

POLIOEPIC, INC.

April-May 2011
Southern Arizona
Post-Polio
Support Group
Est. 1985
P.O. Box 17556
Tucson, AZ 85731-7556
(520) 750-8608
(message)
www.polioepic.org

Membership Meetings every Second Saturday of the Month 10:00A.M.
Education Room
HealthSouth Rehabilitation Hospital
2650 N. Wyatt Road
Tucson, AZ

April 9th
Arizona Center for Disability Law – ADA Changes for Medical Offices and Advocacy

May 14th
John Gravina, Attorney specializing in Social Security Disability

June 11th
Fun, Business, Elections and back by popular demand – our 3rd Annual Polio Jeopardy

If you have a topic of interest, contact Mickiminner@msn.com

There are a lot of reasons why you might agree to take on a project. Here are a few.

FULFILLMENT: maybe we are bored with routine; maybe we have to fill an uncomfortable void.

EGO: affirmation; wanting respect; the need to “keep up with the Joneses”; we want our legacy to impress others.

FEAR: Being left out/behind; retribution from some authority figure; financial insecurity; losing our skills or momentum.

It is fascinating that those of us with a permanent disability still try to look to the “normal” or non-disabled people for our guideposts. Why is that?

Avoidance is easy and cheap but correcting can be difficult and painful. Because we are polio survivors, there seems to be a built-in idea that we need to do projects, or that we are the only ones who can do the project’s correctly. Often we are flattering ourselves and susceptible to other people’s flattery.

Many times others will say “If you want a job well done give it to a busy person.” That is where other’s manipulate us, because they see our history of always doing, and always keeping busy.

I myself accepted that request to work on a project. I should have just said NO in the first place, but I didn’t. It is like spending and budgeting. I have just enough money to make that original purchase/project. After making the purchase with hard-earned money, a more important demand comes out of nowhere and there is nothing left to pay for it. ***Substitute energy in place of money.***

I finally cancelled my participation in the project. After all the angst and worry, the team had three more participants by the next morning. All that worry for nothing. Sometimes we drive ourselves too hard, and we have to learn to think about our energy as money. Yes, that’s right, Money. That way we will be careful of where we spend our energy. If we think of our energy as our money, then we can budget our energy, we can plan what expenditures are the most vital and important, and save our precious bundles of energy for the things that mean that most to us as a person.

Peace and Love -- Frank Frisina

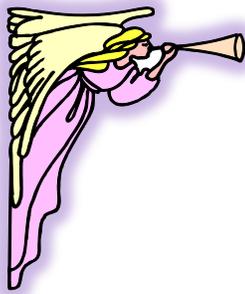


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C ontributions and Donations

*Jane Goins and Nancy Goins
in memory of
Julia Goins*

*Lu Ann Pankratiz
L.W. Nichols*



Condolences to the families

Gene Sherman 2/8/2011

Julia Goins

Melvin Wendrick



**New
On The BLOCK**

**Jesus Saenz - Tucson, AZ
Barbara Terry - New York, NY
Rose Williams - Overland Park, KS**

If Bud Abbott and Lou Costello were alive today, their infamous sketch, "Who's on First?" might have turned out something like this: COSTELLO CALLS TO BUY A COMPUTER FROM ABBOTT

ABBOTT: Super Duper computer store. Can I help you?

COSTELLO: Thanks. I'm setting up an office in my den, and I'm thinking about buying a computer.

ABBOTT: Mac?

COSTELLO: No, the name's Lou.

ABBOTT: Your computer?

COSTELLO: I don't own a computer. I want to buy one.

ABBOTT: Mac?

COSTELLO: I told you, my name's Lou.

ABBOTT: What about Windows?

COSTELLO: Why? Will it get stuffy in here?

ABBOTT: Do you want a computer with Windows?

COSTELLO: I don't know. What will I see when I look at the windows?

ABBOTT: Wallpaper.

COSTELLO: Never mind the windows. I need a computer and software.

ABBOTT: Software for Windows?

COSTELLO: No. On the computer! I need something I can use to write proposals, track expenses and run my business. What do you have?

ABBOTT: Office.

COSTELLO:

Yeah, for my office. Can you recommend anything?

ABBOTT: I just did.

COSTELLO: You just did what?

ABBOTT: Recommend something.

COSTELLO: You recommended something?

ABBOTT: Yes.

COSTELLO: For my office?

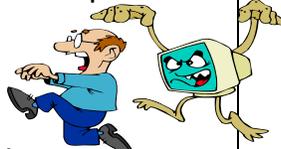
ABBOTT: Yes.

