

February – March 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

### February 14th

We have the pleasure of having the Pima Council on Aging (PCOA) coming to address our group. If the PCOA is unable to attend, we will have a Sharing Meeting.

### March 14<sup>th</sup>

Professor **Michael Kossove** will be coming to Tucson to discuss Post-Polio Syndrome. His name should be familiar. Michael has been a keynote speaker at many Post Polio conferences around the country, and is a Professor at the Touro School of Public Health in the state of New York, and the medical advisor to the IPPSO. We will be inviting the Phoenix group, the Arizona Center for Aging, and the Geriatric Grand Rounds group from the UofA School of Medicine

## I deserve help, and I am allowed to ask for help – My NEW Mantra

I am currently sitting at a desk in a hospital room, while my husband is sleeping in a hospital bed with tubes and wires all around his sleeping form. I had an “epiphany” last night. We carry a load of guilt and shame with us when we survived polio. We carry the guilt of making our families and parents worried about us, and having them be afraid for our lives. Children remember the bright, moist eyes of their loving parents. We also carry the shame of needing assistive devices, extra help, or not be able to do “something” or “anything”.

My husband wouldn't allow me or himself to use the call-button for the nursing staff, or the patient technicians. His response was that they have enough to do, I can wait until their regular rounds. Another response of his was, “I'll tough it out, I don't want to cause any trouble”.

How many of you remember saying the same things? Ask yourself the question, Do you have less rights as a human being, because you had polio? I found myself walking down long concrete hallways, and standing in line at cafeterias for meals, and realized I could have asked for a wheelchair, or I could have asked for room service. Why didn't I?

There is plenty of room here for a psychological study or two at the very least. I am sure that my experiences this week aren't any different than many of you within the Polio Epic readership. We have to work on making ourselves less of “super-people” that can do anything (climbing Mt. Everest, being athletes, workaholics) and quit trying to “earn” our place in this world.

We deserve help, there is no shame in asking for help. I resolve to ask for help when I need it, and not feel any guilt about doing it. That is my New Year's Resolution”. I am not there yet, but I am definitely going to try out my new resolve and ask room service to deliver meals to me. What can it hurt?  
Micki Minner



*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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Most identified viruses are named after the patient the carried the virus, when it was first identified. Where did the names come from? The following are the names of the 3 strains of Polio Virus.

First, there were 3 strains of poliovirus. **Type 1 - Brunhilde**, **Type 2 - Lansing**, and **Type 3, Leon**. **Type 1 - Brunhilde** was named after a chimpanzee used in recovering the original strain from a patient in Baltimore, MD. **Type 2 - Lansing** - from a boy in Lansing, Michigan whose fatal virus was first adapted into a cotton rat **Type 3 - Leon**, for a Los Angeles boy. *This information comes from the book "Four Million Dimes," by Victor Cohn. It was a series of articles published by the Minnesota Star and Tribune in April, 1955. You can find copies of the book on line. It's well worth reading. It's a history of Polio, and the development of the March of Dimes and the vaccines.*

We are disposing of all of the equipment in our Storage Loan Closet in Mesa. We will be throwing away non-working (probably needs only batteries) Power Chair, Scooters, and internal and external lifts. All must go by the 31st of the month. If any one in your organization needs any of these things, please make arrangements with me to pick it up. My number is 602-493-7242 (h)and 602-549-9371 (c).

If anyone would like to see a list, please contact Any Polio Epic board member for the e-mail attachment list.

Roger Buel, DME Manager, Polio Echo, Phoenix

### Autism-vaccine debate back in the news

A Huffington Post essay on why you should vaccinate your kids has sparked yet another raging debate, **Don't Risk Going Unvaccinated**. "If anything, the number of parents choosing to delay or withhold or separate vaccines is increasing. So what will it take? Certainly, as more and more children contract measles and pertussis, deaths from these diseases will follow. And it's not a leap to believe that we could see other deadly diseases, like polio and diphtheria; both of which still occur commonly in some areas of the world; and both of which are only a plane ride away from causing outbreaks in relatively unvaccinated communities in the United States." – Huffington Post, 1/22/09.

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## Polio Survivors Ask...

