

POLIOEPIC, INC.

April - May 2012
Southern Arizona
Post-Polio
Support Group
Est. 1985
P.O. Box 17556
Tucson, AZ 85731-
7556
(520) 750-8608
(message)
www.polioepic.org

This is so important, that I wanted to print it again in this newsletter.

The shot felt around the World: The Untold Pittsburgh Polio Story

Rotary International District 5500 of Southern Arizona and Polio Epic are planning a fundraising event, April 22nd, 2012 at the Doubletree Hotel on Alvernon; to fund the eradication of Polio throughout the world.

We are fortunate to have Dr. Jonas Salk's son, Dr. Peter Salk attending.

We will be screening a new movie (funded by the Bill and Melinda Gates Foundation) called: *The shot felt around the world: The untold Pittsburgh Polio story*. Both groups are going out into the community to garner sponsorships from community, as well as selling tickets to this event. If you want to take a flyer to some business/corporation/community leader, please contact Nannoe or myself to get our flyers.

There is a reduced rate for Polio Survivors and members of Polio Epic to attend the event. The two levels of tickets are \$25 for viewing the movie and a short time for Questions & Answers. \$50 includes the movie and a VIP reception to follow, where you can socialize and meet the celebrities that have produced this film, Dr. Peter Salk, and members of Rotary International.

Although Polio Epic is a support group for Polio Survivors, we want to encourage the work that Rotary is doing in order to eliminate the need for Post Polio support groups in the future.

We are taking money for tickets. Send a check made out to Rincon Rotary Foundation and mail it to: Micki Minner at 2840 N. Tomas Rd; Tucson 85745. I will then mail the ticket to you. Don't worry if we run out of time for mail, because as long as I have your check, I will have the tickets waiting for you at the event.

The Polio Epic mission statement states that we want to empower and improve the lives of people living with Post Polio, and we want to help eradicate this disease from the face of the earth.

Micki Minner

General Membership Meetings every Second Saturday 10:00A.M.

Education Room
HealthSouth
Rehabilitation
Hospital
2650 N. Wyatt Rd
Tucson, AZ

**April 22, 2012
Rotary and Polio
Epic Gala Event,
The Shot Heard
Round the World,
and Dr. Peter Salk**

**NOTE :
December 8th 2012
– NEW location for
our Holiday Party.
We are moving to
the Hilton Tucson
East this year !**

BOARD OF DIRECTORS		
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Case breakdown by country- Data in WHO as of 14 Mar 2011 for 2011 data and
13 Mar 2012 for 2012 data

Countries	Year-to-date 2012				Year-to-date 2011				Total in 2011*	Date of most recent case
	WPV1	WPV3	W1W3	Total	WPV1	WPV3	W1W3	Total		
Pakistan	12		1	13	15			15	198	18-Feb-12
Afghanistan	5			5	1			1	80	15-Feb-12
Nigeria	5	1		6	1			1	62	08-Feb-12
India					1			1	1	13-Jan-11
Chad	1			1	12	1		13	132	09-Jan-12
DR Congo					21			21	93	20-Dec-11
Niger									5	12-Dec-11
CAR									4	08-Dec-11
China									21	09-Oct-11
Guinea									3	03-Aug-11
Kenya									1	30-Jul-11
Côte d'Ivoire									36	24-Jul-11
Angola					1			1	5	07-Jul-11
Mali									7	23-Jun-11
Congo					1			1	1	22-Jan-11
Gabon					1			1	1	15-Jan-11
Total	23	1	1	25	54	1	0	55	650	
Total in endemic countries	22	1	1	24	18	0	0	18	341	
Total outbreak	1	0	0	1	36	1	0	37	79	

Monday, January 30, 2012-**Having an Invisible Illness--** *By Maya Brown-Zimmerman*

How many of you know what it's like to be living with an "invisible illness?" Do you have a condition that affects every part of your life yet people assume you *are* fine because you look fine? I have Marfan syndrome, a genetic disorder that can cause problems in nearly every major body system. While there are skeletal manifestations, many times those symptoms are also found in the general population (just not all together), so you wouldn't necessarily look at me and peg me as someone with a "condition." I don't know how many times someone has made a remark about me taking the elevator, not "pulling my weight" or, my favorite, "you don't look like there's anything wrong with you." While that is annoying, nothing has been as frustrating as the difficulty in being taken seriously by a doctor.

