

POLIOEPIC, INC.

June – July 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**

**June 11th
Fun, Business,
Elections and back
by popular demand**

–
our 3rd Annual
Polio Jeopardy

**July - August
Take the summer
off, have fun, enjoy
and come back
when the Tucson
Weather cools, and
see you in
September !**

**September 10th
First new meeting
of the year**

Slow down! You're goin too fast! Is the occasional command I hear as I breeze down an *empty* hallway or a wide open area in my power chair. While they really may be concerned for their safety or my safety, they want me to go their speed...slow. Allow me to ramble a bit more...

By now each of us has chosen the inclusiveness or involvement or speed of our own lives. I may judge you as doing too much too fast. You may not see it the same way. Speaking of different velocities, years ago Polio Epic *gained* a fast paced individual. One of many unique accomplishments and a worldwide circle of friends...and recently Polio Epic *lost* that wonderful individual, Charlie Minner, a beloved member of the Board of Directors for years. Yes, he once lived a very fast life with many risks and yes, he is gone too soon. But what a legacy.

Before we hear of the lives of those we encounter, they are just black and white. As their stories become revealed they ease into pastel then to vivid color and some to sunlight brilliance.

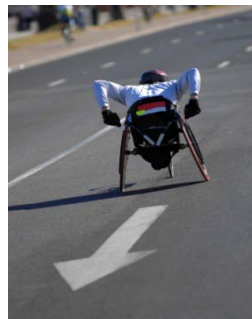
When we encounter each other for the first time with no foreknowledge, only our outside shows and we are to them a nonentity. If we take a risk, we may, in time, experience their heart and soul.

A homeless person came and sat near me in a coffee shop recently, began a conversation, moved to a closer seat and soon asked for money. I gave him a buck. He remained seated and asked many questions about disability, and as a former professional kick boxer he could not relate to not being agile with his limbs. After more exchanges, he confessed how he takes people for granted and began to express genuine empathy for other's awesomely different experiences. He left to buy an energy drink and in a while returned with the register receipt and some coins, insisting that he could not keep more than he needed for the purchase and with gracious thanks, he walked away. I do not know him and probably never will but for an instant we looked into each other's lives and it was refreshing. As a former very untypical New York City resident, I say hello to everyone who allows their eyes to meet mine, often wondering what stories are behind those windows.

I wish I could get to know all of you but only in our mutual willingness to connect can that happen. Polio Epic may be around for years to come *if* we take a chance, interact, and become involved with each other. This support group has given generously to many and with you and thru you it will continue to educate and support many more to come.

Elections for the upcoming year will take place at the General Membership Meeting in June. While we cannot replace Charlie Minner, he does leave a vacancy on the Board. Please consider giving some of yourself, in whatever way you can, to assure this great organization continues. I also ask you to keep in your thoughts and prayers those who have and will serve this organization.

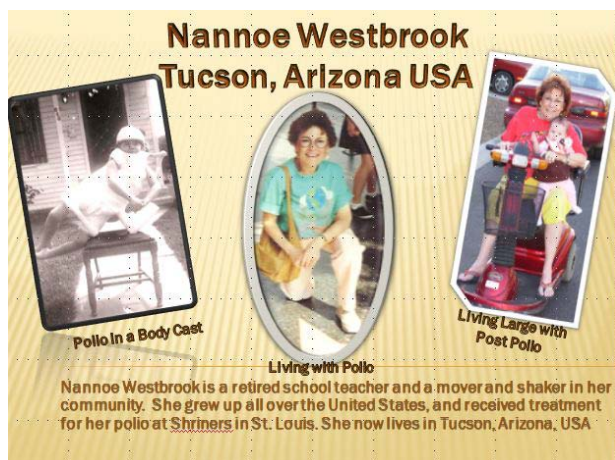
Frank Frisina - President



Board of Directors		
Marty Baldwin	795-6157	martybaldwin86@gmail.com
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Judy Taylor	881-9097	fusserwuz@yahoo.com
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Executive Board 2009-2010		
President, Frank Frisina	327-3252	Shinybear@msn.com
Vice President, Micki Minner	743-1556	Mickiminner@msn.com
Treasurer, Nannoe Westbrook	797-6898	Nannoe1@aol.com
Secretary, CeCe Axton	495-5122	axton@cox.net

POLIO – WORLD PHOTO SUBMISSION CONTEST

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.





