

October - November 2008
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.

Making Progress

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

October 11th, -

The Primavera Foundation,
Providing Pathways Out Of
Poverty for 25 years

November 15th,

Pima County Library, and the
services that they provide for
the disabled community.

December 13th

Our Annual Holiday
Party! Let's Celebrate
TOGETHER!

January 10th

February 14th

March 14th

April 11th

As I begin the process of being the president for Polio Epic for the 2008-2009 year, I realize more than ever, that every success is made of small steps in the right direction. We have so many individuals in our group that make so many steps, it is hard to keep track. We have people like Bobbi, who is new to our group and already participating and finding places where we need to go as a group. We have people like Karla who is constantly looking for places to present our message. We have people like Frank that are constantly looking for ways to make our lives as polio survivors better and to live with more dignity. (isn't that our mission statement). I feel so privileged and overwhelmed to be able to work with the people in this Polio Epic group. I was very encouraged when I prepared an outline for the September general meeting, and realized, that for every item on the list, there was a different individual presenting the progress of their work. We have a lot of president's in this group. We have the president of the treasury (Nannoe), the president of the Wadleigh Fund (Dave) and the list goes on. In this issue of the newsletter, look at what our members are doing!

During this time of Presidential election craziness, I wanted to assure you that every vote is meaningful and important. While you are a member of Polio Epic, everything you do is a campaign, and part of the progress of our group. Keep up the good work. Your campaigns are working. I noticed all of your progress, and you have my vote!

Micki Minner
2008-2009 President

Always vote for principle, though you may vote alone, and you may cherish the sweetest reflection that your vote is never lost.

-John Quincy Adams

Please remember, the **WE ARE STILL HERE**
campaign. During October,
Polio Health International is trying to inform the
public, that Polio Survivors are still here, and we are
still working to get the public and
the medical community educated.

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.

Board of Directors		
Karla Carr	318-1219	KarlaKrazies@peoplepc.com
Dorothy Cogan	326-7979	
Linda Failsmezger	322-0164	gapfamd@hotmai.com
Frank Frisina	327-3252	Shinybear@msn.com
Virginia Hanson	292-0652	vrh13@earthlink.net
Charlie Minner	743-1556	Canthmin@msn.com
Dave Marsh	327-3252	Davejonmarsh@msn.com
Barbara Stough	887-4731	chasbarstough@juno.com
Joanne Yager	296-1471	jyager@mymailstation.com
Executive Board Officers 2008-2009		
President, Micki Minner	743-1556	Mickiminner@msn.com
President-Elect, OPEN		Your name could be here!
Treasurer, Nannoe Westbrook	797-6898	Nannoe1@aol.com
Correspondence & Recording Secretary CeCe Axton	495-5122	axton@cox.net

PPS “We’re Still Here” Campaign – Oct. 12-18, 2008

Post-Polio Health International (PHI) challenges individuals and groups from around the world to make the October 12-18, 2008, “WE’RE STILL HERE!” campaign even more visible than the successful 2007 campaign. The goal is to alert health professionals, policy-makers, and the general public to the fact that polio survivors are active individuals within their communities with successes to tell, and for many, unmet needs.

Focus for 2008

PHI is collaborating with Polio Survivors and Associates (PSA), a Rotarian Action Group, in asking polio survivors and post-polio support organizations to contact the local Rotary Club with an offer to speak during “WE’RE STILL HERE!” week.

Activities Announced

PHI challenged groups to be creative in designing activities for this year’s campaign; the following groups have responded to date.

Manuscript for Post-Polio Players – The brainchild of Vera Moore, Mobile Area Post-Polio Support Group, this fast-moving script of polio survivors chatting before their support group meeting raises post-polio issues in a personal way. The short script, which can be modified to fit any area’s history, is easy and fun for groups to produce. Book the production for Rotary meetings, church and community action groups, school assemblies, social interest groups. Schedule a Q&A session after the skit. The script, needing minimal props, set and characters can be downloaded from the “WE’RE STILL HERE!” section of www.post-polio.org.

Virtual Workshop – The Polio Society, Washington, DC, is developing a virtual seminar/support group to be offered during the week of October 12-18, 2008. Polio survivors and their loved ones and caregivers will be able to register for this free program by mail or through the Polio Society website. The only cost will be a long-distance phone call to the telephone bridge line. Contact the Polio Society online (www.poliosociety.org) or by phone (301-897-8180) for additional details.

Locating local polio survivors – The John P. Murtha Neuroscience and Pain Institute (JPMNPI) and the Rotary Clubs of District 7330 in Johnstown, Pennsylvania, are collaborating to locate and assist area polio survivors. Ideas include a public service announcement highlighting polio history, Rotary’s involvement in polio eradication and rehabilitation, and the services at JPMNPI; developing a grant to fund continuing education for Emergency Medical Services Personnel; and a “Post-Polio Walk.”

