

POLIO , INC.

**General
 Membership
 Meetings
 Every Second
 Saturday of the
 Month
 10:00 am.
 HealthSouth
 Rehabilitation
 Center**

Wyatt Road
 • December 10th,
 our 20th
 anniversary
 celebration and
 annual holiday
 luncheon. This
 Meeting and
 Celebration will
 be at the
 Holiday Inn Palo
 Verde at 11:30
 a.m. in place of
 our usual
 meeting.
 Please make
 sure to reserve
 your place now.
 Our guest
 speaker will be
 Guy Atchley, an
 author, and
 news anchor.

Individual Highlights:

Presidents Letter	1
Are you a Polio Survivor?	2-3
Friends & Loved Ones	4
A Clarification of Non-Paralytic Polio	5-6
PPS Forum	7-8

Caveat Emptor

Many of you know of the dream I have talked about for years, the dream of housing for the disabled. Functioning in a home designed for our individual disabilities is very different from living in a space designed for the able bodied person. Last Sunday's Star newspaper had a short article about planning ahead for the aging process. Better Homes & Gardens, AARP and Bob Villa from PBS have all promoted planning and changing (today) the living conditions while the occupant is still enjoying healthy years...to accommodate their lessening abilities in future years.

They speak of planning and modifying our homes to make life easier. Then as we arrive at a time in life where arthritis requires lever handles on all doors and faucets and stove controls...they will already be in place. If one day we find the need for wheelchairs or other mobility assistance to move about within our homes, foresight and change have already provided wider doors and hallways and deeper spaces under sinks and stoves. Very close proximity of garage to kitchen for grocery, etc. unloading is

efficiency by the able bodied persons and an urgent need for the disabled. And often overlooked feature when a potential house plan is considered.

As I "interview" local builders there is little interest in providing for the aging and/or disabled...the minority populations. As the wise sign says...*"If aging is not your issue...it will be."* Not only does it cost relatively little to accommodate these "minorities" but it makes smoother function for the able bodied person as well. Most elements designed for disability are, simply put, more efficient. Another reason to have these benefits in our homes...all homes.

The low demand for including these accommodations make most home builders unfamiliar with these features. If it's not common or cookie cutter to the labor force, it's "an extra." We pay much more for relatively cheap innovations. Note the uproar several years ago when contractors were confronted with "visitability." A concept that required all new homes to

have wider doors and at least one level entrance so a disabled person could come to visit.

In a short time the Baby Boomers will become seniors and we will see a higher demand for more efficient living designs. Designs we, the polio and post-polio population have needed most, if not all of our lives.

Sadly the excitement of a new home can cause us to overlook the built in obstacles like the subtle hill of our driveway...car doors (and gravity) fighting us. Distance from house to mailbox. Windows easily opened by arthritic hands or one hand. There are hundreds of features which could make our lives smoother and living without them adds stresses and maybe pain to our daily lives. In time we will be familiar with homes which fit our lives instead of what is presented to the buying public at inflated prices. We wouldn't dream of selecting a garment that was overpriced and didn't fit. Or would we? (Those too-tight-waists are killing us.)

Is it possible that *Caveat Emptor* burned with Rome?
 Frank Frisina

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

Local Polio Epic Support Group wins Regional Award

RECOGNITION of all our hard work! Last month, the Board of Directors at D.I.R.E.C.T. had their 15th anniversary celebration of the passing of the ADA (Americans with Disabilities Act) and selected their annual winners of the Diane Lane Anderson award. Polio Epic was one of the recipients of the "Diane Lane Anderson" award for disability education. The

Polio Epic group was given the award at a wonderful dinner and a check for \$125 for our work in outreach and education for the disabled in Tucson and Southern Arizona.