Enforcing the ADA: A Status Report from the Department of Justice April - June 2010 (new May 11, 2011)

- In Massachusetts, a husband and wife filed a complaint alleging that a tour bus company failed to provide an accessible bus, so the wife, who uses wheelchair, was unable to board the bus and the couple could not take the pre-paid trip. The company modified its policy, contracted with another bus company to provide an accessible bus when needed, added questions on its registration form so individuals with disabilities could indicate if they need accommodations, and donated \$1,018 to a service organization.
- In Alabama, an individual alleged that two branches in a bank chain had inaccessible parking and entrances. The bank installed one van-accessible parking space at each branch. In addition, at one branch the bank provided directional signage to the accessible parking and entrance, and at the other, installed an accessible ramp from the sidewalk to the entrance and widened the doorway.
- In Texas, an individual with a mobility disability who uses a scooter was unable to attend his grandchild's basketball game because the youth organization's gymnasium where the game was held was inaccessible. The organization installed a curb cut from the parking area to the sidewalk, extended the sidewalk, and posted directional signage to the accessible entrance.
- In Michigan, an individual whose father has a mobility disability and uses a scooter alleged that a city failed to provide accessible parking and restroom facilities during city-sponsored events. The city agreed to install accessible parking spaces and curb cuts, as well as to provide accessible portable restrooms at city sponsored events. The city also modified its permit application and vendor contract to ensure that vendors accommodate individuals with disabilities for all city events.
- The friend of a person who uses a wheelchair complained that a Southeast aquarium lacked sufficient accessible parking, passenger drop-off areas, and paths of travel. The aquarium installed 18 additional accessible parking spaces with signage on multiple levels of the parking structure and an elevator to connect the parking area to the covered pedestrian walkway leading into the facility. The aquarium also created accessible passenger drop-off and loading zones and accessible paths of travel. In addition, it updated its website to include information about the new accessible features.
- In North Carolina a person who has cerebral palsy affecting his manual dexterity and who uses crutches and a wheelchair complained that a check-cashing store refused to

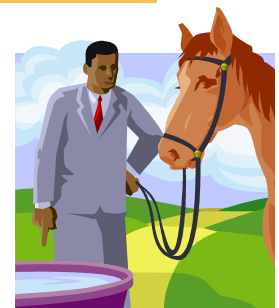
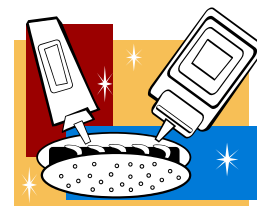
provide assistance filling out forms it required. The business reaffirmed its policy of providing assistance upon request, retrained staff on the policy, sent a memo to other stores in the network reminding them of their ADA obligations, and apologized to the complainant.

- Parents whose son uses a wheelchair complained that a Texas fairground was inaccessible. The fairground installed van-accessible parking, a sidewalk from the parking lot to the accessible entrance, a passenger drop-off area at the main entrance, and accessible routes and accessible seating within the main arena. In addition, the fairground installed amps, signage, and grab bars at three permanent restrooms and placed accessible portable restrooms throughout the fairground. The fairground also trained staff on the ADA and apologized to the complainants.
- In Texas, an individual with a mobility disability alleged that one elevator at a concert venue was blocked off for a private party and the other elevator was broken. The concert venue agreed to discontinue the practice of blocking off an elevator for private parties, improved its process for elevator repair, trained staff on the ADA, and gave the complainant two complimentary tickets to a performance of his choice.



A “Con” Quiz-Every answer is a word that begins with “CON”

- 1) Focus ones attention?
- 2) Overcome the opposition?
- 3) Musical performance ?
- 4) Worry?
- 5) To keep secret?
- 6) Defunct aircraft?
- 7) Bring to an end?
- 8) Agree with ?
- 9) Declare unfit for use?
- 10) Reduce?
- 11) Lead?
- 12) Protection in electrical installation?
- 13) Hostility?
- 14) Small pieces of coloured paper?
- 15) Seasoning?
- 16) Evergreen?
- 17) South American vulture?
- 18) Gathering of college of cardinals?
- 19) Pleasant and agreeable?
- 20) Seize?



Post Polio Patient Assessment

A doctor's assessment of any condition (including Post Polio Syndrome)

1) Chief Concern - What brings you into the Doctor's office today?

