



# ALPS

Volume 1, Issue 2

ARIZONA LEAGUE OF POLIO SURVIVORS

AUG & SEPT 2012

## WHAT ISSUES MAKE YOUR VOTE IMPORTANT? Bills that matter to the disability community.

Here are some of the important disability related issues that you can use to select a candidate. Ask the candidates or their Staff if they will oppose or support the following bills/issues: Arizona legislators: healthcare – will they vote to use the affordable care act to expand Medicaid coverage in Arizona? (see page 8.) Next year, when the one cent sales tax goes away, Arizona will face a budget shortfall. What programs will they cut to meet budget needs or will they raise funds in some other way to preserve the health and human service programs we have? Congressional issues ADA in danger! Your civil rights under the Americans with Disabilities Act (ADA) are at stake. There have been several Bills introduced this congressional session that threaten to weaken our civil rights under the ADA. Even worse, several of our Arizona congressmen have sponsored or co-sponsored these bills: **H.R. 4200** - to amend the Americans with disabilities act of 1990 to prohibit the attorney general from administering Or enforcing certain accessibility regulations relating to pools at public accommodations or provided by public. This bill Was introduced March 16, 2012, by AZ representative David Schweikert (D-17) and co-sponsors Arizona representatives Paul Gosar, Ben Quayle and Trent Franks of

Arizona. It has 19 co-sponsors. It has been referred to the committee on Judiciary's subcommittee crime, terrorism, and homeland security.

**H.R. 4256** - pool safety and accessibility for everyone (pool safe) act directs the attorney general to revise certain Rules under titles ii and iii of the Americans with disabilities act of 1990 relating to accessible means of entry to pools. It has 74 co-sponsors including Arizona representatives David Schweikert, Trent Franks, Ben Quayle and Jeff Flake. The bill Was introduced march 26, 2012, and has been referred to the committee on judiciary, subcommittee on constitution.

**H.R. 6061**, the WIPA and PABSS Continuation of Services Act of 2012- Social Security Work Incentive Planning and Assistance (WIPA) services and related protection and advocacy (PABSS) – this program has helped people on SSI and SSDI understand how employment affects their cash and medical benefits and helps them use available work incentives to Ease the transition back to work. This program has not been funded as of 6/30/12 because congress failed to reauthorize It. SSA rules are complicated and this expertise is still needed. This is urgent. Programs are shutting down all across the country. This bill will permanently reauthorize the program. Ask the candidates if they will co-sponsor this bill now.

**H.R. 3423 and s. 1872.** The Able Act – the achieving a better life experience act.

Encourages and assists individuals and families in saving private funds for the purpose of supporting individuals with Disabilities to maintain health, independence, and quality of life. The legislative intent is to provide secure funding for Disability-related expenses on behalf of designated beneficiaries with disabilities, will supplement, but not replace, benefits Provided through private insurances, the Medicaid program, the supplemental security income program, the beneficiary's Employment, and other sources. Ask candidates to co-sponsor this bill. Referred to house subcommittee on health November 2011. **H.R. 3423** has 168 house co-sponsors – none from Arizona!!!

**S. 1872** has 21 senate co-sponsors – none from Arizona!!!

The SSI Savers Act of 2011 (**H.R. 2103**) would help low-income seniors and people with disabilities through work Incentives, increasing personal savings and helps them achieve the financial self-reliance they need to escape poverty and Transition off of federal assistance. This bill was referred to the subcommittee on human resources of the house ways And means committee on June 6, 2011. No action since. **H.R. 2103** has 10 house co-sponsors - none from Arizona!!! All federally supported programs are at risk: due to budget deficits, and depending upon who is elected to us

Congress and the us senate: health and education, social security, vocational rehabilitation, independent living centers (ABIL included), housing and human services all face cuts.

***“Vote as if your life depends on it, because it does!”***

**- Justin Dart -**

**The Bridge - August 2012 7**

**Polio eradication this week :Security incident in Pakistan:** On the morning of **17 July 2012**, a serious security incident took place in Gadap Town, Karachi, Pakistan. One World Health Organization (WHO) staff member and one international consultant were injured when their vehicle was shot at by armed men. The WHO employees are in stable condition. Both men were supporting the currently-ongoing polio National Immunization Days (NIDs).