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

**Q:** *We have known about the late effects of polio for almost 30 years. I've gotten a lot of advice during that time and wonder about other polio survivors. What's the best post-polio advice you ever received?*

**A:** I've always felt I got wonderful advice from Dr. Ann Bailey at Warm Springs. My body had hit a patch of frightening paralysis, and I called her to cry on her shoulder. After listening to my weeping and wailing for quite a while, she finally said, "Accept it, Nancy." These simple words gave me the serenity I needed to go on. No amount of teeth gnashing could help me in the way that accepting the reality of the situation did. This is lasting help—I use her words of wisdom often. But this is a question with a million answers. I wondered what others would say. Curiosity caused me to contact a number of polio friends around the country to get their responses.

From Illinois, Jan says, "Rest. Schedule it into your day. It's as important as anything else you may do and will possibly give you the oomph! to do what you must."

"The best advice I've ever gotten is 'walk the knife edge: too much exercise can hurt you and too little exercise can debilitate you,'" says Larry in Minnesota. "Just in case you're interested, the second best advice was 'take charge of your own health care.' Certainly that does not mean ignore the advice of your health care professionals but it does mean make sure you understand their recommendations and that those recommendations fit with everything else you know. If they don't, it is your responsibility to question the provider until you do understand."

What popped into Becky's mind in Texas is "PACE YOURSELF. Conserve energy—stop along the way when we need a rest from walking; stop to admire a rose halfway up the staircase. This reminds me of a favorite quote from Georgia O'Keeffe: 'Nobody sees a flower really; it is so small. We haven't time, and to see takes time—like to have a friend takes time.' I am encouraged to enjoy the precious things in life, and that doesn't require physical energy."

Richard, in California, tells us "You must acknowledge to yourself that you have a disabling condition. Don't be consumed by that reality, but be honest with yourself. Ignoring or denying this reality leads to anger and frustration. It can also lead to counterproductive behaviors. When you make peace with your body you can begin to make appropriate adjustments. And, don't be afraid of all the things available to assist you in life. These assistive devices can be your friends, not your enemies."

"In looking back, the best advice I received was that when judging my activities and exercise, I should be aware that there is weakness from disuse as well as from overuse," says Missouri's Joan.

"Pace myself," Peggy, another Missourian, replies. "I must be a hard learner, because on the good days, I find myself trying to do more to sort of catch up with things I was unable to do on the bad days. I call it 'Hallelujah I'm healed' syndrome, on the good days, and it drives my husband nuts! I try to be good, I really do. But there is a little voice inside that says 'Go for it Peggy. You'll be able to do all of it, and then rest.' I can tell you with certainty that life at our house is not boring."

Aren't these terrific! Now I'm thinking many of you have gotten excellent post-polio advice, as well. Why not share these gems with us—send them to [info@post-polio.org](mailto:info@post-polio.org) and we will post them on [www.post-polio.org](http://www.post-polio.org).

*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))

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# POLIOEPIC Holiday Luncheon 2008

Over sixty members and guests attended our annual Holiday Luncheon, held at The Holiday Inn this last December. Our entertainment was **Batucaxé** (pronounced **bah-too-cah-SHAY**). Five of their members entertained us with lively Brazilian music using a variety of drums and percussion instruments. We had more door prizes than guests, so some received two prizes! We want to thank **everyone** who contributed to our wonderful door prizes. Especially the following businesses:

- ★ Holiday Inn
- ★ Sears
- ★ Bashas'
- ★ Sunflower Market
- ★ Olive Garden
- ★ The Pecan Store
- ★ Taz Massage
- ★ Terry's Hair Salon



## **DONATIONS:**

DeAnn & Charlie Riley ✨

Ruth Creagh

Fran Hobgood

Darryl Jakes

✨ \$100 or over

*In memory of Floyd Sharp- deceased November 3, 2008*

**Donations by – Dorothy Sharp and Glen & Dorothy Overton**

## New Members

Robert Kitzing er – Tucson, AZ

Carol Valentine – Tucson, AZ



## From the Treasurer ...

Check the date on your address label. If it says **2009** then you are paid up through next September!

