

December 2008 – January 2009  
Southern Arizona  
Post-Polio Support Group  
Est. 1985  
P.O. Box 17556  
Tucson, AZ 85731-7556  
(520) 750-8608 (msg)  
www.polioepic.org

# POLIOEPIC, INC.

## 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

December 13<sup>th</sup>  
Our Annual Holiday  
Party! Let's Celebrate  
TOGETHER!

January 10<sup>th</sup>  
George Kuck with Pima  
County Parks and  
Recreation will talk with us  
about the disabled services  
available at Tucson parks

February 14<sup>th</sup>  
Valentines Day, we are  
hoping to bring in  
Professor Kossove from  
Touro Medical College to  
speak to us and the Phoenix  
group.

March 14<sup>th</sup>  
We have Jim Murphy, the  
new director of the Pima  
Council on Aging (PCOA)

April 11<sup>th</sup>

## This Economic Crisis isn't *NEW* to us!

I read an interesting article last week, about how Polio Survivors are more inclined to survive BETTER than others during this time of economic crisis. The basis of the article (included later in the newsletter) is that we have had lots of practice at overcoming, and making "do". As I think about the group here in Tucson, I come to the realization that the author (Nancy Baldwin) might be correct. I tend to laugh when other's whine that if they can't hop in the car and go anywhere anytime. I hesitate to tell them, that we have to charge the wheelchair, find our crutches and braces, go to a place that we have already scoped out for parking and access, and that is only the small trips to the grocery store, or to pick up some milk.

When I hear someone whine about not being able to afford their vacations to the Caribbean, I hesitate to tell them about how expensive it is to be disabled in the USA. A wheelchair lift starts at \$1,000, upwards to \$7,000. A vehicle that can accommodate the lift costs twice as much as a small energy efficient vehicle. Each walker, cane, crutch is an extra cost that the non-disabled do not have.

When I received notice that I am eligible for Social Security Disability, I was amazed that I had worked my entire life, and the disability allotment was a monthly income, that was an average of a two-week income when I was able to work. Now of course, I have additional expenses, extra vitamins, food supplements, medications that insurance won't or doesn't cover, assistive devices, special transportation costs and the like.

Thank goodness, I have a good support group, who keep me from laughing in the faces of the non-disabled, as they whine about today's economy! Thank you everyone for being there to teach me! I am truly blessed to be surrounded by people who already know how to make "do", overcome, and survive with smiles and spirit. *Micki Minner*

*When you get to the end of your rope, tie a knot and hang on."*

- Franklin Delano Roosevelt




*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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I found this on a “blog”, and thought it was important. - micki

### PPS EFFECTS THE WHOLE FAMILY posted: 11/12/2008 at 12:19 pm - Disaboom.com

I have been dealing with post polio syndrome for a while now , it has changed my life in so many ways , the big one is I went from walking to a wheelchair full time . what I never knew is how much it affects my daughters to see me lose my mobility . I was always a active mother from a soccer mom to girl scouts . I ran with them daily it was always one thing or another ! then as they got older we would have our saturday trip to the mall and lunch . Sunday was mass and then off to see family . now I don't get out much anymore and at times I do get jealous and lash out at them , i know that's wrong and it is not thier fault . . . . well once about a month ago I was depressed and I was crying how hard this is and how I want my old life back and it was then that they told me how much it hurts them as well, and I screamed back , “no you don't know !!!!” I woke the following morning to a letter on my nightstand .

Dear Mom , this is not easy on us , it hurts to see you fail, and have pain in your life . We miss you doing all the fun things we did together as well . You were the best mother any child could ask for even with your disability you were there and never missed a beat! Every time you fell you picked yourself back up and forward we went . You never let us down mom and you're not now . This is not your fault . When you're in pain or having a bad day our hearts go out to you . This is not just about you , its US . We are a family , We share love , hopes , dreams and whatever we're given to deal with . Post polio is here to stay. Mom always remember you're not alone for we are in this together , We all feel the pain . When you adopted us you gave us a love that could never be measured , Let us take care of you now mom , you deserve the same love and respect you gave us ....We are a family and no disability is ever going to change that , and if you need to cry, mom we are here for you . What you don't see, mom, is our pain .  
Your Daughters

**PPS is effecting my family as well , there is just no easy answer to all this .I need to heal and accept so that my children do not have to endure this pain as well**



Is it safe to come out now?

