1916). Second, transplanted cells might, over time, be vulnerable to the disease they were intended to treat.

- **Lewis Sudarsky, MD** -Director of Movement Disorders, Department of Neurology, Brigham and Women's Hospital, and Associate Professor of Neurology, Harvard Medical School, Boston.

National Public Radio-Morning Edition -May 11, 2009
Polio Pioneer Helps Survivors Hold On To Strength

Edition: 11:00-12:00 PM-Index Terms:-103892252 – RENEE MONTAGNE, host:

It's MORNING EDITION from NPR News. Good morning. I'm Renee Montagne.

Today in Your Health, another virus that created enormous fear for years and to this day - polio. It's true, there hasn't been a case of polio in the U.S. from the live virus in decades, but there are about a half million Americans who contracted polio when they were young. Some are still paralyzed, most of them aren't, and you'd never know they had polio from looking at them. Still, all of them face the threat that polio can return as they get older. NPR's Joseph Shapiro reports.

JOSEPH SHAPIRO: There are only a handful of doctors left in this country who specialize in polio. Dr. Lauro Halstead is one of them.

Dr. LAURO HALSTEAD (National Rehabilitation Hospital): Do you know, did the patient come over from PT?

SHAPIRO: Halstead is a tall lanky man in a white lab coat with a black stethoscope slung around his neck. At the National Rehabilitation Hospital in Washington, D.C. he comes down the hallway on an electric scooter. Nurses and administrators vie for his attention and there's a patient waiting.

Dr. HALSTEAD: So finally, finally.

Ms. EDITH GERVER (Polio survivor): Yes, please.

Dr. HALSTEAD: We're just a little bit behind.

SHAPIRO: Edith Gerver's 83. She sits in the exam room with a bamboo cane at her side.

Ms. GERVER: Ok, Dr. Halstead, I'll tell you. I am here because, as you would expect, my muscles are getting weaker and weaker.

SHAPIRO: Halstead speaks with authority. Twenty-five years ago he published early evidence of a startling medical problem: post-polio syndrome. People who'd had polio as children were reporting a new weakening of their muscles as they got older. Halstead understands his post-polio patients not just as a scientist. He's a polio survivor, too.

Dr. HALSTEAD: I mean, I'm having a lot of the same issues that she is. In my legs, so I can walk shorter and shorter distances. I continue to use a motorized scooter for longer distances, more than 20, 30, 50 feet. I take afternoon naps. They help get me through my afternoon fatigue.

SHAPIRO: Halstead is 73 now. He sees patients only two days every other week. He can't retire. The number of aging patients who want to see him, like Edith Gerver, is growing.

Ms. GERVER: We're survivors, you and I, right?

Dr. HALSTEAD: Yeah.

SHAPIRO: And every polio survivor's got their own polio story. Halstead was 18, a college student touring Europe, when he got sick. He boarded an overnight train to Madrid. When he got there his arms were too weak to fetch the suitcase over his head. He ended up in a darkened children's hospital with high frescoed ceilings. He scrunched his 6 foot 4 frame into a breathing machine - an iron lung built for a child and made of wood not metal.

Dr. HALSTEAD: Franco was in power. And to conserve electricity throughout Madrid, the whole city went dark from 2:00 AM to 6:00 AM So I'm in this iron lung - or wooden lung - and it's going...

(Soundbite of inhaling and exhaling) ...which is the noise an iron lung makes as it pumps air in and out. So at 2:00 AM the lung stops and I'm lying there. Fortunately, I could just breathe

enough to get me through 'til the 6:00 AM. I did hallucinate a fair amount. And then at 6:00 the lung kicked in.

SHAPIRO: Over several months Halstead recovered, except for the right arm he could never fully use again. He went back to college and then med school. He played soccer and tennis. He didn't think of himself as being disabled. Edith Gerver was a baby when she got sick in Germany. She was 11 when her family fled for the United States.

Ms. GERVER: One step ahead of Hitler. Coming to the United States I could not get a visa ' cause I'd had polio. They took us off the ship with a little tug boat and took us to Ellis Island. There was a hearing. And at the time, Roosevelt had polio. But, you know, he hid it. But fortunately they allowed me in.

SHAPIRO: Two uncles already in this country signed papers guaranteeing she'd never become a ward of the state. Gerver's led a good and prosperous life in America. Now her daughter is moving to Florida and she's thinking of going with her, but lately she's started falling down. She's come to Halstead for a solution.