Incidents like these highlight the incredible bravery of the more than 200,000 mainly Pakistani volunteers who run every vaccination campaign. WHO, UNICEF, and all polio partners remain committed to supporting the Government of Pakistan and the people of Pakistan in their efforts to eradicate polio.

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**KARACHI/NEW YORK/GENEVA, 21 July 2012** – The World Health Organization (WHO) and UNICEF are deeply saddened by the killing of Mr. Muhammad Ishaq, a local community worker supported by WHO, who was part of the polio eradication initiative in Pakistan. Mr. Ishaq was shot and killed in the Gadap town area of Karachi on Friday evening. Polio immunization activities were suspended in this area of Karachi earlier this week after a shooting incident injured two WHO staff members who were supporting the implementation and monitoring of a vaccination campaign. Until activities were suspended, Mr. Ishaq had worked with the national polio eradication effort as a Union Council Polio Worker for several months, helping to plan and implement vaccination campaigns to protect the most underserved and vulnerable children against this debilitating disease.

Polio is a highly infectious disease caused by a virus that can cause permanent paralysis in a matter of hours. There is no cure, but there are safe and effective vaccines. Polio can be eradicated if every child is immunized until transmission stops worldwide.

## **Northern Arizona & Phoenix**

### **POLIO ECHO BOARD MEETINGS**

All meetings are open to the public.  
Anyone wishing be on the agenda should notify President Brad Dowden, at (480) 370-8986 in advance.

#### **BOARD MEETINGS:**

Are normally held the third Tuesday of each month at the Disability Empowerment Center, located at 5025 E. Washington Street, Phoenix 85094. Meetings start at 11:30 am and conclude around 1:30 pm.

### **2012 MEETING SCHEDULE**

**October 16, 2012** –11:30-1:30 at the Disability Empowerment Center in Phoenix.

**November 20, 2012**– 11:30– 1:30 at the Disability Empowerment Center in Phoenix.

**Saturday, December 15, 2012** Annual Holiday meeting at the Disability Empowerment Center. This is also the annual meeting and election of directors and officers. It will be held in the Pullium Conference Center with a luncheon beginning at 11:30 a.m. The program will be announced in the next newsletter. The luncheon cost is partially subsidized by Polio Echo.

## **Southern Arizona & Tucson**

### **POLIO EPIC BOARD MEETINGS**

All meetings are open to the public.  
Anyone wishing be on the agenda should notify any board member in advance.

#### **BOARD MEETINGS:**

Board meetings are normally held the first Thursday of each month at the DIRECT Center at 1023 N. Tyndall Ave., in Tucson.

#### **GENERAL MEMBERSHIP MEETINGS:**

General membership meetings are held at 10:00a.m. on the second Saturday of each month. They are held in the Education room, at Healthsouth Rehabilitation Hospital at 2650 N. Wyatt Rd in Tucson

**September 8th** -*Sue Lemmon, Pima Council on Aging, on the topic of "Medicare Fraud".*

**October 13th** – **Reeds Compounding Pharmacy** – *a unique opportunity to communicate with a pharmacist that makes topical prescriptions to order.*

#### **NOTE :**

**December 8th 2012** – new location for our holiday party. We are moving to the **Hilton Tucson East** this year !



The quarterly combined meeting of Polio Epic and Polio Echo will be Saturday, October 27<sup>th</sup>. The location is in Casa Grande, at Mimi's Café in the Promenade Shopping Center.



*Sizzling Summer Social and Scintillating Symposium Certainly Significant Stuff for Syndrome Survivors*

On Saturday, June 23, 2012, we held a general meeting of Polio Echo membership and guests in the Miriam Pulliam Conference Center in the Disability Empowerment Center at 5025 E. Washington Street, Phoenix, AZ 85094. The meeting began at 11:00 a.m. and concluded at 1:00 p.m. It can only be said that it was *Phabulous Phantistic Phun!*

Our keynote speaker was, **Micki Minner**, currently President of **Polio Epic**, our sister organization in Tucson. Micki provided an array of very interesting information about polio and post-polio syndrome, which we all found invaluable. Micki presented a PowerPoint presentation that was fascinating, current and fast-moving. Micki entertained questions from the audience following her presentation.