## Polio Survivors Ask...

**Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska, ([n.carter@cox.net](mailto:n.carter@cox.net))**

**Q. Do you have suggestions for a person with disability during this economically difficult time?**

**A.** If you're hoping I'll offer a discourse on using generic drugs and house brands, cutting back on lattes, and turning that dream of vacationing in Hawaii into cheery tips on camping out in the back yard, you may as well stop reading right here. Wonderful advice on living less expensively abounds on the Internet. Entire websites are devoted to solving the physical needs of those of us with disabilities who are caught in an economic crunch. There isn't a notion on this issue that isn't tackled more thoroughly there than we can do in the space of this column.

And yet, there is still much on this subject to talk about. Times are tough for many of us, no question. Some have lost their retirement nest eggs, some their homes. People are without jobs, businesses are going belly-up. We would not wish this economic climate on anyone. I'm interested in how we can get through it emotionally.

I can't help thinking that those of us who are disabled may be uniquely equipped to deal with hardship. We've done this before, big-time—we figured out how to move from a "normal" existence to one that must accommodate permanent disability. We're survivors. Surely we have an edge on understanding how to handle change in our lives. We pull out all the stops—our faith, our families and friends, that mysterious instinct that gets us where we need to go. We know how to adjust.

When I told a friend I was doing this column, she suggested I channel FDR. Good idea. Who better? Here's a polio survivor who led this country through several major crises. Could prospects have been more dire? Wall Street had crumbled, bread lines to feed the poor extended for blocks, jobs didn't exist, destitute farmers struggled through the Dust Bowl. And then the topper, World War II. We had a lot to overcome!

And yet a man in a wheelchair engendered hope, created possibility, and patched this great country back together. Roosevelt began by calming our fears, assuring us that we could do what needed to be done. We heard the confidence in his voice on the radio, saw his friendly, unwavering smile in news reels. Nothing seemed insurmountable. Together, we could do it.

I was just a kid, but I learned from that. Don't let fear get the upper hand. Live with optimism and joy. Make opportunity work. Help ourselves by helping one another. And do it all with humor, that indescribable something that transforms anger and frustration into fun and gets us through the night.

Come to think of it, aren't these the qualities we brought with us in designing our post-polio support groups? Haven't our meetings provided a forum for discussions of our frustrations and disappointments, a place for members to get together at crucial moments in their lives and work with each other to find peace?

Aren't these the messages we find in our best post-polio newsletters? At our conferences? Words of strength and courage as we struggle to keep our balance, hurtling through life? Opportunities to fortify our resolve?

It isn't only the name of a fine doctor or the news of a promising treatment that we get from each other, important as those are. There's a human element here that can't be found in a directory or a scientific journal. We must be here for each other, someone to touch that hand reaching out for help, someone to say, "We are not alone." We can do this. Nancy Baldwin Carter, B.A., M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.

Source: Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org))



Don't mind me, I am just getting my PPS nap in before the next page

## POLIO EPIC RESOURCE DIRECTORY

Last call for your input!

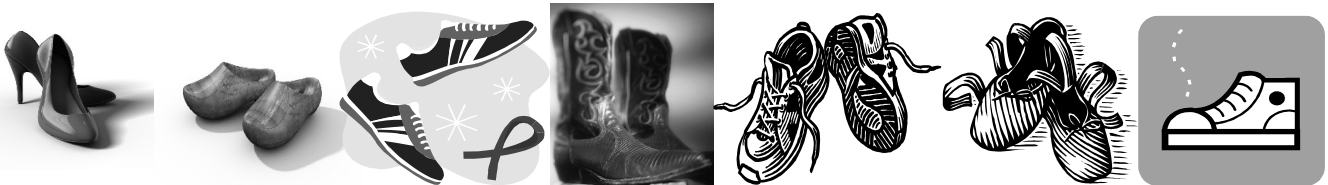
Due December 31, 2008

With your help, Polio Epic will develop and distribute in 2009 a much needed, unique Resource Directory to be used by polio survivors, families and the community at large. Please send me names, businesses, addresses and phone numbers of the professionals that you want to see included in this directory. Remember, everything from doctors to dog groomers; those people who make your life easier, keep you healthy and help you "make it through the day." Thank you!