The doctor asks her to take off her shoes. Her feet are strange. There are scars but no ankles. Multiple childhood surgeries fused her bones so she could put weight on her feet and walk.

Ms. GERVER: ...feel it on...

Dr. HALSTEAD: And I'm going to give you some resistance. Up. Up, hurry, hurry, hurry. That's hard. This one.

SHAPIRO: Halstead uses his arms to press against her feet to test her strength.

Dr. HALSTEAD: Up, high as you can go.

Ms. GERVER: That's it.

Dr. HALSTEAD: Ok.

SHAPIRO: Then Halstead tries to persuade Gerver it's time to start wearing a leg brace. He rolls up his pant leg and shows the one he uses. She says she tried one before, but it was too uncomfortable. He tells her she should get a scooter, like his. She says it would be too hard to get around with it. People with polio worked hard to overcome their illness, so it goes against their nature — when post-polio syndrome kicks in — to slow down.

Dr. HALSTEAD: So you may think, you think that maybe that's like giving in?

Ms. GERVER: I feel that as long as I can stand on my two legs, I'm ahead of the game. I know that doesn't make much sense.

Dr. HALSTEAD: No, it doesn't.

Ms. GERVER: But it's who I am. And I think polio made me that way.

Dr. HALSTEAD: Ok, I will accept that.

SHAPIRO: But Halstead doesn't give up. He keeps pushing her gently over the hour long appointment. By the end, she agrees to let him call the orthotist. She'll try one more time to wear a leg brace.

There is another patient today Julie Lewis who says polio probably made her the hard charging person she is today. She's got an important job at a hospital and she is reluctant to take Halstead's advice that she start taking a nap at the office. For one thing, until now at least she has always been able to hide her polio. But right away, Halstead spots the one visible tip-off. He holds his hand to hers. On both of them, the usually thick muscle at the base of the thumb has withered.

Dr. HALSTEAD: Yeah, I mean looking at this hand there is no question.

Ms. JULIE LEWIS (Polio patient): You mean polio wise? Oh, okay. Everybody else but you that looks at it, goes wow, what's that? You know? (Soundbite of laughter)

Ms. LEWIS: What did you have?

SHAPIRO: This is a relief to Lewis. She's 55 now. She remembers being nine and so sick that for weeks her mother had to hold her up in bed, but she couldn't find a doctor to confirm that early memory.

Ms. LEWIS: Well I've been told all my life I've had polio — by my family, my early doctor. But as I got older and I had trouble finding doctors that could recognize and confirm that, I started doubting at times. Maybe I had an injury, maybe something else happened to me that I wasn't sure about.

SHAPIRO: Lewis waited six months for this appointment. Post polio patients come from all over the country and the world to see Dr. Halstead. And that raises a question.

Ms. JOAN HEADLEY (Executive Director, Post-Polio Health International): Our concern as an organization, is, you know, who's going to replace these early champions and these early physicians?

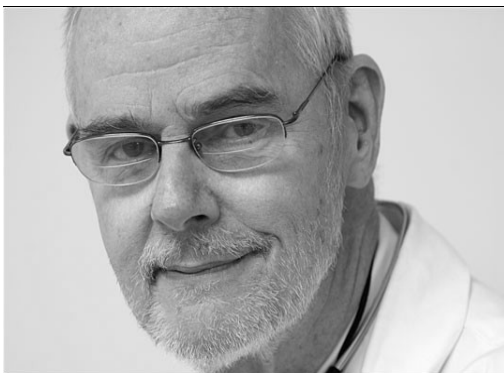
SHAPIRO: Joan Headley runs a polio survivors group called Post-polio Health International. In the early 1980s, Halstead was the first doctor to survey the groups members, and then with a handful of other polio doctors, spread knowledge about the extreme fatigue of post-polio syndrome. Headly sees some reason for optimism that now other doctors not just polio specialists can give good care.

Ms. HEADLEY: I mean Dr. Halstead has certainly been the champion of the post polio community over the last 30 some years. Because of his work, most physicians now know about late effects of polio and post-polio syndrome.

SHAPIRO: Back at the clinic, Halstead agrees there is the new generation of doctors who can take over.

Dr. HALSTEAD: There is quite a number of younger physicians and other health care providers who have gotten interest in this population because there is one of them and they present challenging and interesting issues.

SHAPIRO: Halstead is hopeful that his hospital might be close to finding one of those young doctors who he can then mentor to take over his polio practice.



