

August-September 2009

Southern Arizona

Post-Polio

Support Group

Est. 1985

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POLIOEPIC, INC.

My Parting Thoughts

I am always amazed at the amount of talent, skills and resources that all of us seem to have within us at Polio Epic. I have been rewarded by being with this group. The last year has gone by so fast, and as much as I am glad it is over, I am sad at stepping down. I am glad that it is over, because I did the usual Post Polio type-A personality thing and did too much and stressed over everything. I am sad, because I felt so empowered, and part of something that was important, and I was doing my share. Because Polio Epic is so important, I am staying on the board and continuing to work with Polio Epic. I have been given support, information, guidance, and even a hand to hold when I needed it. Nothing can replace how important we are to each other as a community.

I am passing the baton to a great group of leaders. Frank Frisina is picking up the reins as VP, and as you may know, he was one of the founding members of Polio Epic. How lucky we are to have him keep stepping forward again and again. Karla Carr is picking up the mantle of President. Karla is a great presenter, speaker, and listener. With the traits that these two have, I know that our group will be in good hands for the next year or two.

This new year, we have added two new board members, and we should welcome them, and appreciate their time! They are Lorna Kenney, and Bobbi Harmon. We are so lucky to have found these witty and intelligent women!

Once again, thanks to all of you, and we WILL be seeing you again...and again...and again

Micki Minner

The world is round and the place which may seem like the end may also be the beginning

Ivy Baker Priest

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

September 12th

Presentations from our own members that attended the Warm Springs Conference. Updates/Information and Research

Board Meetings are the first Thursday of every month at DIRECT offices on Tyndall at 10:00 AM and all are welcome!

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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Social Security Compassionate Allowances Means Quick Determinations for Some

In October 2008, Michael J. Astrue, Commissioner of Social Security announced the beginning of a new program named "Compassionate Allowances." This program is designed to give very quick (in some instances six to eight days) awards of social security disability for claimants whose medical conditions are so severe that their conditions obviously meet the Social Security disability standards. This fast track approach deals, at least at this point, with people who have cancers and rare diseases.

The "50" conditions are: acute leukemia; adrenal cancer; Alexander Disease; amyotrophic lateral sclerosis; anaplastic adrenal cancer; astrocytoma; bladder cancer; bone cancer; breast cancer; canavan disease; cerebro oculo facio skeletal syndrome; chronic myelogenous leukemia; creutzfeldt-jakob disease; ependymoblastoma; esophageal cancer; Farber's disease; Friedreichs Ataxia; Frontotemporal Dementia; gallbladder cancer; Gaucher disease; glioblastoma multiforme; head and neck cancers; infantile neuroaxonal dystrophy; inflammatory breast cancer; kidney cancer; krabbe disease; large intestine cancer; Lesch-Nyhan syndrome; liver cancer; mantle cell lymphoma; metachromatic leukodystrophy; Niemann-Pick disease; non-small cell lung cancer; ornithine transcarbamylase deficiency; osteogenesis imperfecta; ovarian cancer; pancreatic cancer; peritoneal mesothelioma; pleural mesothelioma; pompe disease; Rett Syndrome; Sandhoff Disease; small cell cancer; small cell lung cancer; small intestine cancer; spinal muscular atrophy; stomach cancer; thyroid cancer and ureter cancer.

According to the **POMS**, while the medical documentation may be "minimal" it must be "sufficient" and "objective". Social Security believes that as many as 250,000 cases under this program will be decided in an average of six to eight days.

From the Justia Law dictionary librarian on the internet:

What is **POMS**? According to an informative librarian who has Social Security experience:

"**POMS**...is a claims processing manual. It instructs SSA employees as to how to handle claims for various types of benefits and how to deal with other specific situations, e.g. earnings problems, Social Security number problems, etc. So each **POMS** section is either going to give instructions for processing claims for a specific type of benefits (**DI**=Disability, **RS**=Retirement&Survivors, **SI**=Supplemental Security Income, **HI**=Health Insurance), or cover some general aspect of the SSA claims processing operations (e.g. **RM**=records maintenance, **TE**=Telecommunications, **SM** = Systems, GN = General). Second...**POMS** is NOT primarily a public information tool. It is a technical manual for employees of the organization. It does not really lend itself to casual browsing. "The main people who will want to use it are those who have had an adverse ruling on a Soc. Sec. Matter (or their attorneys) who want to understand why their claim was denied and/or are gathering information for an appeal. Anyone else would be better off using the SSA Handbook or the public information pamphlets, leaflets or SSA Web site, where the information IS geared toward public consumption."