## Chapter News

### Central Phoenix Chapter

The Central Phoenix chapter meets on the Second Thursday of the month from 1:00 to around 3:00 p.m. On Thursday, September 13, 2012, the group will meet and eat at the **Village Inn Restaurant**, located at 4040 E. Bell Road in Phoenix. The location of the

October meeting will be determined at the September meeting. Please contact Pam Harper, (602) 281-2840, or email [pharper@cox.net](mailto:pharper@cox.net), to make reservations and for information on future meeting schedules.

### East Valley Chapter

The East Valley chapter meets and eats at 1:00 p.m. On the 3rd Wednesday of each month.

On Wednesday, August 15, 2012, The group will meet at **Iguana Mack's Roadhouse**, located at 3355 N. Alma School Road in Chandler, just south of Knox Road.

On Wednesday, September 19, 2012, the group will meet at the **Islamorada Fish Camp, inside Bass Pro** at 1133 N. Dobson Road in Mesa. Wednesday, October 17, 2012, the meeting will be held at **C-FU Gourmet** at 2051 W. Warner Road, #13 in Chandler; the southeast corner of Warner road and Dobson road. Please call advance reservations to Jane Crawford at (480) 899-5857 or email to Jane at [janwec94@q.com](mailto:janwec94@q.com).

### Scottsdale Chapter

The Scottsdale chapter meets on the first Thursday of each month at 1:00 p.m. The group will not meet on Thursday, August 2nd, 2012. The Thursday, September 6, 2012, at **Olive Garden Restaurant**, 3380 N. Scottsdale Road, the southwest corner of Scottsdale Road and Osborn road. On Thursday, October 4, 2012, the group will meet at the **Red Lobster**, 3360 N. Scottsdale road in Scottsdale. It is just south of Osborn Road. For reservations and additional information contact Eleanor Coup at (480) 874-1534.



### Shoprider Power Chair for Loan:

The following **Shoprider Power Chair** is in like new condition and is available to members of Polio Echo and Polio Epic Support Groups. There will be a nominal charge of \$180.00 to defray the cost of the new batteries installed. For pick-up only in north Phoenix. If you are interested, please contact Roger Buel at 602-493-7242 or send email to [polio\\_echo@polioecho.org](mailto:polio_echo@polioecho.org) to my attention.

### Marking the 22nd Anniversary of the ADA

Posted by Valerie Jarrett on July 26, 2012 at 01:49 PM EDT



Today, I had the pleasure of delivering remarks at the White House observance of the 22nd anniversary of the Americans with Disabilities Act (ADA). In 1990, America took a bold step forward when President George H.W. Bush signed the ADA into law. This law was based on the fundamental principle that Americans with disabilities should have the same basic rights and opportunities as everyone else, and it established America as a world leader on disability rights.

From the day he took office, President Obama has sought to extend this legacy and fight for Americans with disabilities. He championed the Affordable Care Act, so insurance companies can no longer impose lifetime or restrictive annual dollar limits on coverage. And, beginning in 2014, no one will be denied insurance based on a preexisting condition or charged more based on health status or gender. More than 5 million Americans with disabilities and senior citizens on Medicare have already received an average of over \$600 to help pay for prescription drugs, and in 2014 30 million people who do not have insurance will be able to obtain it.

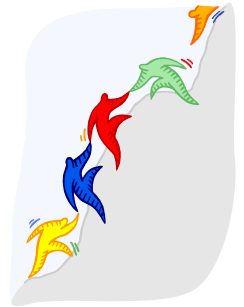
We've ramped up our enforcement of the landmark ruling in *Olmstead v. L.C.*, in which the Supreme Court ruled that, under the ADA, the institutional isolation of people with disabilities was a form of unlawful discrimination. Our efforts have led the Department of Justice to intervene in more than 40 *Olmstead* matters in 25 states. Thanks to this work, thousands of people now live in their communities.