COSTELLO: OK, what did you recommend for my office?

ABBOTT: Office.

COSTELLO: Yes, for my office!

ABBOTT: I recommend Office with Windows.



COSTELLO: I already have an office with windows! OK, let's just say I'm sitting at my computer and I want to type a proposal. What do I need?

ABBOTT: Word.

COSTELLO: What word?

ABBOTT: Word in Office.

COSTELLO: The only word in office is office.

ABBOTT: The Word in Office for Windows.

COSTELLO: Which word in office for windows?

ABBOTT: The Word you get when you click the blue "W".

COSTELLO: I'm going to click your blue "w" if you don't start with some straight answers. What about financial bookkeeping? You have anything I can track my money with?

ABBOTT: Money.

COSTELLO: That's right. What do you have?

ABBOTT: Money.

COSTELLO: I need money to track my money?

ABBOTT: It comes bundled with your computer.

COSTELLO: What's bundled with my computer?

ABBOTT: Money.

COSTELLO: Money comes with my computer?

ABBOTT: Yes. No extra charge.

COSTELLO: I get a bundle of money with my computer? How much?

ABBOTT: One copy.

COSTELLO: Isn't it illegal to copy money?

ABBOTT: Microsoft gave us a license to copy Money.

COSTELLO: They can give you a license to copy money?

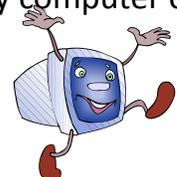
ABBOTT: Why not? THEY OWN IT!

???????? (A few days later)

ABBOTT: Super Duper computer store. Can I help you?

COSTELLO: How do I turn my computer off?

ABBOTT: Click on "START"...



Rotary clubs to host polio awareness dinner

Posted: Tuesday, March 15, 2011--Audrie Palmer -Midland Reporter-Telegram

He was the first of 27 in Midland to catch polio in the year 1948. Donald DeVore said he had spent the summer with his father in Lorenzo and a lot of time in swimming pools while there.

That's where he believes he contracted the disease.

DeVore had a high fever, and after three days began to start losing strength in his legs. His father put him in their family car and drove him to Abilene where he was diagnosed and spent the next 29 weeks in the hospital. He became totally paralyzed while he was at the hospital. Midlanders got together then and hired a private plane to take him to South Texas and Warm Springs Hospital, the top polio treatment center in the world at the time.

"Two years later, I walked out with a slight limp and was totally recovered," DeVore said.

Next Thursday, the four Rotary clubs in Midland will host a "We are THIS Close" to ending polio dinner at Green Tree Country Club. Officials said they are hoping to raise awareness of the global crisis.

Dinner tickets are \$50 each and are being sold through MARC. The event will start with cocktails at 6:30 p.m. and dinner at 7 p.m.

During the first half of the 20th century, the disease crippled millions of children and adults, those like DeVore. But by 1988, there were 125 countries around the world still transmitting polio; last year, there were only four: Nigeria, Afghanistan, India and Pakistan.

The Rotary club has spearheaded a campaign with the World Health Organization, UNICEF and the U.S. Centers for Disease Control and Prevention to eradicate the disease. Officials said that once it's eliminated, it will join smallpox as the only two diseases no longer in existence.

There are 1.3 million polio survivors still alive today and approximately 70 percent of them have been diagnosed with post polio syndrome. While it's been more than 60 years since he contracted and survived the disease, DeVore said he still feels the effects it has on his body and, in 1989, became one of that 70 percentile when he was diagnosed with PPS.

"I am one of about one million left that had a life. Just because I can't walk anymore, I was blessed 60 years longer than they said I would be," he said. "Once we survived polio, we felt like we could do anything and survive anything."

Audrie Palmer can be reached at apalmer@mrt.com. For more information on the dinner and to purchase tickets, contact Jean Jones at MARC at 498-8590.



Editor's Note: After reading this article, what would you do? With our special needs (crutches, power wheelchairs, bi-paps, etc.) would you be able to keep yourself safe in an emergency? It never hurts to think ahead, and ask yourself, "what would I do?"



Coast couple caught in quake terror

Peter Gardiner | 4th March 2011--Trish Poole from Tewantin relives her Christchurch earthquake terror. Geoff Potter

TEWANTIN'S Trish Poole should have known what was hitting their rental car in down-town Christchurch on that Tuesday morning when the city went to hell and buildings started crashing down.

The naturalised Aussie was born in Invercargill and lived in Christchurch for more than a quarter of a century before moving to Noosa 16 years ago. Minor quakes and tremors were something she had lived with for most of her life.

