

June - July 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.

KEEPING OUR BALANCE

General Membership Meetings

**Every Second
Saturday of the
Month
10:00A.M. - 12:00N**

Education Room

**HealthSouth
Rehabilitation
Hospital**

**2650 North Wyatt Rd
Tucson, AZ**

June 14th – Fun and
Sharing, elections, and
summer send-off.

July – No meeting

August – No meeting

September – Pima
County Extension office
Master Gardner –
Container Gardening for
the disabled.

We as Polio survivors find it difficult to maintain a healthy balance in our lives. No, I'm not just talking about staying upright and not falling flat on our faces, or other parts of our anatomy when we lose our balance. Let's think about our relationship between health and balance in everyday living. This may include physical, emotional, spiritual, social and even environmental issues.

Each and every day we encounter demands of our time and energy. Perhaps some of these we place on ourselves, others come from outside sources such as, friends, family, community, church or work. A healthy balance requires "self-care", please don't consider this as something that is OK for someone else but not for you. Consider what you can do to maintain a healthy balance, but still be involved in living your life to the fullest.

I feel it necessary to mention that there has been no further news about Kay Read. She has been missing since February 14, our thoughts and prayers go out to her family.

Many of us will be traveling this summer, keep a "healthy balance" during this busy season, have fun and stay safe.

Until next time, Joanne Yager, President

Note from Micki:

Joanne left me some room to make my pitch for your participation in our active, growing, and fun group. This is the first year in ages that we don't have a nominee for a couple of important board positions. I know that as we age and get worse with our Post Polio symptoms it is hard to imagine taking on a responsibility. Let me assure you that I had the same problem. Before I quit working I thought I could NEVER assume a role with Polio Epic's board. However, it has turned out to be a wonderful blessing for me. I have learned to balance myself, maintain my well-being, and stay current with all of my friends, in an outlet that I had never used before. You can too. The board is a friendly group, and the most important responsibility is merely attendance and voicing your opinion. We can't continue to make Polio Epic work for everyone, unless we have everyone's participation. Check your heart, and schedule to see if there isn't something you can do!

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		
Cecelia Axton	495-5122	axton@cox.net
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Please send newsletter additions/contributions to: Micki Minner, Editor at mickiminner@msn.com

2 Power Wheelchairs are available. 1 is free to any polio survivor. These are battery operated wheelchairs Please contact Micki or Charlie Minner at (520) 743-1556.



From the Treasurer...

ARE YOU ARE MOVING? OR GOING TO A COOLER CLIMATE FOR THE SUMMER?

Did you know that the Post Office will NOT forward your newsletter?

Since our newsletter has **RETURN SERVICE REQUESTED**, your newsletter is not forwarded to you but returned to us indicating a forwarding address or 'TEMPORARILY AWAY.'" Please help us keep the cost of postage down and your address up-to-date -

You can do this by letting us know if. . .

- you are moving, please contact us with your new address.
- you are seasonal (snow birds), please give us your summer address and let us know approximately when you are leaving and when you are due to return.
- you will be away for awhile and wish not to receive the newsletter for that time, let us know that, too.

Please call a Board member or contact Nannoe at 520-797-6898 or Nannoe@aol.com.

WHAT YOUR DUES AND DONATIONS COVER

Polio Epic functions as a support group to empower our members and their families with the knowledge necessary to make adjustments they need to continue living a life of dignity and independence

We rely on your dues and donations, which help Polio Epic reach out to our members, health professionals in our community, and network with many Post-Polio Support Groups around the country and abroad.

Your dues and donations make it possible for us to continue to reach our goals.

Remember, we are a 501(c)(3) non-profit cooperation and all donations are fully tax-deductible

DONATIONS

**Joseph Duchene
Bev Motta**



NEW MEMBERS:

Rev. Jean M. Trench – Sagamore Beach, MA

In loving memory:



Kenneth Wilkens
Donald Bauman
Ann Forshay

FRANK WADLEIGH MEMORIAL FUND

Polio Epic, Inc., Southern Arizona Post-Polio Support Group, is accepting applications from its membership who are encountering the effects of post-polio syndrome.

This program is made possible by a bequest Polio Epic received from Frank Wadleigh, a long-time member and supporter of Polio Epic.