My mother knew there was something not typical about me shortly after birth. Although I was much longer than other babies in the family, needed multiple surgeries in my first year of life and was slow to meet physical developmental milestones, doctors continued to insist that I was just fine and that my mother was a paranoid first-time mom. Looking back, I'm pretty lucky that my pediatrician eventually recognized the [physical manifestations of Marfan](#) when I was 8 years old; too many "Marfs" don't get diagnosed until much later in life...often in the ER when they're having an aortic dissection (a tear in the large artery that takes blood away from the heart, which is always very serious and can be fatal) or in the morgue. Part of what makes

Marfan tricky is that individually, many of the symptoms are common. These include being tall (but sometimes just tall for your family), very flexible, having a curved back (scoliosis) and having long fingers. However, when all these symptoms appear together in one person, it warrants a closer look and an echocardiogram to check the heart valves and aorta is necessary. There are no outward symptoms of potentially life-threatening aortic enlargement. Of course, Marfan syndrome isn't the only invisible illness. In November, I heard from many of you with fibromyalgia, a disease with no physical manifestations, which causes debilitating pain. Rheumatoid arthritis is another painful, hard-to-detect illness. My three-year-old son has autism and, much as people seem to think there is one, I've yet to find a mark on his body that reads "this is what autism looks like." So we need to try to keep in mind that we don't know everyone's struggle. That seemingly able person with the handicap placard might use it because fibromyalgia makes it too painful to walk, or because Ehlers-Danlos syndrome causes their joints to dislocate. The teen walking instead of running in gym might have a heart condition. That child having a meltdown in the grocery store may be having a sensory overload due to autism or sensory processing disorder. And if you think someone around you might have an invisible illness and not know it, don't be afraid to gently speak up. You might save a life!

Maya Brown-Zimmerman, MPH, is a patient advocate and volunteer with the [National Marfan Foundation](#) as a member of the board of directors and coordinator of the teen program. She also chronicles the ups and downs of parenting two sons with special needs while having a chronic illness herself at [Musings of a Marfan Mom](#) and the [Sensory Processing Disorders Blogger Network](#).

Contributions/Donations

Ernie Anderegg

Neal Markin

Edna Waldron

Susan Womeldorf

*DeAnn & Charlie Riley

*Jacquie Schmidle *

*Donation of \$100 or over

*Tucson Lions Club
Susan Johnson
I.E. & Charlotte Reep
in memory of
Garrett Johnson



Welcome to our New Members
Peggy Robbins - Fruitland, MD



KWANZAA



***NEW** place for our 2012 Holiday Party!
We are going to the Hilton Tucson East on
December 8, 2012. We look forward to every-
one being together again next year!*

Friday, February 10, 2012-Who Owns your Medical Records?

Stories from behind the examining room door, as told by Rod Moser, PA, a primary care physician assistant with more than 35 years of clinical experience.

“We are really sorry, but we can’t seem to find your chart.”



We often heard this in years past, but since the advent of EMRs (Electronic Medical Records), lost charts are uncommon. Instead, we hear: “I am sorry, but the computers are down. We cannot access your files.”

Many years ago, to augment my meager teaching salary with the University, I worked part-time in the Urgent Care at a local Air Force base.

Lost charts were so commonplace that the excuse was expected, and pulling charts when the patient arrived sometimes took longer than the actual visit. Much to my surprise, a large number of patients came into my office, chart in hand. Why? The simple reason was that they never returned the chart to medical records after their last visit! They would keep it so it would not get lost. While this practice may have violated a dozen Air Force regulations, I just looked the other way and was glad they had their chart. Since it was the patient’s responsibility to take it back to medical records at the end of the visit, I really didn’t care. The real problem with this practice was lab and x-ray reports. If there was a chart that could not be found, how would these reports be posted? Medical records would have to create a temporary chart, or perhaps the reports would be lost. Twenty years ago, at this same Air Force base, the ceiling in medical records caved in from the sheer weight of stacks and stacks of unfiled lab reports, x-rays, and charts. Apparently, a disgruntled airman, anxious to get home at the end of a busy day, removed one of the ceiling panels, and when he was ready to go home, he would simply toss the files up into the ceiling space. When reports were requested, he played stupid and claimed he never saw them. The number of tests that had to be repeated was enormous. Not only were frustrations and costs involved, some of the unfiled tests were abnormal. A delay in getting results may have caused unnecessary harm or worse. I heard that he was court martialed.

I wanted to see what a former urologist wrote in his notes since he did not bother to examine me, nor did an ER doc I saw. What would they record in the notes? Thinking they may lie about doing an exam, I reviewed my records. They did not lie. They did not write anything!

I am no longer allowed to read my own medical records. I can get my lab test results and a few other reports on line if I sign up for a service, but if I “break the glass” to access my own records, all kind of alarms sound. When we had paper charts, I would freely access my records, so what is the difference? Of

course, my records (nothing to hide, incidentally) could be read by anyone in the clinic. Now, anyone who tries to read my electronic chart will be quickly identified.