Karla Carr, Board Member -- 1825 N. Woodland Ave.

Tucson, AZ. 85712 -- phone #: 318-1219

*Note from the Editor: How many of you remember your first contact with Polio Epic? I can guarantee you, that one of the first questions out of your mouth included, who can I find to.....???? Please help us and give your contact information to Karla. Karla and her committee, will contact the provider, to get their permission to be in the directory. All you have to do is tell us who you found!*



### **REPLACE THE SHOES IN YOUR CLOSET WITH MONEY IN YOUR POCKET!**

Welcome to [Oddshoefinder.com](http://Oddshoefinder.com), a free site that connects people with odd shoes with people who need odd shoes! Many people with feet of different sizes buy one pair of shoes for each shoe size and use only one shoe from each pair, leaving a closet full of unused shoes. The purpose of this site is to help you get those shoes out of your closet and put money into your pocket.

Tens of millions of people have severely mismatched feet. The problem may be due to injuries, polio, lymphedema, clubfoot, problems related to diabetes, or any number of other reasons. Regardless of the reason, these people generally face the choice of paying much more for shoes or wearing ill-fitting shoes on at least one foot. This site aims to help those people by allowing site users to list their single shoes or mismatched pairs of shoes for sale and to search for other single shoes or mismatched pairs of shoes for sale in their sizes.

## BAD MEDICAL INFORMATION

By Dr. Richard L. Bruno - *United Spinal Magazine*

[Last issue](#), (United Spinal) I described a 2006 Mayo Clinic article presenting a 15-year follow-up study of 38 polio survivors in which the authors omitted data from their own two previously published articles, which found progressive muscle weakness and loss of ability in those very same polio survivors, and concluded “our polio survivors did not age any differently than a normal population.”

There is a more dangerous issue than the publication of twisted, truncated and tortured data in a little-read medical journal. The bigger problem is that the authors “published” their findings in a press release. So, when the media got hold of the distorted data, the headline generated was a dismissive, “People who survive polio in childhood will not suffer further effects later in life.” Unfortunately, “publishing” research findings in media press releases is the new trend in medicine. Forget peer-reviewed medical journals. Just put your findings in a press release and wait for the reporters to start calling. Drug companies, universities, hospitals (frequently, the Mayo Clinic), national medical associations—even the Corn Refiners Association— distribute press releases about unpublished medical research to reporters. Research presented at medical conferences that frequently is never published is also distributed to reporters by press release. A recent release from the American Urological Association conference begins, “Young researchers presented innovative, early-stage research.” I don’t know about you, but I’d like to wait until older researchers actually publish late-stage research before deciding what I should do with my urological system.

The latest study involving polio survivors was released to the press on August 26, 2008: “Pharmalink AB today announces positive results from a...study of Xepol, its candidate for the treatment of post-polio syndrome (PPS). The data have shown the candidate to be effective and well tolerated with no serious adverse events attributed to the product being reported in the treated patients. Xepol, the first medical PPS treatment, is an injectable biologic product, administered once per 9-12 months. This novel treatment modality for PPS (caused) a significant reduction of symptoms of PPS while also showing that Xepol is safe and well tolerated with few or no side-effects. Full results are to be published in a peer review journal.”

Having reviewed, consulted on and performed studies of drugs to treat post-polio symptoms, believe me I know the difficulty of designing and conducting drug studies. The biggest issue with PPS treatment studies is that data on symptoms must be collected daily—not weekly, let alone monthly or at the beginning and end of a study—because polio survivors’ symptoms change daily, if not hourly. I want to see the specific details of the design and execution of the Xepole study when “full results” are indeed “published in a peer-review journal,” and not take the word of the drug company’s press release that Xepole is “the first medical PPS treatment...effective and well tolerated.”