- a) Be specific, what is the issue for today? Not for the last few years, or generalizations.
- b) Example: I made the appointment today because I am having another flare up of pain in my lower back
- c) Example: I am unable to use my crutch without an intense pain in my right shoulder

2) Past General Medical History

- a) The important parts of your medical history, such as chronic conditions, major surgeries, and emergencies
- b) Example: I had polio at age 5, I had a hospitalization two months ago for pneumonia, I have a chronic problem regulating my diabetes
- c) Don't tell the doctor about every case of measles, or a cold, unless the doctor asks. It might be important for him to know about the Chicken pox, if you have shingles, or if you get colds several times a every year, but not if you had a cold once three years ago.

3) Current Health status

- a) Review the problems that you are currently having, like the chronic problems mentioned in #2, but your problems associated with it
- b) Examples: New weakness, I am having problems breathing at night and snoring, or I can't stop gaining weight, or losing weight
- c) List ALL of the medications you are taking, including vitamins, over-the-counter, health food additives, and intake of items that are unusual.
 - i) It would be beneficial for you to make a list and add and delete as your medications change, and keep the list handy for emergencies or new doctors.

4) Family and Social History

- a) Tell the Doctor if you have a history of Cancer in your family, or if you smoke or drink alcohol daily.
- b) Tell the Doctor if you have a problem or concern about depression or anxiety
- c) Tell the Doctor if you have a problem with being abused or hurt by anyone (Most Doctors will ask this of new patients)



5) Physical Exam

- a) General and/or focused Orthopedic Exam - looking for deformities, or other structural problems, such as joint instability or leg length discrepancy.
 - b) General and/or focused Neurological Exam, such as muscle tone and atrophy, reflexes, sensation, coordination, mental status and affect.
 - c) Provocative Pain Examination-checking to see if the pain can be reproduced, or when and how the pain occurs
- 6) Focused Evaluation of Gait and other body functions, such as with and without canes, or crutches and limping.

7) Diagnosis

a) This is the portion of the visit where the doctor gathers all the pieces of the puzzle that you have given him and it helps him figure out what to do with the problem that you came into the office to have solved. It is not at this first visit with a new doctor that he can address issues that have been going on for years, this visit is just to address your CHIEF complaint. It will take many visits and tests to deal with issues that have degenerating over years. Make sure to tell a new doctor that you would like to build this relationship to deal with Post Polio, or any other chronic problem, so that the Doctor will be able to make the appointments with specialists, order lab tests and other tests that he will need to make an accurate diagnosis. Doctor's are trained to make each diagnosis on their own, with their own observations, and not rely on second-hand information, or information related by patients. No matter how intelligent or smart the patients may be. This is part of the process that is drilled into them during medical school and their practices.

8) Recommendations

- a) The Doctor will set up several things if more information is needed, such as lab studies, specialists, EMG tests, Pulmonary function studies, sleep studies, or Physical Therapy.
- b) Preliminary Goals will be set and discussed with you, so that you both agree on the plan. There will be short term goals (Use orthotics, exercise, physical therapy)
- c) There will be long term goals, such as sleep studies, pulmonologist tests and evaluation, weight loss plan.
- d) The Recommendations are ALL part of the treatment plan. If you disagree with the Doctor, tell him that you don't think you can follow the plan and why. Do not agree, and then not follow the plan, or try to change the Doctor's mind about a recommendation.
- e) This is not the time and place for his "education". If you feel that his plan is not correct, you can tell him that you would like to send him some information to review, or tell him that you don't think you can follow his advice. You want to have a partner in your healthcare, you don't want to create the idea that you are more knowledgeable than the doctor. The time to talk to the doctor about your "knowledge, or information that he does not have, is after he has had a chance to read the information you gave him, at another visit made specifically for that purpose. Most doctor's are given 5-15 minutes per patient, and if they are prepared, they will be able to read the information you gave them, and give you their knowledgeable input.



**A new update on Dr. Selma Harrison Calmes
article on Anesthesiology for Polio Survivors.**

Dr. Calmes has updated her important information about Polio survivors and included the latest research into anesthesia and the polio survivor. Check out www.Post-polio.org

Post-Polio Thoughts

Nancy Baldwin Carter, BA, M Ed Psych, Omaha, Nebraska, (n.carter@cox.net)

HOME SWEET HOME?

FACT: 90% of Americans polled said they definitely do not want to live in a nursing facility.

FACT: 80% of Americans polled want to continue living in their own homes until the end.