To apply, Polio Epic members:

- ❖ Must live in Pima County and be a member of Polio Epic.
(Exceptions to be determined by the Board of Directors)

- ❖ Must be experiencing financial hardship.
- ❖ Must be at risk for health or safety hazards
- ❖ Must apply for durable goods (such as walking aids, automotive or wheelchair accessories, tub or shower equipment). Or for health services by a qualified healthcare provider, (such as diagnostic testing related to post-polio syndrome.)
- ❖ Must mail the completed application by February 1st or August 1st to the P.O. Box listed below

One time maximum funding per member, not to exceed \$400.

Applications are reviewed and approved by the Board of Directors. Applicants will be notified in writing shortly after the board meetings held in February and August.

Applications are available by contacting a board member or can be downloaded from our website: www.polioepic.org and mailed to:

Polio Epic, Inc.
P.O. Box 17556,
Tucson, AZ 85731-7556
(520) 750-8608 (message)

Revised 3/2008

No let-up in polio cases

May 02, 2008 Friday Rabi-us-Sani 25, 1429--By Mukhtar Alam

KARACHI, May 1: There has been no let-up in polio cases in the country as a 27-month-old girl, a resident of Mirpurkhas district, Sindh, was confirmed as suffering from the disease on Thursday. The latest victim of the dreaded virus had an attack of paralysis on April 5, following which stool samples were collected and sent to the National Institute of Health.

The latest detection took the number of cases in the country so far this year to five, mocking the government's claims that Pakistan was all set to give the disease "one final push". Earlier this year, Sindh reported one polio case each from Nawabshah Jan1), Hyderabad (Jan 25), Shikarpur (Feb 25) and Karachi (April 1). The province has been reporting one case per month since May of last year. While 13 polio cases have been confirmed in Sindh over the past 13 months, Punjab showed only one case, NWFP seven, Balochistan six and Fata two over the same period.

Islamabad has not reported any case since Dec 2003, the AJK has not had any case since June 2000 and Fata has remained polio-free since Jan 1998. According to a source, the trend of polio cases reporting in Sindh is similar to last year's when the province reported seven new cases from January to April. Of the five polio-affected children, three happened to be girls. The latest affected girl was given 12 doses of oral vaccines, claimed another source.

Till Thursday night, the polio eradication executives of the province had not admitted that Reshma, the Mirpurkhas girl, had tested positive for polio. Dr H.B. Memon, National Manager of the Expanded Programme of Immunisation, confirmed that the fifth polio case had once again been reported from Sindh.

According to the World Health Organisation, there is a discrepancy between figures furnished by the district administrations and independent evaluators vis-à-vis the polio immunisation drive. "The difference of five per cent or more in the cases of Qillah Abdullah, Qilla Saifullah, Masgung, Khuzdar, Karac hi, Badin and Umerkot reinforces the need for improving campaigns quality as well as the post-campaign assessment," a summary said.



FYI - We received the following e-mail from one of our members, Ernie!

Those three-wheel scooters that so many of the disabled are utilizing these days each comes with it's own auxiliary battery charger. Many of these chargers can be utilized as a backup for motorized wheelchairs, when the on-board charger fails to function (see three-prong female outlet below joystick on Invacare models).

Most medical supply facilities pronounce the defective charger as DOA, and they convince the customer that a new purchase is the only solution. If you are not covered by some form of insurance for this expense, one could expect to spend upward of \$200 - \$300 for a replacement charger. I found myself in this same situation during the past month, but did not have \$285 to replace the trickle charger for my Bruno scooter. As fate would have it, a source advised me of a small shop near the Holiday Inn on Palo Verde that specializes in conveyor systems and charger repairs. Long Story short - the charger was repairable and at less than 15% of a new one. In this instance, it was a \$10 circuit breaker which had fatigued from 7 years of weekly use. Here is the name and address of engineer, Roger, that afforded me the savings:

ROGER ROBERTS
@ Cienega Tek Serv
3433 E. Milber Street
Tucson, AZ 85714

(520) 903-9214 Hope this will be helpful, Ernie

Polio Survivors Ask...

Nancy Baldwin Carter, Omaha, Nebraska

Q: I keep hearing about the shingles vaccination. Should polio survivors get one?

A: Currently there is no experimental data regarding polio survivors getting this vaccine. PHI polled nineteen doctors (experienced in treating polio survivors) about your question and received a variety of responses. The most prudent thing to do seems to be to study the information we provide below, talk with our doctors about our individual circumstances, and then each make our own decision.