Remember to **PLEASE** let us know if you are moving or going on vacation. The post office will **NOT** forward the newsletter, but returns it to us adding to the cost of postage.

## **Support Polio Epic** **with Bashas'**

**September 1, 2008 to March 31, 2009**

Reminder to continue using your Bashas' card. Very time you shop at Bashas' they will donate 1% of the total sales linked to Polio Epic through March 31!

Visit [www.bashas.com/charity](http://www.bashas.com/charity) for more information on the program.

Our group number is:

**27169**

## **New Membership Directory**

**We have a new membership directory. If you wish to receive a directory, send \$2.00 for the cost of postage to our address, Polio Epic, Inc., P.O. Box 17556, Tucson, AZ 85731-7556.**



**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.**



## **DID YOU KNOW?**

As compiled and brought to us by: Karla Carr

**AARP – Money**

**Management Program**

[www.aarpmmp.org](http://www.aarpmmp.org)

**AARP– Travel Center**

[www.expedia-aarp.com](http://www.expedia-aarp.com)

**1-800-675-4318**

**“50 Ways to Love Your Money”**

**Free tips and budgeting tools**

[www.chaseclearandsimple.com/aarp](http://www.chaseclearandsimple.com/aarp)

**Websites that let you trade  
gift cards**

[www.plasticjungle.com](http://www.plasticjungle.com)

[www.cardavenue.com](http://www.cardavenue.com)

**Free Brain Backup:**

**Saving to-do lists, notes, etc.**

[www.evernote.com](http://www.evernote.com)

**Appointment Reminders:**

[www.wakeupland.com](http://www.wakeupland.com)

[www.snoozester.com](http://www.snoozester.com)

**Send Text messages to**

**a cell phone:**

[www.text4free.net](http://www.text4free.net)

**To find recipes based on**

**ingredients, difficulty or time**

<http://recipes.ivillage.com/recipes/>

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Polio Epic proudly announces a guest speaker coming to Tucson to speak about Polio and Post-Polio Syndrome, **Professor Mike Kossove**. He will be speaking to us on **March 14, 2009**. He will be holding his seminar at **10:00 a.m.** for approximately one hour. The presentation will be held at the **University Medical Center** located at 1501 Campbell Road. Parking is difficult, please try to carpool and arrive early.

Many of you may recognize the name of Mike Kossove. He has been a guest speaker at many PHI and polio support group's throughout the country. Mike is a professor of Microbiology at the Touro School of Health Sciences, and himself a polio survivor. Mike is also the medical advisor for the IPPSO (International Post Polio Support Organization).

The University of Arizona will be inviting several groups of medical professionals to this seminar. The University of Arizona Center for the Study of Geriatrics, the medical college students, and the members of the new University of Arizona College of Public Health will all be attending. We should be able to accommodate approximately 150 attendees for this informative seminar. This presentation will be more on the basis of a grand rounds presentation and seminar. There will be no charge.

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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.

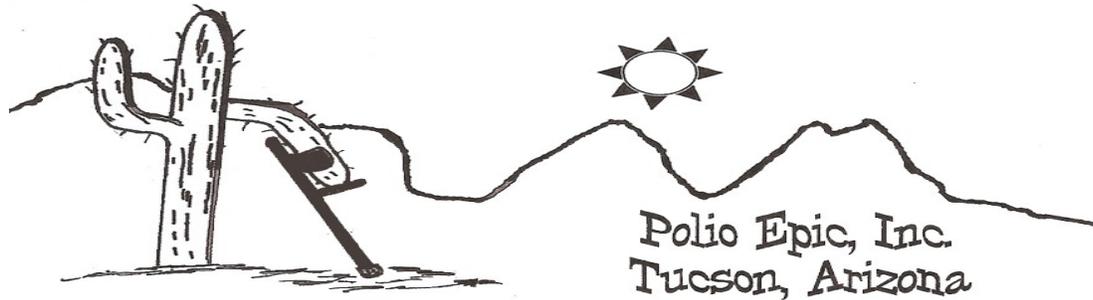
\_\_\_\_\_ Please remove my name from the mailing list. I do not wish to receive newsletter.

\_\_\_\_\_ 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!**