WE’RE STILL HERE! Home Base – Post-Polio Health International’s website (www.post-polio.org) is home base for facts, ideas and latest updates on the “WE’RE STILL HERE!” campaign and will have links to all participating groups. As plans develop, send them to director@post-polio.org to be added to the “WE’RE STILL HERE!” section of www.post-polio.org.

**PHARMALINK REPORTS POSITIVE PHASE III RESULTS FOR XEPOL®,
A TREATMENT FOR POSTPOLIO SYNDROME**

STOCKHOLM, SWEDEN – 26 August, 2008 - Pharmalink AB today announces positive results from a follow - on Phase III 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.

The Phase III study, involving 142 patients, is a placebo controlled, double blind trial designed to evaluate the efficacy and safety of Xepol® in PPS, a neurological pain and weakness syndrome in patients that have survived poliovirus infection. The original placebo controlled, double blind Phase III trial was six months (Gonzalez et al (2006) Lancet Neurology 5:493 - 500) and this followup period was another six months. The follow - on results strengthen the position of this novel treatment modality for PPS by demonstrating a reduction of inflammatory cytokines in the cerebrospinal fluid and a significant reduction of symptoms of PPS while also showing that Xepol® is safe and well tolerated with few or no side - effects. Endpoints studied were pain, walking ability and SF - 36 scores (a common self assessment scoring system that measures physical and psychological variables). All showed significant and clinically meaningful results. Full results are to be published in a peer review journal. Xepol®, the first medical PPS treatment , is an injectable biologic product, administered once per 9 - 12 months, which down - regulates the inflammatory process in the nervous system of PPS patients. The concept and medical hypothesis was first developed by Dr Henrik Gonzalez and Professor Kristian Borg, scientists at the Karolinska Institute (Sweden). Pharmalink licensed the invention and is now working to bring the candidate towards registration.

“We are very encouraged by the outcome of the follow - up analysis as it is clear from the results that Xepol brings relief from pain and muscle weakness to PPS patients,” said Johan Häggblad, Managing Director of Pharmalink. “We are very excited about this data as currently there is no medical treatment for PPS and patients in the treated group have experienced a reduction in disease symptoms after just 12 months.” “It is very rewarding to see that Xepol is demonstrating efficacy and the potential to help PPS patients,” said inventor and principal investigator Professor Kristian Borg.

“We are looking forward to expanding the Xepol treatment procedure following product registration.” Pharmalink is actively seeking a partner to bring Xepol® to the market. More than 1000 PPS patients have been treated with the drug and many return on an annual basis for new treatment courses. **Xepol® has already achieved Orphan Drug Designation in the US and is patented in the major markets.**



My paintings will be on exhibit from September 29th through October 28th at the Joel D. Valdez Main Library 101 N. Stone Ave., 85701, 594-5500. Please join me for refreshments at a reception in the Children’s Meeting Room on the first floor on Thursday, October 9th, from 4-5:30 pm.

This is one of our own Polio Epic membership, let's support Katherine and view her beautiful art.

Effective September 1, 2008, Dave Marsh (board member) has agreed to send out or e-mail applications for the Wadleigh grant to anyone interested. Dave's phone number and e-mail address are listed in the Board Members director on the second page of the newsletter. I have printed the original information sheet that was created. If you need something, and could use a little bit of financial assistance, a Wadleigh grant could be just what you need!



FRANK WADLEIGH FUNDS GRANT

Polio Epic, Inc., Southern Arizona Post-Polio Support Group, is accepting applications from its membership for “one time” financial assistance.

This program is made possible by a bequest Polio Epic received from Mr. Frank Wadleigh, a long-time member and supporter of Polio Epic. The purpose of the program is to improve the quality of life for Polio Epic members, while supporting the overall mission of Polio Epic. Reasons for requests will be as varied as the members making the request.

To apply, Polio Epic members must:

1. be in need of financial assistance
2. be at risk for health or safety hazards
3. live in Pima County and be a member of Polio Epic (exceptions to be determined by the Board of Directors)
4. have not received a previous Wadleigh Grant
5. apply for durable goods and/or services only
6. mail the completed application by **February 1st** or **August 1st** to the P.O. Box listed below

Assistance is limited to a maximum of \$400 per grant. Selection is based upon economic and social need with priority given to those individuals who have no other resource. All applications are prioritized by the Polio Epic Board of Directors, with assistance from Polio Epic Professional Advisory Board, as needed. Applications are available by contacting a board member or can be downloaded from our website: **www.polioepic.org** **OR contact: Dave Marsh 327-3252 or e-mail Davejonmarsh@msn.com**

All applicants will be notified of the Boards decision, in writing, by March 1st and/or September 1st.