THE VACCINE: In the year 2006 a vaccine called Zostavax was licensed to prevent shingles in people over age 60. In the clinical trial, the vaccine was successful in 51% of the participants 60 and older and was most effective in those aged 60 to 69. Shingles-related pain may also be reduced in many of those receiving the vaccine. **PRECAUTIONS:** The Centers for Disease Control says those who should not get this vaccine are people who have had a life-threatening **allergic reaction to gelatin**, the antibiotic **neomycin**, or **any other component of shingles vaccine**. They advise those who have severe allergies to inform their doctor about this. They also recommend certain people do not get shingles vaccine (which contains live though weakened chickenpox virus): Individuals who have a **weakened immune system** because of HIV/AIDS or another disease that affects the immune system, treatment with drugs that affect the immune system, such as steroids, cancer treatment such as radiation or chemotherapy, a history of cancer affecting the bone marrow or lymphatic system, such as leukemia or lymphoma. Those with active untreated **tuberculosis** and those who are **pregnant** or might be pregnant should not get the vaccine. Individuals who are moderately or severely ill (including those with a temperature of 101.3° or higher) should wait to get their vaccine until they are well. **THE DISEASE:** Approximately one million cases of shingles (also known as *Herpes Zoster*) occur in the United States each year. The same virus that causes chickenpox causes shingles. When people recover from chickenpox, the virus lies lurking in the nervous system for the rest of their lives. Certain circumstances (perhaps stress or immune deficiency or something else) reactivate this virus and cause shingles. This usually occurs after age 50. Shingles may begin as a sensitive or burning feeling in the skin that turns to a rash, usually down a certain nerve on one area and one side of the body. Shingles blisters then form for a number of days before they pop and finally crust over and heal. The entire process can take several weeks. **SYMPTOMS AND COMPLICATIONS:** Fever, chills, upset stomach, and headache can indicate shingles. Very rarely, shingles can result in pneumonia, hearing difficulties, blindness, encephalitis, or death. A common complication of shingles is nerve pain. When this pain continues for more than a month, it's known as post-herpetic neuralgia, which occurs in more than 40% of those over 60 who have had shingles. This can be devastating. In some cases, certain medications may be used to alleviate the situation.

INTERESTING FACTS: People who've had shingles can get it again. Only people who had chickenpox or chickenpox vaccine can get shingles; the chickenpox virus stays in the body forever. Shingles is not contagious. However, a person who never had chicken pox or the chickenpox vaccine can get **chickenpox** from someone with shingles.

COST: A number of factors determine what the shingles vaccine costs individuals. For example, in Omaha, Nebraska, the vaccine is administered in pharmacies for the cash price of \$220. Plan D picks up from \$25 to the full amount, depending on the coverage one has chosen. Medicare itself won't pay for the vaccine, though it will pay a \$20 administration fee. Getting a firm price may take a few phone calls in each separate locality.

Source: Post-Polio Health International, www.post-polio.org

12 Tucson businesses facing suits alleging Disabilities Act problems

Filings by Fla. law firm stem from 6 plaintiffs who say they are due full access under U.S. law

By Josh Brodesky *arizona daily star* Tucson, Arizona | Published: 03.28.2008

Twelve Tucson businesses, including two hospitals and several well-known restaurants, have been sued in the last week, accused of not being fully accessible to people with disabilities. The suits, filed by a small, Florida-based law firm, target St. Mary's and St. Joseph's hospitals as well as the Doubletree Hotel, El Charro Cafe, Foothills Mall and Coffee Xchange, among other businesses.

The same law firm has filed hundreds of similar suits in nine other states and Washington, D.C.

None of the businesses knew it had been sued until it was called by the Arizona Daily Star. The few owners who would comment said they weren't doing anything wrong and that their buildings were just built before the Americans With Disabilities Act standards were adopted in 1990. The federal court actions focus mostly on issues involving parking, access and bathroom size.

For example, the suit against Silver Saddle Steak House claims its bathrooms are too small for a person in a wheelchair to use. One targeting the Bum Steer restaurant claims there aren't enough handicapped-accessible parking spaces. At the Doubletree Hotel, the suit claims accessible guest rooms lack benches in showers as well as guardrails in bathrooms.

"A lot of my clients have gotten frustrated" about not having full access at these businesses, said Gene Zweben, a partner in the firm Schwartz Zweben & Slingbaum, which filed the suits. "They felt it's time now to force (the business owners) to do what they are required to do by law."