With the total of elderly citizens on the upswing, innovative choices are beginning to pop up, attempting to offer new ways to allow us to live where we want to as age and disability continue to do their number on us. Now comes PACE (Programs of All-inclusive Care for the Elderly), one more entry in community-based living that may keep many of us out of institutions. PACE is a government-inspired program, decades in the making, and now individually operated by a variety of non-profit companies throughout the country.

Check www.npaonline.org to see if your state is one of the 30 currently involved.

Who Can Join? Those of us who are 55 or older and living in a PACE-served area can join if we meet our state's Medicare and Medicaid nursing home level of care guidelines. This is determined by the 11-member Interdisciplinary Team in each local PACE area.

How Does This Work? Participants sign a contract allowing PACE to provide services. PACE is Medicaid and/or Medicare funded on a per person basis, rather than on a fee-for-service basis. Participants not on Medicaid would have to make up the difference, paying a monthly charge, plus a hefty Part D fee. Joining PACE dis-enrolls us from other health insurance, and PACE becomes our health and Part D insurer.

PACE also provides doctors, nurse practitioners, therapists, and other participants of a health-care team to work with us, rather than using the health professionals we had before. Members are free to leave PACE at any time, and PACE social workers will help with the transition of finding a doctor, health and medicine insurance, and other care and services.

What Do We Get? Most of us get to live in our own homes. A large part of PACE activity centers around an Adult Day Center, to and from which participants are regularly transported by PACE. Here we might find a chapel, TVs, a coffee bar, and a dining facility, all comfortably arranged for maximum sociability. Also at the Center is a Health Clinic, designed to provide primary care, dental and podiatry care, therapists, and all the exam rooms and equipment necessary at that facility. Certain types of in-home care and services are provided, as determined necessary by the Interdisciplinary Team on a person-to-person basis. They decide what is needed according to the impact this has on our health. Participants requiring more care (about 7% now) go into nursing facilities, still under the auspices of PACE.

And Others? Family caregivers are not forgotten. At the Center, PACE offers support groups and even training in how best to deal with us in our homes. Overworked caregivers appreciate a much-needed break during the day while members are at the Center.

PACE presents an option. If we like it, it's ours. If this isn't our cup of tea, we move on to the next possibility.

Many of us who have spent a lifetime with disability might hope for more independence than I see in PACE. Personally, I'd like to be the one who decides what I do with my day—and with whom I do it. I want staying in my home to mean more than merely sleeping here—I want to *live* here. Eat here, Watch TV here. Get my laundry done here. I want my regular doctor and my usual pals. Give me my phone and my computer and let me soar. I don't want to be left to rely upon the kindness of volunteers among my family and friends to get my house cleaned or my personal needs met. There must be a way.

We have tough choices to make. You know: "Old age ain't no place for sissies."

Nancy Baldwin Carter, B.A., M.Ed.Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.

Source: Post-Polio Health International (www.post-polio.org)

Take A Shot At Changing the World - Carl Kurlander | Bill & Melinda Gates Foundation

Posted by Carl Kurlander on May 03,2011
Take A Shot At Changing the World

For two decades, I worked as a screenwriter on films and television. But in 2010, I was moved to produce a film featuring first-hand interviews telling the story of Dr. Jonas Salk and his research team. I wanted to tell the story of how they – along with the entire nation – pulled together to conquer the most-feared disease of the 20th century: polio.

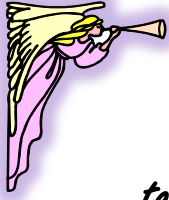
Then, six months ago, we launched a related video contest to engage a new generation to realize what is possible when we all pull together to change the world. On World Polio Day, October 24 2010, this innovative viral video contest, “Take A Shot At Changing The World,” was launched by the Steeltown Entertainment Project, working in partnership with local Rotarians, educators, and the Bill & Melinda Gates Foundation. When this digital media initiative was launched, most students in Western Pennsylvania had little knowledge of what polio was, much less that it still existed in the world or that they could help in ending the fight to rid the world of this dread disease once and for all. It is easy for us to forget just how far we have come, or for us to realize just how close we are to eradicating polio from this planet. But by April 12, 2011, the 56th anniversary of the world’s first polio vaccine being declared “safe and effective”, 265 middle school and high school students from around Western Pennsylvania had made 79 short films which connected the development of the Salk vaccine with present day efforts (by groups like Rotary International and the Bill & Melinda Gates Foundation) to make the world polio free. Over 12,500 votes were cast for the best high school and middle school videos, and a panel of judges also selected their favorites. The grand prize winning video receives \$5000 split between the young filmmakers and their schools, and the video gets posted on the Gates Foundation website. As you can see from the film below, these students created moving, inspiring pieces that we hope will not only help raise awareness of the importance of polio eradication and funds for www.rotary.org/endpolio, but also will remind us all that, together, it is possible to change the world.