Contributors to **POLIO**EPIC

James LaDuc *
 DeAnn Riley *
 Dana Vinci *
 Russell Amling
 Lucy Anderson
 Leanora Benson
 Joan Bernardi
 Barbara Campbell
 Lawrence Carnicelli
 Dorothy Cogan
 Joann Cummings
 Jennie Curlee

Joseph Duchene
 Polly Elson
 Linda Failmezger
 John Geiger
 Carol Mayfield
 Lu Ann Pankratz
 Elaine & Larry Perry
 Richard Piskun
 Mary Raihofer
 Keve Sankman
 Irene Schmoller
 Nannoe Westbrook

*\$100 or over

*Eugene Sherman – Donation In memory of wife, **Laura Sherman***

In loving memory:

Kathleen Smith
Minna Feilbelman



*"We are, each of us, angels with only one wing,
and we can only fly embracing each other."*

- Luciano Decrescenzo

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 21st Century" 10th 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 25th. 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. or visit their web site at 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



shop & give

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 for more information on the program.

Our group number is: 27169



For Sale: Frigidaire Room Air conditioner. 12" 18 1/2" with expansions. Excellent condition, 2 years old \$75.00. Call 326-7979 Dorothy

Wheelchair Accessible Home for Sale

Price: \$219,000.

Location: Northwest Tucson; 9260 North Moon View Place

Beautifully maintained Santa Fe home is fully wheelchair accessible and ready for occupancy. Located in northwest Tucson, the home has lovely ceramic tile throughout; hickory cabinets in the kitchen; extra wide hallways; high ceilings; newly painted inside in warm neutral colors; beautifully landscaped front and rear; with delightful mountain views. Three bedrooms two baths, 1600 square feet, single family residence in community of 32 homes. The home is located one mile from Arthur Pack Recreational Center and golf course, three miles from the new YMCA and the newest campus of Pima Community College, three miles from the Omni International Golf Course, and close to shopping malls. The house is located within an excellent school district. Will consider renting: \$800 down and \$800 a month Contact Mary Raihofer for additional information. 518-766-3660 or grasshopper@taconic.net



A ceremony long overdue

Published: 09:36AM September 5th, 2008-Northwest Guardian

Lt. Col. Jonathan Neumann, commander of 1-17 Inf., pins the Bronze Star Medal on Edward Boyles for his actions in Leyte during WWII at the Fort Lewis Museum. Boyles also received the Purple Heart. Edward Boyles finally received his Bronze Star Medal and Purple Heart last week in a long-overdue ceremony for his actions during the most intensive week of combat in his 20-year Army career.



The 1st Battalion, 17th Infantry “Buffalo” Regiment presented the awards to the 89-year-old Boyles in recognition for his bravery and leadership as a 2nd-lieutenant platoon leader during some of the fiercest fighting of World War II. “A leader is only as good as the men he leads,” Boyles said. “I led some fine men.” Lieutenant Colonel Jonathan Neumann, the battalion commander, pinned on the medals as the battalion adjutant, Capt. Antwan Brown, read the citations that sounded like the stuff of movies, Boyles was assigned to B Company, 1-17 Inf. The regiment belonged to the 7th Infantry Division, which, with the 96th Infantry Division, landed in the Philippine Islands under Gen. Douglas MacArthur in October 1944 to keep MacArthur’s famous promise to return and free the islands from the stranglehold of Japanese occupation.

Boyles had been stationed at Wheeler Army Airfield during the bombing of Pearl Harbor, fought at Midway Island and Kwajulein, but was recognized last week for the brief period during which he helped push back an entrenched enemy at Leyte in the Philippines. Two corps landed on the island on Oct. 20; the XXIV Corps had responsibility for the southern sector, rice paddies and huge bogs that channeled approaches for miles leading to the mountainous part of the island. As Boyles recalled it, the 1-17th had been organized as a task force and was ordered to move forward across the XXIV Corps front. From Oct. 24 through Oct. 26, the companies of the 1-17 Inf. task force were in almost constant contact with the enemy. On Oct. 27, his 2nd Platoon took the left side of a densely overgrown strip between paddies and 3rd Platoon the right. The Japanese forces had had time to improve their positions in the days leading up to MacArthur’s landing. The U.S. forces waded into a thicket of mines, tank traps, pillboxes and avenues of approach covered by murderous indirect fire.