But Trish's mind was far away. She was focussing on flying home after a social two-week holiday with family and friends as her husband, Kewal Gill, drove in the CBD toward what would be the worst-hit of the earthquake zone.

"It was our last two or three hours of our holiday...we had our luggage in the rental car, which we were returning to the rental company before they drove us out to the airport," Trish said. "That didn't happen."

When the car started to slide all over the road she thought Kewal was to blame and asked what he was doing. "The car was going this way – west, then east and then I saw the dome topple off the (Catholic) basilica." Kewal was witnessing his own horror scene of the Canterbury TV building collapsing as the quake slewed the road, not the car, from side to side.

Their family and friends, like themselves, would all somehow survive their ordeals and the aftershocks, but a cousin of Trish's would have to climb five storeys down a building using a fire hose to what passed for safety in a city shaking apart.

Trish said her only thought was how to stay safe, not the easiest of prospects in streets raised and lowered with gaping crevices and streets full of rubble where people once worked and bodies lay.

And for 60-something Trish, the fact she was a "post polio chick" still suffering the effects of the childhood disease and needing a walking stick to stay mobile at the best of times, surviving the next 48 hours was going to be purely up to fate. In the minutes afterwards they drove over ruined roads, saw a bridge over the Avon River collapse, but somehow found a sort of sanctuary in a 110-year-old homestay near a half-collapsed restaurant and bottle shop. The owners took the couple in with about 14 others and assured them foundations had been

especially pile-driven to withstand the after-shocks. "Through the night there were well over 100 after-shocks. Some were really large," Trish said. She spent the night in a chair at the front door of the old house meditating, while Kewal tried to sleep on a mattress on the floor, but jumped up with every tremor. In the morning they set out for Christchurch airport, under the guidance of the Army troopers.

"We had to go a long way around to get there, but finally got to the airport at 9am, which was all crowded, of course, and there was not much food and water that day." "The Good Samaritans came in late that night and brought boxes of water and fruit, cakes and scones people had cooked." There were blankets and pillows and, during another long, sleepless night, signs of hope with the arrival of international flights full of helpers. Trish said the Australian Federal Police, as well as the Japanese and Taiwanese rescue teams, were all cheered by the airport's earthquake refugees.

Trish said she felt safe in the airport, but was resigned to a long wait until 7am Friday when they were re-booked to fly out on a commercial flight. But on Thursday at 2pm, an Australian Embassy staffer said a RAAF Hercules would be flying out in 30 minutes and they could fly back on that. Trish and Kewal were among the lucky 13 passengers flown back on the "once in a lifetime" military flight. The other night at her Tewanin home she thought she felt a tremor, but believes it was only her imagination. Kewal started back at work on Monday at Aldi supermarket, feeling a little tired still. Their physical aches are gone, but what they lived through will stay with them for all their days.



British Polio Fellowship Leads Discussion On Use Of Orthotics In The Treatment Of Post Polio Syndrome Article Date: 08 Mar 2011 - 0:00 PST

The British Association of Prosthetists and Orthotists (BAPO) conference (4 - 6 March) featured a joint presentation on the effects of Post Polio Syndrome (PPS), a neurological condition that can occur in those who contracted polio. The speech, focusing on the use of orthotics in PPS treatment, was given by Dr Mark Edworthy and Dr Robin Luff, representing the British Polio Fellowship, a charity dedicated to the support of those living with the effects of polio and PPS. Up to 80 per cent of those who contracted polio early in life have now developed PPS and frequently require orthotic solutions to enable them to maintain their personal and professional lives. Dr Mark Edworthy, a member of the British Polio Fellowship Orthotics Panel, spoke about how orthotics services have enabled him to sustain his quality of life. He said: "I am an active individual and have demanding jobs as both a commercial pilot and professional speaker. I started to experience symptoms such as pain and increasing weakness and was eventually diagnosed with PPS. "I rely on orthotics to continue working and enjoying an active social life." Consultant in rehabilitation medicine, Dr Robin Luff, gave a clinician's view of the characteristics of PPS based on his experience in treatment. He said: "The impact of PPS varies considerably between individuals and simple interventions can be enormously effective. However, the analysis of the intervention required is not simple and needs considerable experience." It takes on average six years to diagnose PPS and only 18 per cent of GPs know how to treat it thereafter. The symptoms of PPS include increasing weakness, [fatigue](#) and pain in previously affected or unaffected muscles, a general reduction in stamina, breathing, sleeping and/or swallowing problems as well as severe cold intolerance.