# POLIOEPIC, INC.

## Wadleigh Grants

Tucson, Polio Epic Members only: Could you use up to **\$500.00** to help get the Disability help items you need?

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. Please view our website at [www.polioepic.org](http://www.polioepic.org) for the rules and an application form or contact: Dave Marsh at 327-3252 or [davidmarsh74@yahoo.com](mailto:davidmarsh74@yahoo.com)



*From the Treasurer...Of Polio Epic*

**MEMBERSHIP DUES are DUE!!**

**LOOK AT YOUR ADDRESS LABEL!**



Our **2011-2012** fiscal year ends on **August 31, 2012**. If your label says **2012** or lower, then you owe for the 2011-**2012** fiscal year. If your label reads **2013** or higher, then you are paid up through **August 2013**.

We have many members whom we have not heard from for a very long time. If you are unable to pay but wish to continue receiving our newsletter, **please** contact us and we will be happy to make arrangements.

Contact me if you have any questions at **520-797-6898** or email me at [Nannoel@aol.com](mailto:Nannoel@aol.com). Also, remember that Polio Epic is non-profit and all donations are tax deductible!!

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 address book [Mickiminner@msn.com](mailto:Mickiminner@msn.com)

# POLIOEPIC, INC.

## **D**ONATIONS AND CONTRIBUTIONS:

L.W. NICHOLS\*

\*Donations \$100 and over

### **Top Ten Ways to Carry on the dream of Justin Dart** By Carolan Quenneville

10. Don't just get sad! Get active!!!
9. Take charge of your life, even if only a small part of it.
8. Empower others to live up to their god-given Potential
7. Forget the politically correct. Present a clear, Uncluttered message.
6. Present your message with love, praise and Positives.
5. Present your message to the media by letter, phone, Email or up close and personal.
4. Join a local advocacy group - if you don't have one, Start one.
3. When all else fails. A little militant action can garner Attention to the cause.
2. Register to vote, or register someone else.
1. "Vote as if your life depends on it, because it does!"  
- Justin Dart – Polio Survivor and Founder of ADA Disability Advocacy



**Save the Date:** Combined Polio Echo and Polio Epic meeting in Casa Grande – October 27<sup>th</sup>, 12:00 Noon at Mimi's Restaurant in Casa Grande, Promenade Square.

**Save the Date:** the 2nd Annual Sahaurita Disability Awareness Resource Fair, which will be held on Saturday, December 1st in Sahaurita.

**Save the Date:** Rotary International is having another viewing of "Shot heard around the world – the Untold Pittsburgh Story" Dr. Peter Salk, and Micki Minner will be available for a Question and Answer Session. The date is October 7<sup>th</sup>, 2012, in Yuma, Arizona.



## Patient's bill of rights

The affordable care act puts consumers back in charge of their health care. Under the law, a new “patient’s bill of rights” gives the American people the stability and flexibility they need to make informed choices about their health.

The patient's bill of rights:

- **Provides coverage to Americans with pre-existing conditions:** you may be eligible for health coverage under the pre-existing condition insurance plan.
- **Protects your choice of doctors:** choose the primary care doctor you want from your plan’s network.
- **Keeps young adults covered:** if you are under 26, you may be eligible to be covered under your parent’s health plan.
- **Ends lifetime limits on coverage:** lifetime limits on most benefits are banned for all new health insurance plans.
- **Ends pre-existing condition exclusions for children:** health plans can no longer limit or deny benefits to children under 19 due to a pre-existing condition.
- **Ends arbitrary withdrawals of insurance coverage:** insurers can no longer cancel your coverage just because you made an honest mistake.
- **Reviews premium increases:** insurance companies must now publicly justify any unreasonable rate hikes.
- **Helps you get the most from your premium dollars:** your premium dollars must be spent primarily on health care – not administrative costs.
- **Restricts annual dollar limits on coverage:** annual limits on your health benefits will be phased out by 2014.
- **Removes insurance company barriers to emergency services:** you can seek emergency care at a hospital outside of your health plan’s network. Since the patient’s bill of rights was enacted, the affordable care act has provided additional rights and protections.