*Anybody see my Thorazine?
I need it to understand this
Social Security Administration stuff.*

I had a phone call from a Polio Epic Member earlier this month, asking questions about Social Security Disability, Supplemental Security Income, and if they had to work in order to get social security disability and or supplemental Security income. I realized it had been a while, since we gathered information about this for our members, so I am attaching some information to help get through this difficult process. Micki

For disabled, two-year wait for Medicare is 'devastating'
12:00 AM CDT on Sunday, July 19, 2009 -By BOB MOOS / The Dallas Morning News-bmoos@dallasnews.com

On her good days, Metta Johnson can sit by a friend's pool and enjoy the sun. On her bad days, the 61-year-old Dallas woman with severe arthritis can do little more than lie in bed, writhing from the pain. But whatever each morning brings her, Johnson at least knows she's one day closer to receiving Medicare and the health care she hopes will improve her life. Besides covering 38 million Americans 65 and older, Medicare helps pay for the health care of more than 7 million younger Americans who suffer from significant disabilities. Under current law, however, those with disabilities aren't eligible for Medicare until two years after they begin receiving Social Security disability insurance checks. Johnson is one of 1.8 million disabled Americans in that two-year waiting period. No longer able to work, she became eligible for Social Security disability benefits in February 2008, which means she has seven months left until she goes on Medicare. Because she can't afford private insurance, she prays that her condition doesn't worsen before then. "It's not my fault that I'm disabled," Johnson said. "I paid my Social Security and Medicare taxes during my entire working life. Why now, when I most need the care, must I wait so long? It doesn't seem fair." Advocates from 120 consumer groups are asking the same question of Congress as the lawmakers work on health care reform legislation. The coalition – which includes the Alzheimer's Association, American Cancer Society Cancer Action Network and National Multiple Sclerosis Society – has called for an end to the Medicare waiting period for people with disabilities. "No one with disabilities severe enough to qualify for Social Security should be without health insurance," said Joe Baker, president of the Medicare Rights Center, a consumer advocacy group and coalition member. "Many people skip medical treatments and medications while waiting, and one in seven dies. Medicare should be immediately available." **The wait's origins**

When Congress extended Medicare coverage to people with permanent disabilities in 1972, it also established the waiting period. Lawmakers added the wait to hold down the cost of the new government benefit, avoid overlapping with private insurance and make sure Medicare would be available only to people whose disabilities were long-lasting. Despite what seemed like sound reasons for its enactment at the time, the 24-month waiting period has left millions of Americans vulnerable at the worst time of their lives, draining their finances and jeopardizing their health, said Stuart Guterman, a policy analyst at the Commonwealth Fund, a private foundation that researches health care issues. Mary Sue Welch, who counsels North Texans with disabilities at the Reach Resource Center on

Independent Living in Dallas, said she witnesses the personal hardships created by the Medicare waiting period every day. "These people have lost their jobs because of their condition and wait anywhere from several months to several years for Social Security to decide whether they qualify for disability benefits," she said. "When they finally get their checks, many think their problems are behind them. But then they learn they still have to wait for Medicare coverage. It's devastating." Forty percent of those in the waiting period go without coverage at some point. Many can't afford to take advantage of the federal COBRA law, which lets them keep their former employer's group health plan but requires them to pay four to six times their previous employee contribution. Others can't afford to obtain insurance in the individual market because of their pre-existing conditions, Guterman said. When Johnson's arthritis becomes so bad that she can't stand it, she heads for Parkland Memorial Hospital and sometimes waits 10 hours to see a doctor and get a prescription. "For someone with chronic pain, sitting in one of those waiting-room chairs from 9 a.m. until 7 p.m. is torture," she said. "When I start on Medicare, I'll be able to go to a private doctor." **Savings dwindle**