The lawsuits stem from six plaintiffs, many of whom are polio survivors and use wheelchairs. The lawsuits do not call for compensation.

"These were places that we normally go to, and we couldn't have access," said Charles Minner, a polio survivor who uses a wheelchair. "We just talked about it amongst ourselves for years."

Minner's wife, Micki, who also has survived polio and now uses a cane for support, said the couple's disabilities make even the most routine errands an ordeal. She said it can be overwhelming to go out to eat only to find her husband's wheelchair can't fit in a bathroom stall or there is a lack of parking.

"The No. 1 thing that was a shock to me is how much planning it takes to do anything," she said, referring to

life with a physical disability.

"To go to the movies, to go to the grocery store, you have to know the place and already scoped it out so you can do what needs to be done. You can't even take a quick minute trip to the convenience store." The Minners brought suits against the Doubletree Hotel, St. Joseph's Hospital and St. Mary's Hospital. The lawsuits against the 12 businesses caught all the businesses by surprise, and most owners declined to comment. Those who did said they believe the lawsuits are frivolous.

"Why is a lawyer from Florida being hired for something in Tucson?" said Ray Flores, an owner of El Charro Cafe. "It's not going to impact the lives of the handicapped." Heiko Langrehr, who bought the Bum Steer in December, called the suit a "slap in the face."

"It's all about the money," he said. "It's not about if those people get a better quality of life. It's lawyers making money." While Zweben is not charging his clients, he said that if the suits are successful, the defendants will have to pay his fees. And because of the way the Americans With Disabilities Act is written, he said it's very difficult for the businesses to collect their legal fees if the suits aren't successful. Almost all the suits get settled, he said. "I don't think it should matter whether we are from Florida or from Arizona," Zweben said. "Some business owners just think that everything is about making money. It's about accessibility. It's about access. A 1-inch threshold for someone in a wheelchair is like a brick wall."

Many of the restaurant owners, such as Jane Alva, owner of Silver Saddle, said they thought they were grandfathered in under the Americans With Disabilities Act because their buildings were older than the act, which was enacted in 1990. "This is a very old building, and there are a lot of things grandfathered in," Alva said, adding that she already was trying to fix the accessibility issues with the restaurant's restrooms.

The idea of being "grandfathered in" under the Americans With Disabilities Act is something of a misconception, said Ed Myers, executive director for the Arizona Center for Disability Law. For those buildings built before 1990, repairs must be affordable to owners, he said. If not, he said, accommodations need to ensure that all people can be served.

For Physician Assistant, Empathy Goes Two Ways
By ANTHONY RAMIREZ--Published: May 5, 2008

A Man Who Understands Challenges Helps Others Face Death Mr. Welton is a physician assistant. Because of his job and what he has lived through, Mr. Welton is unusually familiar with the wounds that flesh is heir to. He has therefore learned something important: to savor life, in his patients and in himself.

Now 60, he has survived polio. In 1953, he and two of his brothers contracted the virus on the same summer day at Orchard Beach in the Bronx. His brothers made a full recovery. Mr. Welton did not.

From the neck up, Mr. Welton looks like Santa Claus before his beard turned white. From the chest down, he is atrophied. He walks with crutches, his right leg bearing the weight of his 130-pound body.

Mr. Welton's spine is curved. His clothes hang on his 5-foot-6-inch frame. Metal braces thicken his legs. He does not wear a long white coat because it might tangle his crutches. Still, Mr. Welton's appearance is a professional advantage, he said. "A lot of times when I come into the room and a patient sees me," he said, "there's this feeling of, O.K., he's going to understand what I'm going through."

Mr. Welton works the late shift at Montefiore Medical Center in the Bronx, where on quiet nights the only thing that can be heard in the corridor is the sucking sound from the rubber tips of Mr. Welton's crutches on the floor.

A physician assistant for 26 years, Mr. Welton works on what is known as the palliative care unit for patients with progressive, incurable illnesses, like terminal cancer. The unit has 15 beds. He takes patients' medical histories, prescribes their medication, checks their vital signs and declares time of death when their end comes. He started working at the palliative care unit last year. Physician assistants, as some have tartly observed, do 80 percent of a doctor's job for 50 percent of the pay. (The annual salary averages about \$82,000.) They are not legally entitled to be called doctor, although some patients do call Mr. Welton "Doc."