Christopher Templeton –Polio survivor, Model, Actress Business Woman and Advocate for the Disabled



My first modeling job - I contracted polio along with 13 others in my neighborhood when I was 6 months old. That was in 1952 in a suburb north of Chicago called Highland Park

I was born and raised in and around the Gold Coast of Chicago. I went to one of the best high schools in the country, New Trier East in Winnetka, Illinois. My first jobs were for doctors in medical offices – Veterinarian, Oral Surgeon and Pediatrician. I trained in all phases of manual bookkeeping (this was pre-computer, of course – ugh!), patient relations, scheduling, etc. I went to college for one year – Texas Christian University. I moved to Arizona in the mid-70's. I worked for First Interstate Bank for 5 years doing various phases of financially oriented banking procedures including; customer relations, teller, foreign exchange, international transfers of funds and collections. I also worked for Plaza 3, which at the time was considered the number one modeling school in the country. At the school I prospected for and sold classes to ducklings who wanted to be swans. Also, I took all the classes and traveled around the state of Arizona as the school's representative. After that I worked as a "Head Hunter" for a short period of time, lining up professional business people with corporate jobs.

I moved to Los Angeles in the early 80's to pursue acting. I went over on a whim and stayed – I had \$90 in my pocket. I worked for Trailways Regional Headquarters in the World Trade



ADA demonstration in Washington, D.C.

Center, Downtown, LA, where I did various manual accounting procedures, handled phones and worked directly for the Regional VP. During that time I became an activist for disability rights. I was hired because producers were actively writing to educate the public regarding the normalcy of disability rather than the abnormalcy of it – to subliminally eradicate the "fear factor". I was awarded by the CA Governors Committee, The Dole Foundation, LA's Project with Industry, Public Service Achievement Award for the National Legislation Council for the Handicapped, was the National spokesperson for Rotary International's Polio Plus

Program, Special Consultant on Public Relations to the President's Committee on Employment of Persons with Disabilities (as well as a board member) and an Advisory Board member of the Media Access Office (on disabilities) in Los Angeles. I have also represented CBS's Stop the Madness and Share the Spirit campaigns (PSA's), NBC's Profiles in Pride campaign (bio-docu-commercials) and have done national commercials for IBM, Kodak, Kellogg and Osco Drugs.



After a while I decided to capitalize on my visibility. I started a mail order business. I became computer literate and the business became international. I learned all phases of mail order from manufacturing, to fulfillment, to marketing, to advertising. It took two years to become the only company ever to hold the licenses to all eleven Soap Operas.



Acting exposed me to “celebrity” – what to do, how to act, what to expect, how to promote and how to protect myself. It taught me about fans and politics. I learned that when you’re on top you’re everybody’s friend and how nobody knows you when you’re down and out. I learned about public relations and how to become a “back door” person. When they don’t give you what you want up front, you find another way in. I can’t think of an acting job I did in the 20 years I spent in Hollywood that I didn’t generate myself. At this time I am volunteering at Christ Healing Center in Olmos Park. I just arranged, produced and performed on a CD of healing songs, scriptures and psalms. I am now in the process of promoting, marketing, advertising, selling and fulfilling orders for Christ Heals.

Once again, Polio-World is holding a photograph contest. Each photo should show the three phases of your Polio life 1) *Polio* 2) *Living with Polio* and 3) *Post Polio*. Below are some examples. We will be using the photos to demonstrate the concept “WE ARE STILL HERE”. Post Polio Health International’s-- WE ARE STILL HERE campaign will be the second week of October, 2011. The photos will be shown at various Post Polio conferences and educational seminars throughout the world. Send your photos to Mickiminner@msn.com, with a description of less than 50 words to describe the photographs.

Polio – Age 5



Living with Polio



Post Polio



Lothar Epe - Netherlands

The first one is a photo from 1960 and there I'm about 5 years old. I was in the kinder garden in a kind of orphanage for disabled, playing with a ball.

The second one is from 1983, when I was "in the prime of my life", together with my three sons. It looks a bit like the "Bremer Stadtmusikanten"!

The third is from 2009 (about), getting out my dog (as you can see too), of course after diagnosed with pps.



Prior to Polio 1947



Post Polio



Living with Polio in the Eighties

Margret Embry, German, living in Belgium near Brussels. Polio 1948 – total paralysis from head down. Recovery period 3 years, walking with brace and canes. Mobility getting worse as from 1991, use of wheelchair as from 1994, no more standing or walking as from 2004. PPS diagnosed in 2008.

The following recipe was served at our general meeting in February. Everyone loved it and wanted the recipe.

CHEESE BALL RECIPE By Joanne Yager

2 - 8oz. packages of cream cheese
(softened to room temp.)