Even for those with private insurance, the wait for Medicare can become costly. Paul Gornstein, a 57-year-old Frisco resident with Alzheimer's disease, has been able to remain on his former employer's group plan until he qualifies for Medicare in December. But the high monthly premiums under the COBRA law and the thousands of dollars of other out-of-pocket expenses have taken their toll. "Paul has been fortunate enough to hold on to his insurance," said his wife, Karen. "But we're burning through our savings. I expect the total out-of-pocket costs this year will approach \$15,000." Once Gornstein becomes eligible for Medicare, he'll pay \$96.40 a month in premiums for the standard government coverage and will be able to buy a supplemental plan from a private insurer for an additional \$200 a month. That "Medigap" policy will cover health care costs that Medicare doesn't. Advocates who have pressed for several years for an end to the waiting period view the current health care reform debate as their best chance to make significant headway. Bills introduced by Rep. Gene Green, D-Houston, and Sen. Jeff Bingaman, D-N.M., would phase out the waiting period over a number of years while immediately eliminating it for people with life-threatening conditions. The current law makes only two exceptions. There is a three-month waiting period for people with end-stage renal disease and no wait for people with amyotrophic lateral sclerosis, commonly called Lou Gehrig's disease. **A real solution?**

Advocates aren't convinced that merely broadening the public's access to insurance, as health care reform legislation would do, would solve the problem for people with disabilities. They fear that the private insurance might not be as affordable or as comprehensive as Medicare's coverage and might not be adequate for people suffering from serious illnesses. "A private plan isn't going to be of much use to someone with a disability if it doesn't pay for the medical equipment that helps that person get around and lead a productive life," said Baker, of the Medicare Rights Center. The chief obstacle to making Medicare immediately

available to all Social Security disability beneficiaries remains money. Eliminating the wait would cost the federal government \$6.8 billion the first year and \$110 billion through 2019, according to the Congressional Budget Office. That's no small issue for a Congress struggling to find ways to pay for health care reform. "No one wants to undercut health care for people with disabilities, but this country has to face up to Medicare's long-term financing problem. The system has massive unfunded liabilities," said James Capretta, a fellow at the Ethics and Public Policy Center, a research institute based in Washington, D.C. Abolishing the waiting period without reining in Medicare's broader costs would only add to the problem, he said. Advocates of ending the two-year wait argue, however, that their proposal's estimated cost doesn't take into account all of the savings. Insuring people now stuck in the waiting period might reduce Medicare's spending on those individuals over the long term, said Vicki Gottlich, a senior policy attorney at the Center for Medicare Advocacy, a nonpartisan consumer advocacy organization. By the time people seek treatment after forgoing doctors and hospitals for 24 months, their conditions have worsened, and the cost of their care has increased, she said. "Catching problems early could help control health care costs – not to mention spare lives and relieve suffering," Gottlich said. **The bottom line, advocates say, is that Americans with severe disabilities aren't getting the health care coverage they require. "What purpose is served by idly sitting by and watching these people grow sicker as they wait?" asked Welch, of the Reach Resource Center on Independent Living in Dallas.**

THE DISABLED: SUCH INTERESTING PEOPLE by Hugh Gallagher

The other night, I was living independently, using my electric powered wheelchair, happy as a clam. It had been a good day. My writing was going well. I had driven my car to the library in the afternoon, cooked myself a dinner and now I was getting ready for bed. And then the left rear wheel fell off my wheelchair. No movement was possible: when I gave the chair power, the left axle would just grind itself into the oak floor. There I was, naked, all alone, and marooned twelve feet from the telephone. If I were to save myself, I had to get to the telephone and to do this, I would have to "crawl." I once knew how to get safely to the ground from my wheel

chair. This was done by crossing one leg over the other, turning in the chair, and sort of backing off onto the ground. This is what I tried to do the other night but I have lost strength and I just fell to the floor, all legs and arms in a tangle. Fortunately, no bones or tendons were damaged. By lying on my stomach, I was able to drag my body, inch by painful inch, to the telephone and the help I needed. It took me an hour and a half. The effort left me badly shaken and my muscles were sore and my skin was bruised and burnt. There are times when it is all just too much. One moment you are independent, able to deal with life, the next you are on the floor, stuck, helpless as a