**Diane Lynn
Anderson
Award**

The entertainment of the evening was the famous cartoonist and local speaker, David Fitzsimmons. Please ask to see the award plaque, and the great cartoon done of our own now-famous Karla Carr. (*rumor has it that Karla will tell polio jokes for food*)

Reprinted from Triad Post Polio Support Group – by Millie Malone So, You think you are a Polio Survivor? A Quiz for the Holidays

You may not know this, but many people wish they were polio survivors. I'm sure you have read the surveys pointed out that a higher percentage of us polio survivors are married, have college education and have important, high paying, high profile jobs that those unfortunate non-polio people. So of course, there are those who would like to join our elite group. The following quiz is designed to winnow out polio survivors, wannabes and imposters. Answer honestly, writing down the answers on paper as you go. No cheating, and don't even use a pencil with an eraser. You must use ink.

1. **There is a spot of water on your kitchen floor. You:**
 - a. Get the mop and wipe it up
 - b. Call your child/spouse/service dog to come and wipe it up
 - c. Use the seat of your pants to wipe it up, seeing as how you have already slipped on it and are on the floor on your backside anyhow.
2. **You need the big mixing bowl that you store on the uppermost shelf of your cupboard. You:**
 - a. Climb on a kitchen chair, stretch to the limit of your reach and get it down
 - b. Call your child/spouse/service dog to climb up and get it for you
 - c. Buy a new bowl after climbing on the kitchen chair, stretching to the limit of your reach, straining all the muscles in your arm and dropping it (hopefully not on the dog).
3. **You are comfortable ensconced in your recliner, feet up, a teensy bit of drool escaping from your mouth. The phone rings. You:**
 - a. Gracefully reach over and pick it up, answering in a civil tone.
 - b. Ask your child/spouse/service dog to answer the phone
 - c. Jump straight up three feet in the air, turn a triple somersault while grabbing the phone, and land in the recliner, your heart beating wildly.
4. **You have gone to the grocery store, the cleaners, the post office and library, arriving home with your tongue hanging out and your legs in spasm. You:**
 - a. Make about seven trips to and from the car, carrying everything in to the house.
 - b. Call your child/spouse/service dog to come and get the things out of the car.
 - c. Load everything up in your arms, use your teeth to carry the strap of your purse, put the handles of the plastic grocery bags over your wrists and walk in agony into the house with this load, proud that you have saved yourself many trips.

-
5. **Your church is having a bake sale. They have asked you to bring 12 dozen cookies. You:**
- Mix up a quadruple batch of cookies sitting at the kitchen table, put the dough in the refrigerator and have your grandchildren help you bake them after school.
 - Call your child/spouse/service dog and give them a blank check to go buy 12 dozen cookies at the bakery.
 - Arrange to set up and run the bake sales by yourself, make 24 dozen cookies and assorted cakes, take as many pain pills as you can safely get away with, and then sleep for three days.
6. **You need new curtains in your bedroom. You buy a lovely pair that you are sure will make the bedroom look like a picture from House Beautiful. You:**
- Get the stepstool, take down the old curtains, and put up the new ones.
 - Ask your child/spouse/service dog to take down the old curtains and hang up the new ones.
 - Slip off your shoes and brace, climb on the bed, stretch towards the window, fall off the bed, break your “good” leg and spend the next 18 months in the bed, staring at the old grubby curtains.
7. **Your favorite charity asks you to donate two days a week to helping in their daycare center You:**
- Tell them “yes” and then show up if and only if you aren’t exhausted.
 - Ask your child/spouse/service dog if they are interested in a really fun volunteer job.
 - Start to form your mouth into a “NO’ but hear it come out “nnnnOK” – even though you know you are not able to do the job and resent being asked—go to the daycare center twice as often as you agreed to, take as many pain pills as you feel you can safely get away with and then sleep for three days.
8. **The holidays are looming, you have always had the family over for dinner. This year you:**
- Tell them that it is time they took over and had the family dinner at their house.
 - Ask your child/spouse/service dog to do the actual work while you supervise.
 - Do all the shopping, cleaning, cooking and serving while in excruciating pain, take as many pain pills as you feel you can safely get away with and spend the next three days in bed while planning New Year’s dinner.

