

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

**General
Membership
Meetings
every
Second Saturday
10:00A.M.
Education Room
HealthSouth
Rehabilitation
Hospital
2650 N. Wyatt Rd
Tucson, AZ**

February 11th
Micki Minner will
present the
information « Polio
and Post Polio in
2012 ».
The same as given
to UofA School of
Medicine Grand
Rounds in October.

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

POLIOEPIC, INC.

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 raise awareness and funds to further 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 immediate family. The two levels of tickets are \$25 for viewing the movie and a short time for Questions & Answers. \$50 includes the movie and a 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 diligently passing out flyers to the people in the community to be sponsors. So far, we have gotten sponsorships from businesses like Christies Appliances, Tucson Lexus, Tucson Orthopedic Institute and more. Do not hesitate to be a part of this important work.

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.

There have been successes! You will see from pages inside this newsletter, India has now had an entire calendar year without a single case of polio. These successes are only obtained by everyone pitching in where they can.

Micki Minner

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FIGURE 1 WORLD HEALTH ORGANIZATION



[Global Polio Eradication Initiative > Data and monitoring > Polio this week](#)

Polio this week - As of Thursday 04 January 2012

- India will pass one year without a single child being paralyzed by polio, for the first time in history, on 13 January, if no cases are reported in the coming week and if all pending samples return negative in the coming weeks. Maintaining sensitive surveillance and high childhood immunity will be of prime importance for India to continue protecting its children.
- The UN Secretary-General Ban Ki-moon continues to closely follow polio eradication issues, and has recently written to the heads of state of Nigeria, Pakistan, Afghanistan, Chad and the Democratic Republic of the Congo highlighting the urgent need to complete polio eradication.

Here is the website to sign the petition.
<http://www.theendofpolio.com/home/>



1985 - 2010

Breathing & Sleep/2011 in Review

By Gladys Swensrud - reprinted from the PPS Manager newsletter Jan/Feb 2012



Those of you who couldn't attend Breathing & Sleep/2011 on October 29th were much missed. We had 127 people attend, and it was an

invaluable day of post-polio information sharing at the prestigious Salk Institute for Biological Studies in La Jolla.

You could have heard a pin drop in the auditorium throughout the entire program. Our third event was almost totally focused on PPS this time around, which was by design. Dr. Han's presentation was all about polio in China and how it corresponded to polio in America. Everyone was quiet as a church mouse listening to his every word. Dr. Benditt's presentation was the absolute best overview of PPS breathing I have ever heard...and as most of you are fully aware because of my 10 years of PPS respiratory compromise advocacy, that is really saying something! Dr. DeMaria, U.C.S.D. cardiologist, was a character, filled to the brim with Sleep Disordered Breathing information linking it to heart failure and stroke. Everyone sat wide-eyed and enthralled with his presentation as he connected all the dots. And both of ResMed's RRTs (Angela King and Karyl Scott) talks were wonderful for clinician and patient

alike. They very gracefully straddled the line from professional to general public understanding of equipment and its uses perfectly. The auditorium was warm this year, so no chilly moments...what a delight! The food was plentiful and delicious. During the break we took a group polio survivor picture in front of a painting of Dr. Salk in the Salk Trustee's Room. That was one big highlight of the day for all of us. Corralling 40 (give or take) survivors into a still photograph was a hoot! I am sure you can pretty much visualize it!

Polio survivors throughout the United States will be forever indebted to the Salk Institute for Biological Studies and ResMed Corporation for their generous funding of all three Breathing & Sleep Symposiums. Oftentimes polio survivors feel as though we are tilting at windmills in our efforts to educate the world about issues related to our aged disease, but the Salk Institute and ResMed Corporation have done more than merely listen...they have spoken loudly by supporting us as we attempt to educate not only others, but as we continue to educate ourselves as well.

To view all three events, go to www.poliotoday.org, click on the Videos tab toward the top of the page and a dropdown box will appear allowing you to select the year of your choice to watch. It is not only well worth a bit of your time, but the information could actually be a life changing experience in more ways than one!

Contributions/Donations

* Rosemary DeTurco
Virginia Hanson
Pat Hanson

* James LaDuc
* Merle Kyser
Richard Piskun

* Frann Miescher
* Dana Vincil
* *Donation of \$100 or over*

Every Contributor and New Member becomes an important piece in the puzzle that makes up Polio Epic. Thank you.

Welcome to our New Members
Pat Hanson - Green Valley, AZ
Anímal - Sierra Vista, AZ



Because of our contributors, we had a wonderful Holiday Party, this is another opportunity to say THANK YOU.



Arizona-Sonoran Desert
Museum
Rising Medical
Fry's Grocery

Terry's Hideaway Hair Salon
Michelle Peters at Beau's Hair Salon
Frann Miescher
Carol Mayfield

We apologize if we left anyone out - many others donated to our wonderful door prizes

NEW Location

HOORAY, we have found a wonderful and lovely NEW place to hold our 2012 Holiday Party!

We are going to the Hilton Tucson East on December 8, 2012. We look forward to everyone being together again next year!

POST POLIO SYNDROME -- a challenge of today

EUROPEAN CONFERENCE ON POLIO

Summary-- by Dr. Frans Nollet, chairman of the scientific committee

A Challenge of Today - Copenhagen, Denmark,

31 August – 2 September 2011

Scope of the Conference

The primary aim of the conference was to bring patients, health care providers from different professions, and researchers together to find ways to improve care for polio survivors in Europe and to stimulate research in this area.