There are more than 68,000 such practitioners in the country, according to the Physician Assistant History Center, in Durham, N.C. The profession grew out of a desire to use the real-world experiences of combat medics returning from the Vietnam War.

As patients live longer and chronic illnesses grow more complex, health experts project a shortage of doctors and an even stronger demand for physician assistants. In 1980, Mr. Welton went through a two-year physician assistant course at Long Island University.

Physician assistants are supposed to work under the supervision of a physician. Dr. Rose Guilbe, 52, is one of the physicians who hired Mr. Welton, and she supervises him in the palliative care unit.

The physician assistant is "the bedside provider," Dr. Guilbe said. What Mr. Welton in particular contributes is a rich experience of working with the seriously ill, Dr. Guilbe said.

"He doesn't think in tags," she said. "Tags like, they're substance abusers, they're druggies, they're drug-seekers, blah blah blah. John doesn't come with biases."

Recently, Mr. Welton started the last of his week's three late-night shifts, which last 12 hours, as usual at 7 p.m.

The first hours are the busiest. Patients' visitors are allowed to stay until 8:30. Most patients are asleep by 10. If Mr. Welton has to visit a patient after those hours, it often signals trouble.

The first patient he looks in on is a gaunt 22-year-old man with advanced leukemia and little or no resistance to disease.

The next patient, an 88-year-old woman, is in distress. She has emphysema and advanced Alzheimer's disease. Mr. Welton checks on her frequently.

By the time patients have reached the palliative care unit, most are quiet, communicating in a whisper or a simple head movement. Mr. Welton has to assess



whether a seeming look of fear is disorientation or a signal of pain. Carrying out his work is not easy. To listen to a patient's heart, Mr. Welton steadies himself on crutches, then leans forward like a flamingo, his right hand aiming his stethoscope toward the patient's chest.

To check patients' information on his office computer, Mr. Welton must first plop his chin and chest on a surface in front of him, forming an inverted L. He then unlocks his leg braces and eases into a chair.

The hours pass. At 1:23 a.m., Mr. Welton takes two Tylenol tablets for arm and shoulder pain from using his crutches, and then a caffeine pill.

Hospitals used to frighten him. They still do, in his dreams. When he was a boy recovering from polio, a nurse would carry a pile of hot, wet blankets to wrap around his paralyzed legs, a common treatment for polio in the 1950s. When he dreams about that, he shudders. "It's the smell of wet wool," he said.

Suddenly, at 4:35 a.m., he receives an urgent call from a nurse. An 82-year-old woman is having trouble breathing. She is frail, with a shock of white hair. Mr. Welton notices two words on her chart,

"paranoid schizophrenic."

"I'm going to sit you up a little," Mr. Welton says loudly to the patient. "When was the last time you took your pills?"

"Every day," she hisses.

"Having pain anywhere?" Mr. Welton asks. She says nothing.

"Just trouble breathing?" She nods.

Mr. Welton stares into her face. "Can you tell me who the mayor of New York is?" he asks. "Leave me alone!" she screams.

Minutes later, at 4:50 a.m., Mr. Welton is called to the bedside of a 53-year-old man with liver cancer who has vomited blood. The man's blood pressure cannot be detected, and his jaw is slack. Mr. Welton is worried.

At 4:53 a.m., he telephones the man's wife. "Your husband has taken a turn for the worse," Mr. Welton says, "and it is very likely he is going to die." She tells him that she is getting into her car.

Dues Form

**POLIO EPIC, INC. CURRENT MEMBERSHIP ANNUAL DUES ARE RENEWABLE
THROUGH THE FISCAL YEAR OF SEPTEMBER 1, 2007– AUGUST 31, 2008**

NAME _____ SPOUSE _____ DATE _____

ADDRESS _____ PHONE (____) _____

CITY _____ STATE _____ ZIP _____ - _____

Emergency Contact info: _____

EMAIL _____

_____ I am sending in my/our annual dues of **\$10.00** per person for 2007-2008 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**



Famous Quote

I am still determined to be cheerful and happy, in whatever situation I may be; for I have also learned from experience that the greater part of our happiness or misery depends upon our dispositions, and not upon our circumstances.

--Martha Washington (1732 – 1802)

Polio Epic NEWSLETTER

Southern Arizona Post-Polio Support Group
P.O. Box 17556
Tucson, AZ 85731-7556

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RETURN SERVICE REQUESTED

**Funding for this Newsletter is
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from the MARCH OF DIMES**

**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!**

Al Friedman