SCORING:

If you answered “**A**” to *any* of the questions,

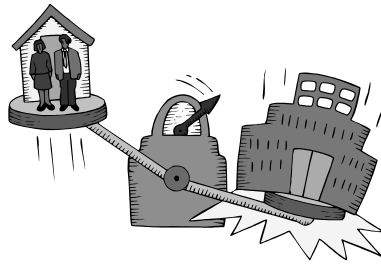
You aren’t even disabled, you faker you, let alone a polio survivor! Get your car out of that handicapped parking space!

If you answered mostly “**B**”:

You’re a polio survivor, but you cheated! Don’t even try to deny it! You’ve read about what you **SHOULD** be doing to treat your post-polio syndrome, knew those were the right things to do and probably don’t do a single one of them. Frankly, we are ashamed of you.

If you answered mostly “**C**”

Congratulations! You are a bona fide polio survivor and entitled to all the rights and privileges therein unto appertaining (my, that sounds fancy, doesn’t it?) and you know very well that you shouldn’t be doing any of those things!



CONTRIBUTIONS

POLIO EPIC expresses

Appreciation for the following contributions...

***BUILDERS**

Dr. Killebrew

Deanna Riley

***FRIENDS**

A. Martin Ronstadt

Carol Mayfield

Charles and Phyllis King

Charles Root

Dana Vincil

Frederick Killion

Helen Crandall

Irene Schmoller

Joan "Tarke" Sweet

Kate Sanderson

L.W. Nichols

Lea Diane Morris

Marian Abbott

Marjorie and Philip Silcott

Mary Raihofer

Nancy Craig

Rex Dunn

Rosemary DelTurco

The Bernardi's

***BUILDERS \$100 and OVER**

***FRIENDS UP TO \$99**

*Our condolences, from Polio Epic,
go out to all the families and friend who
have lost a loved one.*

In Memory of . . .



Sam Speese

By Peggy Speese

In Memory of . . .

Laura Sherman

By Gene Sherman



**We wish to welcome the
following new members to
Polio Epic!**

**Philip Silcott
Frank and Freda Merenda
Amy Merenda
Reen Carter**

Your Dues...How to tell when your Dues are due !

If your label says 2005 or earlier, then you owe for this fiscal year. Many of you have already paid your current dues. If your label says 2006 or later, then you are paid for this fiscal year, or up through whatever future year is listed on your label. Remember, even though postage and supplies have gone up we are still able to continue with our low \$5.00 yearly dues. Please send in your dues. If you are not sure what you owe, please contact a board member.

Bashas' Thanks A Million

Bashas' "Thanks a Million" program is back, offering a way for Polio Epic to raise money. All you need to do is take your Bashas' "Thank You Card" into any Bashas' and ask the cashier to enter our group number – **27169**. The program runs from **September 1, 2005 to March 31, 2006**. Polio Epic will receive 1% of the total dollars attributed to our group identification number – up to \$2,500.

Don't forget to tell **all your friends & relatives** that shop at Bashas' about this program. Again our group number is:

27169

PPS Forum by Dr. Richard Bruno

Q: An article in the New York Times Magazine describes me to a tee. I can't remember people's names and forget what I want to do when I go from one room to another. The article says that early brain trauma can cause middle-aged memory loss. I remember polio as a kid, but I don't remember hitting my head. Did I forget that too?

Maybe you never hit your head, but you do remember early brain trauma. That trauma was polio. The polio virus damaged neurons in your brain stem responsible for activating your brain and focusing attention whether or not it damaged your spinal cord motor neurons. But the polio virus neither damaged neurons in the hippocampus, which is responsible for storing memories, nor in the cortex, the thinking "computer" of your brain. So why, in our 1990 International Post-Polio Survey, did nearly 85% of polio survivors report memory problems, 70% report difficulty "thinking of words I want to say?" First, it makes sense that the more fatigued polio survivors report, the more memory and thinking problems they have. But even our most severely fatigued polio survivors had no trouble when we have them take tests of memory and thinking. However, severely fatigued polio survivors took up to two-thirds more time to complete attention tests and had more errors, than did polio survivors without fatigue. All of the fatigued polio survivors' scores on these tests were abnormally low.