Japanese soldiers who didn't crouch behind or under improved fighting positions dug spider holes and lay in wait. As the American platoons moved along, both units encountered sniper fire and an increasing volume of small arms fire. He saw his fellow platoon leader arrange a squad as skirmishers and advance away from Boyles, who took a different approach. He called a squad leader to reconnoiter the area ahead of him and making an educated guess about the location of an enemy sniper, directed his Browning Automatic Rifle gunner to fire at a stand of coconut palms. The sniping stopped. Meanwhile, 3rd Platoon found itself heavily engaged and pinned down in a nearby rice paddy. Boyles organized a medical evacuation team and under fire, directed his aid man and team on multiple trips across the berm to pull out the wounded. He also called in artillery fire for the rest of the afternoon to protect the trapped platoon and keep casualties to a minimum. The medical team from 2nd Platoon managed to retrieve everyone. That evening, his company commander told Boyles to take command of 1st platoon. It had been mostly held in reserve the day before, although its platoon leader had lost his foot in an explosion. By the evening of Oct. 27, Boyles said he and the company commander, a captain named Davis, were the only two officers in the company who hadn't been wounded.

As he maneuvered his platoon forward on the next day, he and his men encountered the full weight of the Japanese resistance, which the battalion's Presidential Unit Citation described alternately as "violent, bitter, and fanatical." In some of the bloodiest action of the Pacific Campaign, Boyles and his men often found themselves fighting hand-to-hand with soldiers appearing out of nowhere from camouflaged holes. During the thick of the fighting, he remembered hearing the voice of one of his Soldiers from behind him.

"I heard Pfc. Orchowski say "It's alright — I got him," then heard a loud thud. A Japanese officer had popped out of a hole behind him and had advanced to within "five to 10 feet of me. He had identified me as an officer and was about to swing his saber to cut my head off," Boyles said matter-of-factly. "Orchowski was 6'2" or 6'3" and hit him with the butt of his rifle and nearly took his head off." He paused for a moment and added, "They were my people. I trusted them — with my life." By that evening, B Company was for all practical uses, gone, decimated by casualties. A messenger arrived from 96th Division to inform the exhausted lieutenant that the battalion task force had achieved its mission and was being replaced. "Fillers" began arriving. Boyles said he remembered telling one of his few remaining NCOs who stayed behind to help a wounded Soldier to stay off the road between the paddies. He should have followed his own advice. As he walked alone toward the rear, a Japanese artillery round landed nearby, showering him with hot shrapnel and throwing him into a paddy. To his good fortune, he didn't land face first, waking up with piercing pain in his left side but able to still walk. "I wondered when I would see you here," he remembered Doc Beck say to him. Boyles' colorful military career was only one-third finished at the end of the war. He went on to serve as a counterintelligence officer, commanding field stations in San Francisco, Los Angeles and Salt Lake City. He was later stationed at Camp Polk, Camp Riley and Germany before returning to retire at Camp Hood in 1958 as a major.

After two years of selling insurance, he joined civil service to continue his intelligence career that took him to Viet Nam as a DA civilian. Boyles retired from his second government career in 1980. He contracted polio a month after his combat in the Philippines, wears a pacemaker, hearing aids and glasses, but his mind is sharp and always prepared to share the stories of his remarkable service to his country. The Buffalos celebrated their first 17th Regimental Reunion with events over a four-day period from Aug. 27 through a banquet on Saturday. Activities included a memorial service, a visit to the Fort Lewis Museum, a tour of the battalion area, a group photo at the Iron Mike Statue and a training demonstration at Leschi Town as well as the medal ceremony for Boyles.

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 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!

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.

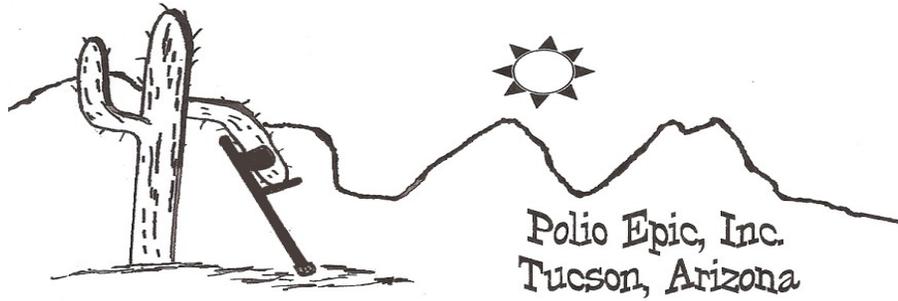
_____ Please remove my name from the mailing list. I no longer wish to receive the newsletter.

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

POLIO EPIC DIRECTORY.

_____ I would like to be more involved in Polio Epic. 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**



E-NEWS

**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**

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!**