The conference was initiated by the European Polio Union, the umbrella organisation of 19 polio patient unions in 13 EU countries, and organized by the Danish Polio Society PTU. The program was decided by a joint committee of European researchers and EPU representatives.

The conference was attended by 330 participants from 25 countries from all continents. Half of them were patients, spouses and carers, and half health care providers and researchers. The program consisted of 21 sessions and included almost 70 lectures.

The conference atmosphere was excellent with high attendance of sessions. The opportunity to meet, exchange ideas and discuss between patients and professionals was highly appreciated and fruitful.

Main conclusions

Research

- The most promising research area to the cause of post polio syndrome focuses on the role of inflammatory factors that may be related to persistence of poliovirus fragments in the genome. Based on this, intravenous immunoglobulines may be beneficial to arrest or reduce the loss in strength and functional decline due to post polio syndrome.
- A recent Cochrane review concluded that the evidence for both pharmacological and rehabilitation interventions are insufficient and guidelines are based on limited levels of evidence.
- Therefore, high quality research to the effectiveness of pharmacological and rehabilitation interventions are needed, including cost-effectiveness evaluations to facilitate implementation in health care systems.
- Research interest needs to increase. Although research is being conducted in this area, the number of intervention studies in progress is scarce. Trial registries mention only one randomized study of rehabilitation interventions including health-cost evaluation.
- Research is hampered by little research interest, based on the false notion that post-polio syndrome is irrelevant because polio is a disease of the past, and, as for many orphan diseases, by funding barriers to execute pharmacological studies.
- The following specific priority topics for intervention studies were indentified:
 1. Effectiveness of immunoglobulines needs to be confirmed. An international multi-center study is in preparation.
 2. Effectiveness of multidisciplinary rehabilitation and its components such as exercise and psychological interventions.

- 3 .Symptom management, especially to reduce fatigue and pain.
4. Interventions to reduce the high rate of falls and subsequent injuries; studies should include the prevention of osteoporosis in underdeveloped limbs.
5. Prevention of secondary damage to the locomotory system in aging polio survivors due to long term abnormal overloading of limbs.
6. To warrant healthy aging and to reduce the negative influence of multi morbidity and life style factors such as overweight and inactivity.
7. The effectiveness of orthotic innovations.

Care

- Care should aim at societal participation at the highest functional level, and should be provided by interdisciplinary rehabilitation teams including the individual with post polio syndrome as full team member.
- An inventory among 19 polio unions in 13 European countries revealed a lack of interest and knowledge in many countries and few specialized clinics and poor access to help. Yet, it is estimated that around 700.000 EU inhabitants will suffer from post polio syndrome.
- To improve care provision in the EU, standards of care should be formulated and published.
- Each EU country should have an expertise centre for post polio syndrome to improve care at the national level.

Networking

- Post polio syndrome must be kept on the political agenda, as major health care issue in the EU, and is a major aim of the European Polio Union.
- EPU will be strengthened by establishing a medical advisory board.
- More national polio patient unions need to join the EPU and EPU may be instrumental in setting up patient union's in European countries so far lacking such unions.
 - A professional European network of health care professionals and researchers with interest and expertise on post polio syndrome to improve care and facilitate research will be established and facilitated by EPU.
 - Priorities of the professional network are to establish diagnostic and therapeutic guidelines and to define a standard set of outcome measures for clinical research purposes.

Endemic countries

- The WHO considers initiatives to improve rehabilitation care, especially in developing countries for the millions of people growing up and living with the lasting impairments of polio, to ensure that they can life full lives.
- The knowledge on post polio syndrome in developed countries should be transferred to developing countries to seek ways to prevent post polio syndrome and the secondary damage due to physical overloading and to set up care for post polio syndrome that will also become a future issue in these countries.

Next Conference

- The next conference will be held in 2 years, likely in Amsterdam



Wadleigh Grant

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

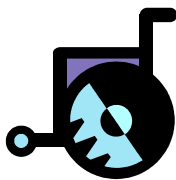
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Polio Epic, Inc., is accepting applications within it's membership for a one-time grant of financial assistance. This program is made possible by a bequest Polio Epic received from Frank Wadleigh, a long time member and supporter of our efforts. The 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**

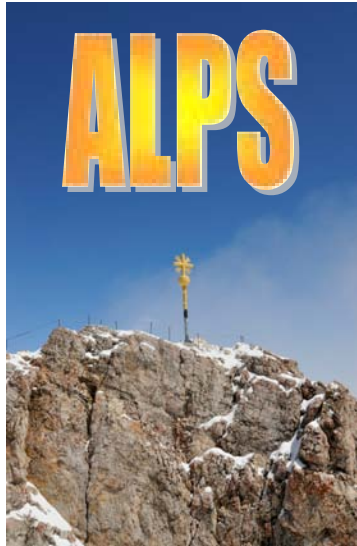
LOOK AT YOUR ADDRESS LABEL BELOW! ↓

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!

On the first ever trial basis, Polio Echo in Phoenix and Polio Epic in Tucson are going to share some resources, and our next newsletter will be combined! The newsletter will have a new look and a new name. We have decided

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.