As my last column showed, it’s not hard to get crummy research published, especially in infrequently-read journals. But, for researchers to go over the heads of all peer-reviewed medical journals and just “publish” their findings in the media leaves us all open to unsubstantiated claims that can promote incorrect beliefs about our bodies, emotional upset and possibly dangerous behavior. If polio survivors believe that they do “not age any differently than a normal population” or that Xepol will cure treat their PPS symptoms, and they keep overusing their poliovirus-damaged neurons, polio survivors will deteriorate, as studies of thousands of polio survivors—not just the Mayo 38—have shown. Much of the research reported by the media turns out to be crap. Medical “facts” presented by the media change from week to week. Chocolate causes obesity, then fights cancer; a daily glass of red wine causes alcoholism, and then prevents heart disease. So, it’s vital, in this age of the 24 hour news cycle and the Internet, that we are extremely cautious when medical research is “published” via press release and the media. Again, be it PPS or any medical condition, we need to read the actual published research studies, not just listen to stories on TV and radio or read newspaper articles or press releases, to understand what’s happening to our bodies and really know how to take care of ourselves.

*Dr. Richard L. Bruno is Chairperson of the International Post-Polio Task Force and Director of The Post-Polio Institute and International Centre for Post-Polio Education and Research at Englewood (NJ) Hospital and Medical Center. E-mail [rbruno@unitedspinal.org](mailto:rbruno@unitedspinal.org).*

I guess Dr. Bruno is right, we should carefully examine ALL research. I have found out how easy it is to make “numbers” say anything you want. We should all be wary of accepting Press Releases as good medical data.



## Contributors to **POLIOEPIC**

Phillis Anderson \*

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Pat Neal

Jacqueline Perry \*

Charles Root

Jacque Schmidle

Gail Watts \*

*contribution in the memory of **Jean Haugrud***

*made by Jeanne Hoyt of San Luis Obispo, CA*

*\*\$100 or over*

### Welcome to New Members

Linda Reuter -- Tucson, AZ

Mort & Belia Sadowsky -- Tucson, AZ

Lois Olson -- Le Grand, CA

### April 18 - 23, 2009 - a pre-conference retreat at Warm Springs, Georgia's Camp Dream

A Post-Polio Wellness Retreat is being planned at 1 pm, April 18 - April 23, 2009. Dr. Frederick Maynard and faculty are modeling it after their successful retreats held at Bay Cliff Health Camp in Big Bay, Michigan in 2006 and 2007. This retreat will go one-step beyond re-rehabilitation and focus on health and wellness. It is open to polio survivors and a care-giver. Rooms have 3-4 beds with private roll-in showers available so you may have to share. Camp Dream is fully-accessible. Cost is \$350 per person and includes food and lodging. **April 23 - 25, 2009 – PHI's "Living with Polio in the 21<sup>st</sup>. Century" 10<sup>th</sup> International PPS Conference at Roosevelt Warm Springs Institute for Rehabilitation in Warm Springs, Georgia** Conference is April 23 at 1 pm – April 25 at 5 pm. and a Social event the evening of April 25<sup>th</sup>. There are a limited number of rooms at the Institute. Hotel rooms are blocked at reduced rates at the Calloway Gardens Resort until March 21, 2009 - call 800-543-7121 for reservations. Also you may need to make transportation arrangements from your lodging to conference sites. For other questions or a registration form, call Post Polio Health International at 314-534-0475 or email [info@post-polio.org](mailto:info@post-polio.org). or visit their web site at [www.post-polio.org](http://www.post-polio.org).

## New Membership Directory

We have a new, up-to-date, Membership Directory. If you are unable to come to a Saturday meeting, but wish to receive a directory, please send \$2.00 for the cost of postage to our address, Polio Epic, Inc., P.O. Box 17556, Tucson, AZ 85731-7556. Please remember, this directory is for Polio Epic members only. Please do not use any of the included information for any kind of solicitation purposes.