baby. Dignity, self esteem, all that evaporates, goes up in air. There you are, out in the world, competing with the able-bodied, kicking ass, and then of an instant, zap, you are a pathetic cripple. It is a life of contrast: at the same time you are both a master and a wimp. You are a live, active player and, concomitantly, you are engaged in a private struggle, fending off the wily advances of disability, helplessness and death. And even more confusing is the fact that an episode like the other night is a real life adventure. It is an unexpected test of grit and courage. My crawl across the living room floor to the phone was, in its way, as challenging, daring and dangerous as Edmund Hillary's ascent of Everest. I will bet the sense of achievement I felt when I reached the phone was just as great. There is a rush of confidence: I will survive; I will prevail. This is a rush of pure joy at just being alive. Flowers, sunlight, loved ones are seen with a new intensity. This is part of what makes the disabled such interesting people. We experience a harsh reality the able-bodied can only read about. We relish the adventure of disability even as we hate it. And from it all we learn to appreciate life as it is, without blinkers. Back in the 1960s when I worked in the Senate, Hubert Humphrey was a force to behold. It was said that the effort that he and his office put into a average day's work would have been sufficient to govern a country the size of France. Humphrey had incredible energy; he

was buoyant and confident. There was no problem that could not be solved and he was the one who would solve it. Yet when I saw him in the last months of his life, he was a scared man. He knew he was dying of cancer and his eyes, once brimming with confidence, had a desperation he could not hide. Humphrey had caught a glimpse of his true helplessness in the face of approaching mortality. Clearly he could not handle this knowledge that we severely disabled people live with, day in, day out. If we are able to live with our painful, fearful knowledge; live with it and transcend it; to have a full, productive and happy life in spite of it, then we have come to have a wisdom that is granted to very few. Oliver Wendell Holmes said once that the wisest of men is the old family doctor. He has seen all the pain and suffering life has to offer and he has seen the best and worst of mankind. The severely disabled person who makes peace with his disability is like the old family doctor. So it is a rich, complex world for us disabled people. Our career out in the world, our private struggles, our adventures and our failures give us a "quality of life" that the able-bodied can only guess at. And yet, strangest of all, it is the able-bodied who feel they have the right to make quality of life judgments about us.* * * *Hugh Gallagher is author of FDR's Splendid Deception. Source of article is: R A L P H, The Review of Arts,Literature, Philosophy and the Humanities, Volume XVIII, Number 2 Late Fall, 1999*



These carts are made in NY State and sent to third world nations for polio survivors and people who have lost limbs in civil war bombings. A \$250 donation buys a cart for someone. I rode in one. They are very easy to pedal with your hands. I wanted one to use here in the country, around my complex. It would be good upper body exercise. But, alas, they will not sell them to anyone in the US even though they are made here in NY State. I wonder what recourse we might have. I bet many polio survivors, even if they have a scooter, if their upper body is not affected, would love one of these.

Mike Kossove

PRESENTATION BY DR. DARIA TROJAN ON POST-POLIO SYNDROME; MAKING A PRACTICAL IMPACT ON YOUR PATIENT'S LIFE

(Dr. Robert Chen, member PPAS of British Columbia, Canada)

Dr. Trojan received her MD in 1984 from Connecticut, received her B.Sc. in Bio-Statistics and Epidemiology and did research in Polio with Dr. Neil Cashman (formerly of the Montreal Neurological Institute, now moved to Toronto). She did her Ph.D. thesis in "Case Control Risk Study in PPS". She is now the director of the Post-Polio Clinic at the Montreal Neurological Institute and Hospital and is Assistant Professor at McGill University in Montreal. She has seen-treated around 800 PPS patients, probably one of the few specialists in Canada who has seen such a large number of patients. Most of her presentation was a review of what we already know about Post-Polio, i.e., a brief history, epidemiology, presenting symptoms, time of onset, predictive factors, patho-physiology (theories of what PPS is caused by), differential diagnosis (what other conditions and diseases to rule out), management of weakness, fatigue, pain, contractures, etc.) and what drug trials have been tried in the past; all these were well-summarized in Dr. Trojan's hand-out, and are also well-presented in the booklet **THE LATE EFFECTS OF POLIOMYELITIS: A RESOURCE GUIDE FOR SURVIVORS**, by Philip G. Ruiz. Dr. Chen adds, I made a few notes which were "new" or just a refresher:

- PPS is second to stroke as the leading cause of paralysis.
- 11% of PPS survivors have fibromyalgia (FM). Treat the fibromyalgia as is usual for FM, i.e.: having PPS does not change the treatment of the FM condition.
- In normal adult, there is a 1-% decline in muscle strength per year. In people with PPS, it is 2-3% per year.
- PPS is rarely fatal, but can produce difficulty with respiratory muscles, thus breathing and dysphasia (difficulty swallowing).
- The main problem in living with PPS is increased difficulty with **ADL** (Activity of Daily Living) and mobility.
- One of the more common orthopedic results of having PPS is carpal tunnel syndrome, due to change in arm use/posture.