Dr. Lauro Halstead is one of the last remaining doctors in America with a specialty in treating people with polio. One reason for his interest: He had polio, too. He's past retirement age, but the number of aging patients who want to see him is growing.

Those who attended the PHI Conference
in Warm Springs, GA
are working on presenting their information
and knowledge gained as soon as possible.
Look at the meeting schedule to see when!

WARM SPRINGS 2009...LEARNING FROM WISE ELDERS – Frank Frisina

Recently on a perfect day...sitting in a park, writing notes before my next meeting. Along comes a young man with his toddler and his dog. He had two normal well developed legs walking with an effortless, playful gait. My mind from a lifelong habit goes immediately to the judging comment and question... You *can't* know how lucky you are. Will you *ever* know just how lucky you are? Does it take a great loss to one day, after grieving our loss, finally realizing our blessings? Then the next comment and questions in my mind... ***I CAN'T know how lucky I am. And will I EVER know just how lucky I am?*** Observing the “lucky ones” is a recurring scenario that brings me directly to my life’s abbreviated personal inventory usually followed by my gratitude for who and what I am. *Wart-and-all* is the popular expression...but you don’t have to be close up to see me limp and tumble. When and how much **do we accept ourselves?** At what stage of our lives do we assess **our particular place in the world?** How soon after those transitions of self-acceptance and societal placement, do we love ourselves and even see how our disability has given us **a place like no other?** Our growth comes in strata...we master one level of our lives while other levels may yet be undiscovered. Most often we disabled live our lives as type A personalities. We accomplish more with much less. Like a child walking with a tall adult, we have had to move faster and harder to keep up with life...and our peers. We are *tougher* than most, more *versatile* than most, more *resilient* than most, and often more *giving* than most. And the list goes on. I don’t see the “healthy people” as less but we are constantly going thru the birth canal with each new ailment from aging. In the story *Fiddler on the Roof* Tevya asks, “Why me, God?” In calmer moments we know the answer to the “why me?” The qualities I mentioned...tenacity, versatility, resiliency, compassion are all gifts born of our maturing struggles. What’s not to be grateful for? So it hurts every day! So it costs every day! So we become more limited every day! We may whine... because we don’t know what and whom we have affected. We have become the “wounded healer”. I used to commute on bicycle, riding about 100 miles weekly and entered races. At first I hesitated to bare my paralyzed atrophied leg until one day a co-worker told me how much he was challenged by my ABILITY to keep on riding in any weather with only about 1 ½ leg power. I was breathless and tearful when he said that. HE WAS RIGHT ! Not only was I doing what most could or would not do but I did it with less. AND it made visible a gift from God as I perceive it. Remember the expression, “if you are dealt lemons, make lemonade.” Every day **you and I** do make the most of our lives. These days I do not bicycle but I do work with medical students. Regardless of the ailment role I am playing (which they must diagnose) the mentoring physician takes time to teach them briefly about polio and the vast differences in my leg temperatures, musculatures, bone structures, neurological reactions and skin textures. We can be and are examples for others to see; and for them to grow. Too often the awe we stimulate in others remains unknown to us but it is happening every day.

Enjoy the gift of your maturing role in life. You worked hard for it.

Shopping While Sitting – Phyllis Dolislager
Polio survivor and author – <http://www.byphyllis.com/>

It happened again. My leg gave out and I had to grocery shop using my power chair. First of all, it's a pain in the butt to have to ask Ron to get the chair out of the car and to assemble it. But the worst part is not being able to see or reach from a chair. Only one-third of the shelves are readable or accessible. This increases the shopping time. Then there are the other shoppers . . . the ones who think you're taking up too much space or moving too slow. However, their response is much worse when I use one of the power carts that stores provide. Then people are just plain rude—as if I'm using it just for the free ride or something.

And speaking of those store carts, perhaps the worst part is the hideous—beep, beep, beep—it makes when you put it into reverse. How embarrassing! Perhaps that's one of the reasons that other customers give dirty looks to anyone using one.

But there is some good news buried in this muck. At least I have my own power chair and a willing husband to help me. And most of the produce is at eye level.

Oh yes, and that occasional meeting with another customer on wheels and the exchange of smiles reminds me that I'm not alone in facing life in a power chair. In fact, there's a whole community of us. We need to reach out to one another—to share the good and the bad—the victories and the challenges.

No, we're not alone. We're not the first ones to “do life on wheels.” Now that's an encouraging thought right there!