## Support Polio Epic with Bashas'

September 1, 2008 to March 31, 2009



Bashas' is again offering a way for Polio Epic to raise money with its 'Shop & Give' program (formally 'Thanks A Million'). Here is how it works: Visit any Bashas' checkout or service counter and ask to have your Bashas' "Thank You" card linked to Polio Epic (our number is 27169). You only need to link the card once. **If you participated in the Thanks A Million program last year, you MUST ask to be linked again.** Bashas' will then donate 1% of the total sales linked to Polio

Epic, up to \$5000. The program runs until March 31, 2009, so remember the next time you stop at Bashas' to show your support and link Polio Epic to your card. Don't forget to tell **all your friends & relatives** that shop at Bashas' about this program. Visit

[www.bashas.com/charity](http://www.bashas.com/charity) for more information on the program. **Our group number is:**

**27169**

### From the Treasurer...

Our fiscal year runs September 1 through August 31. Please look at the DUES date on your newsletter. If it says **2008, 2007 or lower or UP** please complete and return the **Annual Dues Form** in this issue. Without this form, we have no way of knowing if you are really out there, or if you want to continue on our mailing list. The cost to print and mail this publication is, by far, the Polio Epic's largest expense. We do receive partial funding from the **Arizona March of Dimes**, which we are very grateful for. To maintain fiscal responsibility, we need to ascertain that we are mailing newsletters only to those of you who actually want to receive them. No one will be denied a newsletter as long as the *Dues Form* is completed and returned, whether or not one chooses to pay dues.

We do encourage all who can afford it, to send a check for dues of \$10.00 for full membership, which includes the bi-monthly newsletter.

We also welcome donations which have allowed Polio Epic to continue to fulfill our purpose to provide information and support to persons with Post Polio Syndrome; and to educate medical professionals and the community at large about the Late Effects of Polio (PPS). Please contact Nannoe at 520-797-6898 or email her at [Nannoe1@aol.com](mailto:Nannoe1@aol.com) if you have any questions.

### RETURNING TO OUR WONDERFUL WINTER CLIMATE? MOVING? GOING ON VACATION?

Please remember that our newsletter does not get forwarded to wherever you are and it cost Polio Epic **59¢** for each returned newsletter. Please help Polio Epic cut down on expenses by letting us know if you are going to be away or are moving.



You can NOW receive your newsletter via e-mail!  
Just make sure we have the correct e-mail address!  
Be Green and save \$ at the same time!

## You're getting sleepy ...

Published: Sunday, November 16, 2008  
Post-Star, Glen Falls, NY

In the late 1700's, an Austrian physician named Franz Mesmer believed that some people possessed a force, an "animal magnetism," that could be used to exert influence and control over other people's minds.

Mesmer became known as the father of modern hypnosis, and the phenomenon of mental suggestibility became known as mesmerism. Fortunately there were no discotheques in the 18th century, in which case the force would be known as Travolta-ism.

Hypnosis is a bit of a shadowy art, poorly understood by many of us. Here's one thing to know: True hypnosis does not involve a man in a tuxedo with a goatee and a pocket watch.

It does not involve clucking like a chicken or heightened sexual arousal. That is, unless you want it to. And therein lays the rub, so to speak.

Jane Brody recently wrote in the *New York Times* about the possibilities inherent in hypnosis. She highlighted the fact that the locus of control, in effect the element of the change mechanism, resides in the patient not in the hypnotist. Hypnosis, not unlike psychotherapy, only works for an individual who wants a certain change to take place.

Hypnosis is the ultimate manifestation of mind-body medicine. It can affect the messages that the brain sends to the body, and in turn the feedback that the body gives back to the brain. It can be used for pain management, weight loss, addiction to nicotine and anxiety about public speaking or airline travel.

In essence, hypnosis is about suggestibility. Rather than the patient becoming groggy or less

aware, when hypnotized the patient achieves a state of relaxation that makes them hyper-aware and focused -- and therefore better able to address changing customary problematic behaviors.

The vehicle of hypnosis is the hypnotic trance. Dr. Milton Erickson, perhaps the best known of contemporary hypno-therapists, felt that the trance was a daily occurrence for most people. It is best compared to daydreaming, or perhaps to the athletic phenomenon known as being "in the zone," during which extraneous stimuli are excluded. Erickson was quite an amazing figure, self-taught in hypnosis, he used it to overcome the loss of movement from polio and to manage chronic pain later in life from post-polio syndrome.