- Again, some PP survivors need to exercise, but not to the point of pain or excessive fatigue, including doing ADL, i.e., avoid muscle overuse. In some people with PPS, they are not to do ANY exercise (when their muscles are so weak that even ADL, alone, is enough stress on the muscles).
- Energy conservation!!!
- Life-style changes - change job/occupation to more sedentary work.
- Pacing oneself.
- Regular rest periods during the day.
- Improve sleep using relaxation techniques, sometimes may have to use the drug Amitriptyline (Elavil) or Tryptan (Tryptophan) .
- Keep low body weight. Excess weight is just more work for the muscles, especially when we become more sedentary.

So, what is new in treating people with PPS?

There have been a number of small-scale studies using drugs to treat the symptoms of PPS, namely fatigue, muscle pain and loss of muscle strength.

Some of the drugs used in the trials were:

- ➔ **Amantidine** (an antiviral drug) because in one study, there was a suggestion that there is an inflammation of the nervous system in people with PPS. It was used on 25 subjects - **no** significant improvement.
- ➔ **Prednisone** in high doses. Used in 17 subjects to see if it would improve strength and fatigue - **no** improvement.
- ➔ **Human Growth Hormone**. Used by body builders to increase muscle mass and strength, used in 5 subjects - **no** improvement.
- ➔ **Bromocryptine**, a brain hormone, used in 3 subjects - no improvement.
- ➔ **Selegiline**, used in people with Parkinson's Disease, thought to improve the effect of L-dopa, a neurotransmitter for motor nerves. Used in 2 subjects - possible improvement in PPS symptoms.
- ➔ **Pyridostigmine** (Mestinon), an anticholinesterase drug which blocks the breakdown of cholinesterase, a neuro-transmitter substance involved in nerve cell synapses, thereby prolonging its action at the nerve junctions.

Dr. Trojan has almost completed a new study, using Pyridostigmine (Mestinon) in treating people with PPS. The results of the study will be published in about 2 - 3 months from now in one of the Neurological Journals. The study involved six centres across North America, with Montreal as the primary study centre. They enrolled 125 subjects, the largest study to date involving the use of Pyridostigmine in PPS patients. It is a double-blind placebo-controlled study, to see if using Pyridostigmine, up to 60 mg three times a day, would improve symptoms of fatigue, muscle strength and fatigue scoring using three different questionnaires. The study was to check patients' response at the end of a 6 months trial.

Result: Although in the study, statistically, it did not show a significant effect in all the three symptoms (of fatigue, muscle strength and fatigue questionnaire), the

investigators did notice some clear benefit in some patients. The investigators noticed that in some patients, they had an increase in their physical activity level but the fatigue levels reported remained the same. One of the questions raised by the study was: Was the fatigue questionnaire not specific or appropriate enough to bring out that result? When I asked Dr. Trojan personally after the formal presentation was finished, whether it is worthwhile to try taking the drug, based on her noticing some improvement in some patients, she was certainly very supportive and encouraging for me to give it a try. She suggested taking the drug at an initial dose of 30 mg once a day, and increase it by 30 mg every other day, to reduce the chance of its side effects of stomach upset, abdominal cramps and diarrhea, and to keep increasing the dose by 30 mg every other day until 50 mg three times a day is reached, then stay on it for one month. **The future:** As this study is one of the first "larger" drug trials involving Pyridostigmine, and the final data analyses have not been completed, it is not yet to be recommended as a treatment. Hopefully other trials will look into the use of this drug further, possibly using it at even higher doses, possibly to the levels that are being used in people with Myasthenia Gravis, where the drug is used in 2,000 - 3,000 mg levels, not just at the 180 mg level (60 mg three times a day) that this study investigated.