The health care law:

- **Covers preventive care at no cost to you:** you may be eligible for recommended preventive health services. No copayment.
- **Guarantees your right to appeal:** you now have the right to ask that your plan reconsider its denial of payment.

For more information

- read a report on the patient’s bill of rights.
- find detailed technical and regulatory information on the patient’s bill of rights.
- healthcare blog: protecting patients with private insurance.
- fact sheet: the affordable care act's new patient's bill of rights.
- Use our interactive faq tool to find answers to questions about your rights or ask your own at [answers.healthcare.gov](http://answers.healthcare.gov).



## Spinal cord injury research

The latest news and info about what's going on with science and research.

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*Editors Note: As we all know, the Polio virus destroys the Motor Axons. The U of California, San Diego and Dr. Lu, have been able to regenerate the motor axons in animals that have had long-term paralysis. This might be the wave of the future. Below I have excerpted the article.*

Successful regeneration; animals got worse --posted by Sam Maddox Friday, June 15, 2012 --Motor axons are long nerve cables, or processes, that start in brain cells, or neurons, and course the spinal cord to form synapses (connections) with muscle. Brain says move, message goes down the motor axon to the motor, muscle fires. Of course spinal cord injury destroys these axons; the mother nerve cell survives, up in the brain stem. But the broken cable cuts off brain-to-muscle control, which leads to paralysis. There are indeed ways to help these axons. Using a combination of strategies, motor axons can be rebooted, they can grow along a cellular bridge across the scarred-up lesion site, they can overcome inhibitory roadblocks, and once they get a whiff of an irresistible chemical allure below them, they are indeed able to form synapses with muscle units. This finding is supported by a compelling paper that came out this week from the Mark Tuszynski lab at the University of California, San Diego, "motor axonal regeneration after partial and complete spinal cord transection." I spoke with Pengzhe (Paul) Llu, Ph.D., the lead author of the paper. In the eyes of the research team, the paper is an unprecedented success. "a lot of people claim motor axon regeneration – most of them go around the lesion because it is an incomplete lesion. There may be some growth but *nobody* has shown that a motor

axon can penetrate the lesion site and go to the other side. With our motor axon bridge and combinatory treatment, we are the first to do that."

Lu said it was important to use a complete transection model -- to remove any doubt that axons moving across the lesion were not there already. His results showed axons that came from the brain, crossed the damaged area, and hooked up below.

Lu is one of a handful of scientists working on spinal cord research who is informed by his own spinal cord injury. About 15 years ago he was a post-doc in molecular biology at UC Davis; he had a car accident and became paraplegic. Newly motivated, he looked for an SCI research lab, contacted Tuszynski and has been there 14 years. Most of that time has been spent studying motor axon regeneration. In 2009, Lu was on a team that showed motor axon regeneration in a chronic model of SCI, as long as 15 months post-injury: "combined intrinsic and extrinsic neuronal mechanisms facilitate bridging axonal regeneration one year after spinal cord injury." Back to the new paper, which builds directly on the previous work. This one is an acute model but certainly has implications for the chronic SCI community. Said Lu, "anatomically this study was very successful. Other scientists have said they can grow motor axons but only along a ramp, as in a roadway. They are not able to get off the ramp. My paper, this study, I believe it is the first real experiment to show we can get an axon off the ramp. We achieved success with a motor axon bridge. Our next direction is how to maximize the effect."