In Ericksonian hypnosis, consciousness itself is seen as existing on a continuum, with the unconscious mind always being present and aware. The task is to connect with the unconscious mind and get around the distractibility that is created by chronic mental or physical pain. People are seen as adapting behaviors to compensate for their chronic pains, and these behaviors are often quite intractable and serve as the presenting problem for treatment.

When in touch with our unconscious minds, we can imagine and experience suggestions that allow us to act in ways we normally do not. We can tap into potentials and possibilities we otherwise hide from ourselves.

Now, look deeply into my column ...

Dr. Benveniste is a licensed clinical psychologist who maintains a local practice. To e-mail him or suggest a topic, write to [drbenveniste@gmail.com](mailto:drbenveniste@gmail.com).



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**THE BUZZARD:**

If you put a buzzard in a pen that is 6 feet by 8 feet and is entirely open at the top, the bird, in spite of its ability to fly, will be an absolute prisoner. The reason is that a buzzard always begins a flight from the ground with a run of 10 to 12 feet. Without space to run, as is its habit, it will not even attempt to fly, but will remain a prisoner for life in a small jail with no top.

**THE BAT:**

The ordinary bat that flies around at night, a remarkable nimble creature in the air, cannot take off from a level place. If it is placed on the floor or flat ground, all it can do is shuffle about helplessly and, no doubt, painfully, until it reaches some slight elevation from which it can throw itself into the air. Then it takes off like a flash.

**THE BUMBLEBEE:**

A bumblebee, if dropped into an open tumbler, will be there until it dies unless it is taken out. It never sees the means of escape at the top, but persists in trying to find some way out through the sides near the bottom. It will seek a way where none exists, until it completely destroys itself.

**PEOPLE:**

In many ways, we are like the buzzard, the bat, and the bumblebee. We struggle about with all our problems and frustrations, never realizing that all we have to do is look up!

**Sorrow looks back, Worry looks around, But faith looks up!**

Live simply, love generously, care deeply, speak kindly and trust in your faith.

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**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(\_\_\_\_\_) \_\_\_\_\_

CITY \_\_\_\_\_ STATE \_\_\_\_\_ ZIP \_\_\_\_\_ - \_\_\_\_\_

**Emergency Contact info:** \_\_\_\_\_

**Newsletter via Email? Address** \_\_\_\_\_

\_\_\_\_\_ 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 \$ \_\_\_\_\_.

**POLIO EPIC, INC.** is a 501(c)(3) non-profit corporation. Tax ID # 74-2477371

\_\_\_\_\_ I am **UNABLE TO PAY** dues at this time, but wish to continue my membership and receive the newsletter.

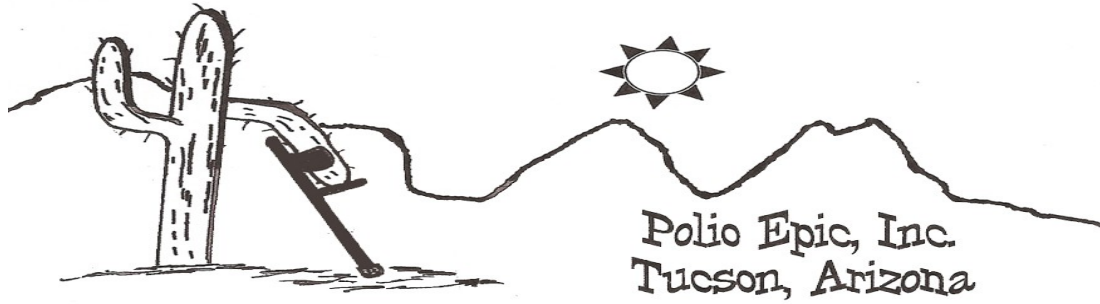
\_\_\_\_\_ Please remove my name from the mailing list. I do not wish to receive newsletter.

\_\_\_\_\_ 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.

**Make checks payable to POLIO EPIC and return this form to  
Polio Epic, P.O. Box 17556, Tucson, AZ 85731-7556**



**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!**