Second, word finding difficulty isn't a memory problem. Trouble with word finding happens when the part of your brain that "thinks" of a word has difficulty with the part of the brain that "says" the word. Our studies found that word-finding difficulty is related to both fatigue and trouble with attention. We found word-finding difficulty, fatigue severity and attention problems were all related to polio survivor's brains making less dopamine. Dopamine is *the* brain-activating neuro-chemical. You may know that low levels of dopamine cause Parkinson's disease. We found that polio survivors and people with Parkinson's had identical levels of word-finding difficulty—no surprise since it is dopamine that connects the word "thinking" and word "saying" parts of the brain.

So, it's early brain trauma, due to the poliovirus killing dopamine-producing and brain-activating neurons, combined with the natural death of remaining neurons with age, that reveal attention and word-finding problems in mid-life. This is the same process that is thought to be responsible for midlife attention and word-finding problems in individuals who had an early brain injury. The normal age-related loss of neurons reveals that they already have a reduced number of brain neurons. It will be a relief to know that polio survivors don't develop Parkinson's disease any more frequently than do other individuals. What's more, polio survivors may actually be protected against getting Alzheimer's disease. The gene that makes the poliovirus receptor – which grabs the poliovirus and pulls it inside neurons, where it does its dirty deeds – is found on the chromosome 19. The poliovirus receptor gene shares space on chromosome 19 with another gene, the one that makes a protein called APOE-4, which is thought to damage the brain in ways that cause Alzheimer's disease. But the two genes have an "either/or" relationship: you can't have one *with* the other. If you have the APOE-4 gene, you can't make poliovirus receptors, and vice versa. With the APOE-4 gene, a person would be less susceptible to polio, but more likely to get Alzheimer's. Without the gene, you would make poliovirus receptors and be susceptible to polio, but be less likely to get Alzheimer's disease.

Shanda Davis surveyed polio survivors and older Drew University alumni, asking if they had Alzheimer's. Remarkably, 3.6 percent polio survivors did. Polio survivors had 12 times *less* Alzheimer's disease than those who didn't have polio. Of Post Polio Institute patients, only 0.4% had Alzheimer's. So maybe, even the dark cloud of polio has a silver lining that becomes evident decades down.

(Dr. Bruno is chair-person of the International Post Polio Task Force and director of the Post Polio Institute and International Centre for Post-Polio Education and Research at Englewood NY Hospital and Medical Center.

Global case count

Polio cases for 15 November 2005 :

Global cases of poliovirus: 1499

Nigeria (endemic)	560
Yemen (importation)	473
Indonesia (importation)	288
India (endemic)	47
Somalia (importation)	42
Sudan (re-established transmission)	26
Pakistan (endemic)	19
Ethiopia (importation)	18
Angola (importation)	9
Niger (endemic)	6
Afghanistan (endemic)	4
Mali (importation)	3
Chad (re-established transmission)	1
Eritrea (importation)	1
Cameroun (importation)	1
Nepal (importation)	1



20th Anniversary Luncheon information and news:

The Holiday Inn Palo Verde has agreed to set aside EXTRA handicapped parking on the north side of the entrance of the hotel. These spots are the closest to the entrance to the ballroom. We currently have 64 people signed up for the luncheon. Make sure that you reserve your spot now before we have to close the reservations. Please use the insert to make your menu choice and send your reservation in before the 5th of December. I know that the insert says December 1st, however, we have extended the deadline to the 5th for all of you procrastinators out there!

We look forward to seeing you at the 20th Anniversary Celebration of Polio Epic Support Group, the 50th Anniversary of the Salk Vaccine, and our Holiday Celebration wrapped into one great party!