2 Tbsp Mayonnaise

1 tsp creamy horseradish (optional)

2 Tbsp DRY Hidden Valley Ranch
dressing mix

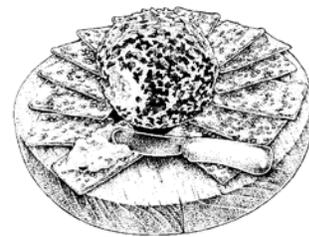
1 tsp lemon juice

1 tsp hot sauce

1 tsp Worcestershire
sauce

1 or 2 Tbsp dry onion
flakes

½ tsp garlic powder



Mix the above ingredients before you add about 1¼ cups of finely grated sharp cheddar cheese. This takes a bit of mixing by hand, form it into a "ball", turn it out on a piece of plastic wrap and mold it into a smooth ball. I usually make it and refrigerate several hours. If you wish to make a smaller ball just cut the recipe in half. Enjoy



BY-LAWS (OPERATING POLICIES) CHANGES

Your Polio Epic board has updated changes to our Operating Policies.

Please review for approval at the general membership business meeting June 11th.

NEW

ARTICLE III – MEMBERSHIP-SECTION 2: The Board of Directors shall have the power to assess membership dues based on the review of outside financial assistance as compared to projected expenses of the organization. Dues shall be a minimum of \$10.00 per member per year with a maximum not to exceed \$15.00 through 2015. Waiver of dues based on financial hardship and for networking exchanges of newsletters will be appropriate. Waivers are to be approved by the Board of Directors.

OLD-2010-

NEW

SECTION 4: DELETED

OLD-SECTION 4: *The Professional Advisory Board shall be established by the Board of Directors. This Professional Advisory Board should include, but not be limited to members from the medical community and others knowledgeable and/or interested in the problems relating to post polio syndrome.*

NEW

ARTICLE IV – OFFICERS–SECTION 1: The officers of the organization shall be a President, Vice President, Secretary, Treasurer, and any other director appointed by the Board of Directors. The Board of Directors is charged with reviewing and approving programs and budget, evaluating and assessing the organizations progress in meeting goals, setting policies and appointing committees as necessary for the overall operation of Polio Epic

OLD- *President, President-Elect, Recording Secretary, Correspondence Secretary, Treasurer,*

NEW

SECTION 2: A slate of candidates for Board positions shall be presented by the nominating committee with nominations open from the floor at the annual meeting. Candidates for any position of the Board of Directors must be willing to assume responsibilities of that position and be currently paid-up members, or have approved waiver of annual dues. Election of Executive Board shall be by majority vote of the membership in attendance. Election of Board Members shall be by majority vote by current board members.

OLD- *Election shall be by majority vote of the membership in attendance.*

NEW

SECTION 3: An election of officers shall be implemented and in effect beginning May, 1987. A President, Vice President, Secretary, and Treasurer will be elected each year.

OLD- *A President, Recording Secretary, Correspondence Secretary, and Treasurer*

NEW

SECTION 4: A minimum of two (2) Board officers shall be polio survivors.

OLD- *three (3).*

NEW

ARTICLE V – MEETINGS–SECTION 3: A quorum of seven board members must be present, two of whom must be officers at a Board of Directors meetings for the transaction of business.

OLD- *A quorum of seven members must be present, three of whom must be officers*

NEW

SECTION 4: Special meetings of the Board of Directors may be called at any time by the President, or by three members of the Board of Directors.

OLD- ~~DELETED - with advance notice of at least 48 hours.~~

NEW

SECTION 6: Any member of the Board of Directors who has failed to attend three (3) consecutive Board meetings, without notifying a board member shall forfeit his/her position upon the Board of Directors discretion. The Board shall then fill the vacancy by appointment.

OLD- *notifying the President*

Revised March 2011

2011



2011

Example of Label:

2010
JOE SMITH
1234 E ANY WHERE DR
TUCSON, AZ 85701

Look at your mailing Label on the last page!

YOUR 2011 DUES ARE DUES

Above your name on the address label is the YEAR YOU ARE PAID UP THROUGH.
(example 2010)

If it is showing 2010 or before, you need to send in your dues for 2011 to be up-to-date.
If you are showing 2011 or later, any money that you do send in will be considered a donation unless otherwise specified.

Please mark all contributions whether they are donations or dues, so we can update your membership properly.

Thank you for your continued support!

Contact Nannoe if you have any questions at **520-797-6898** or email me at Nannoe1@aol.com.

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

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 2010-2011 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

POLIO EPIC, INC



1985 - 2010

Wadleigh Grant

Could you use up to \$400.00 to help get the disabled help items you need?

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