1. What activity outside the house presents a challenge to you?
2. How do you handle it?
3. Do you have any advice that you would give to others?

Just Published: “***Who Hit the Down Button? Life with a Chronic Illness or Disability***, a motivational and inspirational book. By Phyllis Dolislager

18 topics are covered from a personal perspective, and each topic is followed by three questions. Some topics are: We Are Survivors, Special People: Caregivers, Fatigue: the Life Robber, Less Stress = More Energy, The Glass is Half Full, Walking: The Magical Attraction, Shopping While Sitting, and Contentment. This book is suitable for support groups to use for discussion topics and also for individual introspection. The author, Phyllis Porter Dolislager, is a polio survivor. This is her seventh book in print.

Jean E. Holmes, Physical Therapist, says, “Life always has its ups and downs, but for those who struggle with physical handicaps, the downside is often daunting. Struggling with post-polio syndrome, the author of this encouraging book openly shares the challenges she has been forced to confront—facing them head-on. This is a useful book for anyone living with a chronic illness or disability.”

This book is available from www.amazon.com and from www.iuniverse.com



Michael Kossove states that he has an interesting polio survivor story; since he didn't know he had polio until he was diagnosed in the last 10-15 years with post-polio syndrome. Because of his work as a microbiologist, he's been speaking about the polio virus to many polio support groups long before he found out from his 90 year old Aunt that he had polio as a child.

Viruses are dead. They are not alive, but they are active. They grow, replicate and metabolize. During the epidemics that many of us were part of, Michael explained how 300 children could be using the same swimming pool and yet only one child seemed to get polio. How could that be? The polio virus needs a receptor site on a nerve cell to attach itself to. Only a small percent of the population had receptor sites. Many children swimming in a city pool might have had a mild case of polio by getting flu-like symptoms or just getting overly fatigued. The one child with the receptor site who swam in the pool was the only one that became paralyzed from the polio virus. It appeared then, that only one child was affected by the virus, when actually many were affected.

POLIO TITER: The only way to know what type of polio we had is by having a polio titer. If we received a vaccine, there is no reason to have the polio titer done. It won't answer the question about the type of polio unless we have never been vaccinated. Since it's possible to get all three strains of polio, it would be helpful to know which strain we have had so we could be vaccinated against all three strains. However, if we've been vaccinated there is no way to ever know which strain[s] we have had. If we have never been vaccinated; Michael suggests we get a titer done first; and then get fully vaccinated. It's also possible to have been given the vaccine but not have it convert in the body. The titer will then show that you have no protection. If that is indeed the case, you would want to know that!

SABIN/SALK VACCINES: The Sabin vaccine is the sugar cube; involves the active virus diluted to the point that it would do no harm. There is no proof that the Salk was better nor that the Sabin was better. The Salk involves the dead virus.

RESPONSES TO QUESTIONS/POINTS TO REMEMBER:

- ★ It's critical that we each have a good immune system. To determine the kind of and level of exercise appropriate to you, get evaluated by a Physical therapist that knows polio.
- ★ Airborne is a good medication that can help when flying.
- ★ The Sabin vaccine will not exacerbate post-polio syndrome.
- ★ It is possible for the fetus of a pregnant woman who has the polio virus, to be born with polio.
- ★ Polio is the only disease that "gives you something back"; you're initially paralyzed in part of your body, then years later through no fault of your own, you have twice as much wrong with you because of post-polio.
- ★ It's important to always carry a list of your meds with you.
- ★ We each have to be our own "best advocate."



Minnesota Department of Health -News Release - April 14, 2009
Polio virus associated with oral vaccine reported in Minnesota resident
Patient who died had weakened immune system, multiple other health conditions

State health officials are investigating a case of infection associated with the polio virus in a Minnesotan who died last month. The patient was infected with a virus strain found in the oral polio vaccine. The oral vaccine, which is **no longer used in the U.S.**, contained live polio virus. The injected polio vaccine now in use contains only inactivated virus. The patient died with symptoms that included paralytic polio, but it is not known to what extent the polio may have contributed to the death. The patient had a weakened immune system and multiple health problems. The patient most likely acquired the vaccine-derived polio virus from someone who had received the live-virus, oral poliovirus vaccine (OPV) before the use of OPV was discontinued nine years ago.