# Intravenous immunoglobulin treatment of the post-polio syndrome: sustained effects on quality of life variables and cytokine expression after one year follow up

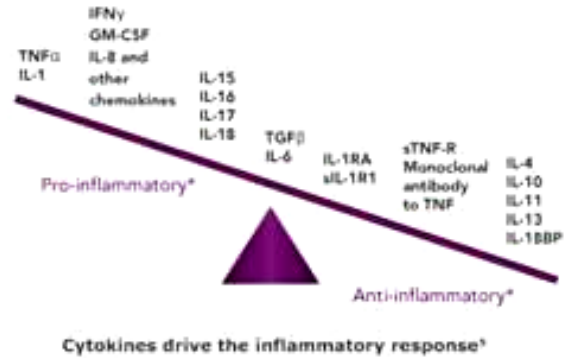
Henrik Gonzalez, Mohsen Khademi, Kristian Borg and Tomas Olsson

*Journal of neuroinflammation* 2012, **9**:167 doi:10.1186/1742-2094-9-167

Published: 9 July 2012

## Abstract (provisional) -- Background

Expression of inflammatory cytokines in cerebrospinal fluid (CSF) has led to the hypothesis of intrathecal chronic inflammation to explain the denervation observed in post-polio syndrome (PPS). It has been shown that therapy with intravenous immunoglobulin (IVIG) improves physical performance and dampens down the inflammatory process at 6 months in pps patients. We here examined the effects of IVIG on cytokine expression and clinical outcome one year after IVIG treatment.



## Methods

From a previous study with 135 PPS patients included, 41 patients were further evaluated before un-blinding for one year (21 placebo and 20 treated with IVIG, Xepol(r) 50 mg/ml), and were assessed for clinical variables by performing the short form-36 survey (SF-36) questionnaire assessment, the 6 minute walk distance test (6mwt) and registering pain level by visual analogue scale (VAS) after IVIG treatment. A separate cohort of 37 PPS patients went through lumbar puncture (LP) at baseline and 20 patients, treated with IVIG, repeated the LP one year later. Thirty patients affected with other neurological diseases (OND) were used as control group. Inflammatory Cytokines TNF, TGFbeta, IFNGamma, IL-23, IL-13 and IL-10 were measured in blood cells and CSF cells with RT-PCR.

## Results

Scores of the physical components of SF-36 were significantly higher at the one year follow up time-point in the IVIG-treated patients when compared to baseline as well as to the control subjects. Pain VAS score and 6mwt improved significantly in the IVIG-treated patients when compared with baseline relative expression of TNF and IFN-gamma in both PBMCS and CSF from PPS patients were increased compared to OND subjects at baseline ( $p < 0.05$ ). One year after IVIG-treatment a decreased expression of IFN-gamma and IL23 was found in CSF of PPS patients, while anti-inflammatory IL-13 was increased ( $p < 0.05$ ).

## Conclusions

IVIG has effects on relevant Quality of Life (QOL) variables and inflammatory cytokines up to one year in patients with PPS. This gives a basis for scheduling IVIG in upcoming trials with this therapy

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**label** – **PHX** =Phoenix, Polio Echo, Inc. P.O. Box 61024, Phoenix, AZ 85082-1024

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Please make check payable to appropriate Polio Support group and send to address listed above.

**Thank You for Your Support!**



**What a great idea from our friend in New York, Mike Kossove!** I have a friend who used her solar lights inside at night when her current was off during the hurricane. She stuck them in a jar or bottle and said they gave off plenty of 'free light'. She put one in each room and would put them back outside in the daytime and bring them in at night as long as the current was off. They are safe to use and cheaper than batteries. Bring in a solar light one night and test it. Due to a thunderstorm, we lost power for about 5 hours. We were scrambling around in the darkness, looking for matches, candles, flashlights, etc. We looked outside, and noticed our solar lights shining brightly all around our patio, stairs, dock, etc. They were beautiful. My wife walked outside, and brought several of the solar lights inside. We stuck the solar light pipes into plastic drink bottles containers and they made the nicest, brightest, safest, lighting you could ever imagine. The lights we have fit into the small (20 oz.) water bottles and they also fit into most of the larger liter bottles. If you need a weight in the plastic bottle to keep them from tipping over, you can put a few of the pretty colorful "flat marbles" that they put in aquariums, and vases. (you can also use sand, aquarium gravel, etc., whatever you have available). The lights we have were perfect inside our home. They burn all night long if you need them. The next day, you just take your solar lights back outside and they will instantly recharge and be ready for you to use again any time you need them. Perfect for power outages, hurricanes, etc. I never thought of it, and now you don't have to.