Dear Polio Epic,

In my very early 20's, I began to have pain and weakness in my left leg. The doctor measured my left leg and informed me that I had had polio. At about 80, I began to experience a general over-all weakness in my body. I met a woman in my church who recognized my symptoms, because of her own; and referred me to a neurologist who specialized in PPS. He diagnosed me and determined that I also had neuropathy. I tried to continue my regular life – doing Christian and Missionary work in Mexico. In my weakness, I began falling and ended up bedfast (4 ½ months). Then I read one of your books and began to learn what I had. I was doing everything wrong – so I learned that the main thing to do was to pace myself – which I did. I am driving again, shopping and in general keeping myself busy. However, I do things one day and rest the next day. Unfortunately, I broke my hip and had to go to a rehab hospital. They didn't know about the strong muscles and the weak muscles. I tried to explain the difference, but they didn't seem to understand. They helped me to get back on my feet, but it was very difficult because of my PPS. Praise the Lord that I have a grandson who is a body-builder, and he gave me exercise for my weak muscles. He showed me the difference on his computer between the stronger and the weaker muscles, and gave me a list of what to do to help with the weaker muscles, which are the ones which have to bear the brunt of my daily life. So, I have learned much about my condition and how to live with it. From what I read, thousands of children had a mild case of polio during the depression; which went undiagnosed, but in later life developed PPS. Basically, the general medical doctor wasn't familiar with PPS, so I was fortunate

to have a neurologist in my town who knows about it. There is no treatment, or medicine for PPS, but your literature has really been the answer for me. What I have is not terminal, and I am in good health for being 85 years of age, so I thank the Lord for showing me how to live the rest of my life – in spite of what I have: PPS and neuropathy. Hope my letter may be of encouragement to someone, just as your Polio Epic, Inc. has been to me. *Thanks much, "Con Agape Amor" With Godly Love, Crawford Sechler (Better known as "Pete") Polio Epic member*

Welcome to our New Member !
Jack Salmon

Polio Score		
	<u>Cases</u>	<u>Deaths</u>
1959		
Que.	1,131	101
Ont.	198	21
Nfld.	139	12
B.C.	132	12
Alta.	81	12
N.B.	62	6
Sask.	46	3
Man.	26	2
N.W.T.	10	4
N.S.	8	0
P.E.I.	7	1

Contributions

Thank you
Basha's
L.W. Nichols
Joseph Duchene

In Memoriam
Albert Eisenstadt, Passed away June 15 at 96 years old

Dues Form

POLIO EPIC, INC. CURRENT MEMBERSHIP ANNUAL DUES ARE RENEWABLE THROUGH THE FISCAL YEAR OF SEPTEMBER 1, 2009– AUGUST 31, 2010

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 2009-2010 fiscal year.

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

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_____ I am **UNABLE TO PAY** dues at this time, but wish to receive the newsletter.

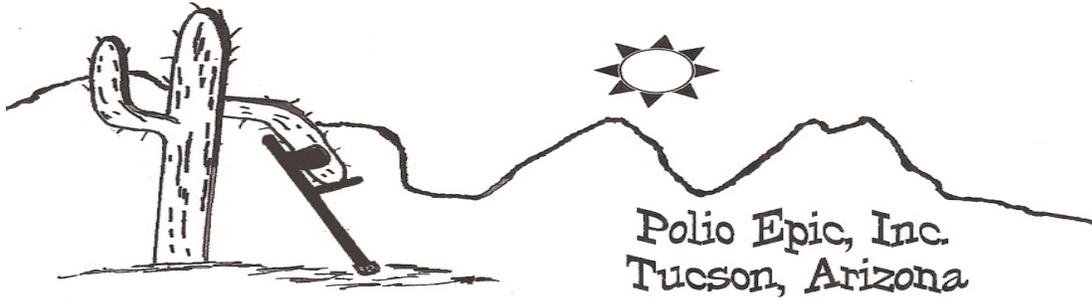
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_____ Check here if you do not want your name, and address info listed in the

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



*Artwork compliments of Charles Root

Let us know if you would like to receive your newsletter via e-mail instead printed! Be Green and Save \$ at the same time. Send an e-mail to Mickiminner@msn.com or Nannoe1@aol.com

A NEW YEAR has started! The dues of \$10 a year are now due for the new Sept 2009 thru Aug 2010 year. Send them in with the dues form, or call Nannoe, the Treasurer, to make sure you are part of this year's Polio Epic team