This type of polio infection is very rare, officials stressed. In rare instances, a person who has either never been vaccinated or has certain immunodeficiencies can acquire the polio virus from someone who has been vaccinated and is excreting the virus in their stool. Sometimes these infections result in illness, as happened in this situation. Only 45 cases of vaccine-derived polio disease in persons with immunodeficiencies have been reported in the world since 1961. This is the second instance of a polio infection caused by a vaccine strain of virus in the United States since **2000**, when use of live-virus

oral polio vaccine was discontinued in the U.S. All polio vaccinations in the U.S. are now done with an injected, killed-virus vaccine. The other instance of vaccine-derived polio infection also occurred in Minnesota, in **2005**, but was very different from this case. It occurred in an un-immunized child from a community that had high levels of non-immunization and that case was not associated with neurological symptoms.

"We suspect that one reason why Minnesota has detected both cases in the United States in the last 10 years is because of the high level of cooperation among astute clinicians, a network of clinical laboratories and the Minnesota Department of Health, which in turn has a Public Health Laboratory that looks for such rare agents as polio virus," Lynfield said. Naturally-occurring polio has been eradicated in the western hemisphere. The last case of naturally-occurring (not from vaccine) paralytic polio disease occurred in the United States in **1979**.

Although members of the general public are not at risk, MDH officials say this unusual case should serve as a reminder to make sure that all of your immunizations are current and that children receive immunizations as recommended. "It's always a good idea to check with your physicians or health care providers to be certain all of your vaccinations are current," DeVries said. "Make sure you're protected and your children are protected." Most people in the United States have been vaccinated against polio and healthy people have developed full immunity to the disease. An estimated 94 percent of Minnesota's two-year-olds have had the full primary series of three polio shots, which are usually administered in infancy.



Isn't it bad enough
that I had to be weighed?
Now you take a
picture too?

Contributors to POLIOEPIC



Thank You

Hal Myers

*Memorial
Ralph Patterson*

From the Treasurer

The end of our 2008-2009 fiscal year is coming to an end August 31, 2009. That means as of September 1, 2009 your dues will be applied for the 2009-2010 fiscal year. CHECK the date on the address label, if it says 2009, you are paid through August 2009. Please remember to let us know if you are vacationing, or at a different address during the summer!

Dues Form

POLIO EPIC, INC. CURRENT MEMBERSHIP ANNUAL DUES ARE RENEWABLE THROUGH THE FISCAL YEAR OF SEPTEMBER 1, 2008– AUGUST 31, 2009

NAME _____ SPOUSE _____ DATE _____

ADDRESS _____ PHONE(____) _____

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_____ I am sending in my/our annual dues of **\$10.00** per person for 2008-2009 fiscal year.

_____ I am sending in a *tax-deductible* donation in the amount of \$ _____.

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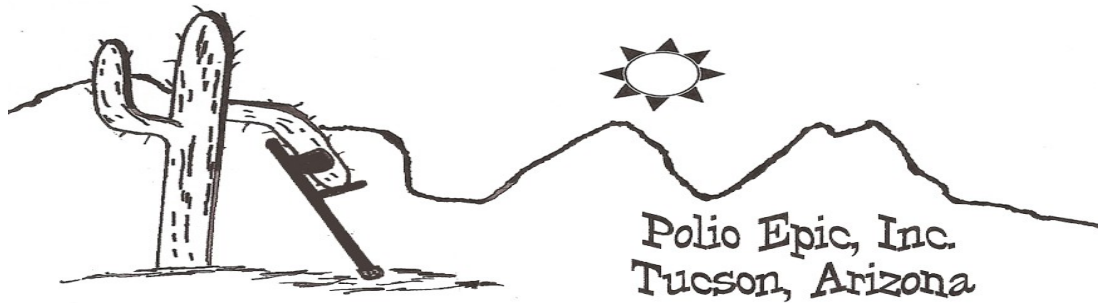
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_____ Please remove my name from the mailing list. I do not wish to receive newsletter.

_____ Check here if you do not want your name, and address info listed in the **POLIO EPIC DIRECTORY.**

_____ I would like to be more involved. Please contact me at the number above.

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**Polio Epic is not just a newsletter
Polio Epic is not only a meeting for
officers**

**Polio Epic is for YOU -
It's getting to know you
All about you
Liking you**

**Hoping you like us too
Meeting to share our victories**

**Artwork compliments of Charles Root*

A bond no one can break

We want you to attend

We want your voice

**We want to help you shoulder your
problems**

We want to help you over the rough spots

We want you present and accounted for

We want you at our next meeting

BE THERE!