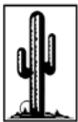
What would happen if patients were required to keep their own medical records and bring them to each visit, like a passport? A recent study reported in the New York Times tried it out, fostering the concept of shared medical records. While many doctors, as you might imagine, voiced skepticism about this practice, the patients loved it. Over 90% of the patients felt that they would exercise more control over their own medical care if they saw and read their notes.

On the [WebMD Ear, Nose, and Throat](#) community board, I am often astounded at the number of postings where the patient was not even told their diagnosis! There was no discussion on any rationale or even a discussion on why they were given a certain medication. These patients were left hanging. If they could read their chart, then perhaps they would have many of those answers.

Here lies a problem. I take pride in the thoroughness of my chart notes, but I have to say that many of my colleagues write lousy notes. I write my notes knowing that I am not the only one who will read them. My chart notes are my only record of the visit, and my only defense should there be an unexpected outcome. I am proud of my notes and would happily give any of my patients a copy of their progress notes, but unfortunately, I am not going to have them completed by the end of their 15-minute visit. Since we have to type our own notes (not dictated and transcribed), I must complete them between patients, over lunch, or after clinic hours. I refuse to dilute my time with a patient by typing during the visit and having a computer screen create a barrier. If a patient wants my notes, they get them. I will email it to them, drop it in an envelope, or create an after-visit summary.

A patient deserves to have full access to their medical records. They shouldn't have to beg for them (or steal them). They should not have to pay extra to get a copy of their records. I am merely a consultant in their care. They are already paying me for the service I provide (or their insurance companies). Legally, we have to maintain accurate medical records, but **there is nothing in the law that states they cannot be freely shared with the patient themselves.**



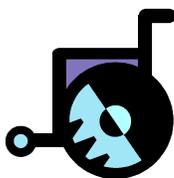


Wadleigh Grant

Could you use up to **\$500.00** to help get the Disability help items you need?

1985 - 2010

Polio Epic, Inc., is accepting applications within its membership for a grant of financial assistance, of any amount up to \$500 in your lifetime. This program is made possible by a bequest Polio Epic received from Frank Wadleigh, a long time member and supporter of our efforts. The purpose of the program is to improve the quality of life for members, while supporting the overall mission of Polio Epic. Reasons for requests can be as varied as the members making them, all are seriously considered



Contact: Dave Marsh at 327-3252
or
davidmarsh74@yahoo.com



DUES FORM

NAME _____ SPOUSE/PARTNER _____ DATE _____

ADDRESS _____ PHONE (____) _____

CITY _____ STATE _____ ZIP _____

If you wish to receive our newsletter via email: _____

PLEASE PRINT CLEARLY

____ I am sending in my/our annual dues of \$10.00 per person for 2011-2012 fiscal year.

____ I am sending my back dues of \$ _____

____ 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.

We welcome your comments and suggestions. Thank you!

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

**FROM THE TREASURER...
MEMBERSHIP DUES**

LOOK AT YOUR ADDRESS LABEL BELOW!



If your label is marked 2012 – you are paid up

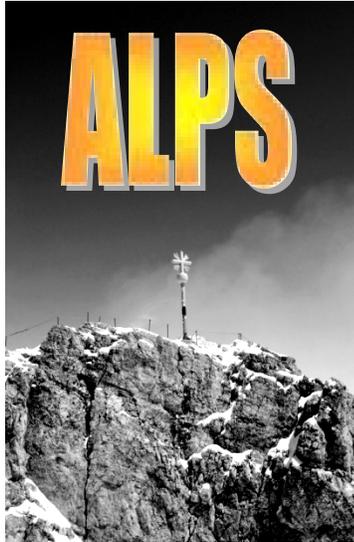


Contact me if you have any questions at **520-797-6898** or email me at [**Nannoe1@aol.com**](mailto:Nannoe1@aol.com).

Also, remember that Polio Epic is non-profit and all donations are tax deductible!! and appreciated !!

If you want to receive our newsletter via email, be sure to add your email to the dues form and add Micki's email to

your Not-Junk safe list in your e-mail program
[**Mickiminner@msn.com**](mailto:Mickiminner@msn.com)



BE ON THE LOOKOUT!

Polio Echo in Phoenix and Polio Epic in Tucson are still looking into sharing some resources, and perhaps our newsletters will be combined. The newsletter will have a new look and a new name. We have de-

ecided that this shared newsletter should have the name of A.L.P.S. – Arizona League of Polio Survivors. I love the idea of comparing our life with Post Polio as climbing the heights of the Alps in our determination to live empowered and dignified lives with Post Polio Syndrome.