A Clarification of Non-Paralytic Polio

By Ernest W. Johnson MD, reprinted fro Polio Heroes of Tennessee, September 2005

(Dr. Johnson is the editor of the American Journal of Physical Medicine and Rehabilitation. He is a well recognized expert on Post-Polio Syndrome.) Reprinted from Polio Canada, Spring 2004.

For many years, most physicians have understood that non-paralytic is a loose clinical term implying that neither the patients nor the clinician-examiner reported functional weakness. This determination was made without the understanding that 50% of the motor units can be lost before a manual muscle grade of four occurs. This means that many patients with acute polio were tabled non-paralytic incorrectly, but certainly in a well-meaning way. When the polio virus is in the gastrointestinal trace of an individual and causes symptoms, the term abortive polio has been used. This is the condition that confers immunity on the individual and also prevents the carrier state. This is why the Sabin (attenuated, live poliovirus) vaccine prevents the invasion of the polio virus into the central nervous system, but not the polio virus from living in the gastrointestinal tract.

In those individuals whose immunity systems, for whatever reason, permit the invasion of the central nervous system by the poliovirus, a population of anterior horn cells will die. The number of these cells that die will determine whether the clinician will be able to identify paralysis. In the late 1950s, our electromyographic studies suggested that in all patients who experienced the invasion of the central nervous system by the virus, pain, meningismus, and positive spinal fluid findings revealed abnormal irritability (fibrillation and positive ways) in many muscles that were clinically "normal".

It should be absolutely understood that patients who were told that they had non-paralytic polio did, in reality, have polio which affected their anterior horn cells. Now 30 to 40 years later, these patients are potentially subject to all of the vagaries and insults to the body that affected other persons with post-polio syndrome.

Dues Form

**POLIO EPIC, INC. CURRENT MEMBERSHIP ANNUAL DUES ARE RENEWABLE
THROUGH THE FISCAL YEAR OF SEPTEMBER 1, 2005– AUGUST 31, 2006**

Name _____ Spouse _____ Date _____

Address _____ Phone (_____) _____

City _____ State _____ Zip _____ - _____

Optional: Email _____

____ I am sending in my/our annual dues of \$5.00 per person for 2005-2006 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 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.

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

**LUNCH AT FRANK'S . . .
Third Wednesday of the month.**

**NOTE: NOT SCHEDULED FOR
DECEMBER**

January 20th
at 11:30 AM –Enjoy a
wonderful lunch and socialize
with other Polio Epic members at



**Campaña Del Rio,
1550 E River Rd.**

Cost is \$8.00 and
well worth it!
Call no later
Than the
Tuesday
before!

**Frank
Wadleigh
299-9052
or
Bill Hatton
321-1703**

Board of Directors

Lucy Anderson	520-294-5104	
Cathy Bleyer	520-572-0599	CatBley@aol.com
Chris Christensen	520-742-8528	Ochris4131@aol.com
Dorothy Cogan	520-326-7979	
Virginia Hanson	520-292-0652	vrh13@earthlink.net
Bill & Susie Hatton	520-321-1703	sbhatton@cox.net
Charlie Minner	520-743-1556	Canthmin@msn.com
Carol Phelan-Smith	520-579-0078	Handthx82@cs.com
Alice Smedley	520-792-2758	
Barbara Stough	520-887-4731	chasbarstough@juno.com
Joanne Yager	520-296-1471	jyager@mymailstation.com

MARK YOUR CALENDAR

General Meetings:

December 10th – 20th Anniv. Lunch

Next meeting: January 14th, 2006

Refreshments are always served!

Board Meetings:

First Thursday of each month at

DIRECT

ALL ARE WELCOME!

Executive Board Officers 2005-2006

President, Frank Frisina	327-3252	Shinybear@msn.com
President Elect, Karla Carr	318-1219	KarlaKrazies@aol.com
Recording Secretary Virginia Roberts	886-2236	Virgaz1@cox.net
Treasurer, Micki Minner	743-1556	MickiMinner@msn.com
Correspondence Secretary, Nannoe Westbrook	797-6898	Nannoe1@aol.com