For more information on the "Take A Shot At Changing The World" contest, please contact poliocontest@steeltown.org or Carl Kurlander at carl@steeltown.org.

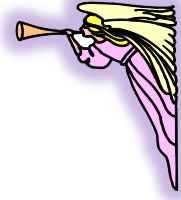
More Posts on: Polio-Carl Kurlander was a screenwriter on films (“St. Elmo’s Fire”) and television (“Saved By the Bell”). Now, he is the executive producer of the non-profit Steeltown Entertainment Project.

Contributions and Donations

Joseph Duchene
Patricia Lamb



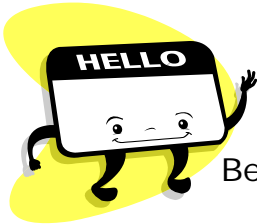
Condolences to the families
from Polio Epic,



to all the families and friends who have lost a loved one

Charlie Minner, May 12, 2011

Betty Pudloe, April 20, 2011



HELLO and WELCOME to our NEW MEMBERS
Be Sure to meet and get to know our new members!

Roy Gardner – Tucson, AZ

FROM THE TREASURER...

The end of our 2010-2011 fiscal year is coming to an end August 31, 2011. That means as of September 1, 2011 your dues will be applied for the 2011-2012 fiscal year. CHECK the date on the address label; if it says 2011, you are paid through August 2011. If it says 2012 then you are paid up!

Keep POLIO EPIC Up-To-Date:

Are you moving? Are you going to a cooler climate for the summer?

Please let us know...

- If you know you are moving, please contact us with your new address.
- If you are seasonal (snow birds), please remind us of your summer address and let us know approximately when you are leaving and when you are due to return.
- If you know you will be away for awhile and wish not to receive the newsletter for that time, let us know, too.

THIS WILL HELP POLIO EPIC KEEP OUR RECORDS UP- TO- DATE

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



Charles Anthony Minner (Charlie "Lite")

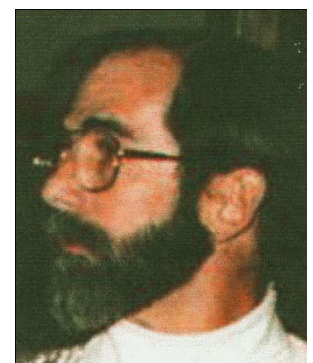


Charles Minner died on May 12, 2011 in Tucson, Arizona at the age of 64. He was born July 30th, 1946 in Jamaica Queens, New York. He contracted Polio in 1952 and afterwards paralyzed in both legs. Despite his physical limitations, he was known to enjoy playing golf, Tennis, Basketball, Baseball, and Football. Most years of his childhood were spent in iron lungs, body casts, surgical wards and a Catholic children's hospital. He studied English Literature at the University of Arizona Class of 1968. All while on crutches, he was a member of the Gymnastics team(Rings), a Service Fraternity, and hiked and camped throughout the Tucson Mountains. Charlie also helped entertain at the Cup, a coffee house in the campus Christian Center of the University of Arizona where he played guitar and sang.

Charlie worked as a microbiologist and his work published in the *Journal of Microbiology*. He earned a degree in nursing from Pima Community College in 1977, masters degree in Special Education at the University of Arizona in 1971, and worked as a CCRN (Critical Care Registered Nurse) at El Dorado Hospital, University Medical Center, and St. Mary's Hospital until his retirement in 1990. He built his own ultra-light aircraft, glider, his home in the mountains of Tucson and others. He was a master craftsman. Charlie loved to fly Gliders, watch Soaring and work at Soaring Contests. He also loved sailboats, bird watching, gardening, sports, University of Arizona Wildcats, and was a volunteer in the Children's play room at the University of Arizona, Medical Center

He started evidencing Post Polio Syndrome in 1986 and finally went into a wheelchair in 1998. Charlie was a member of the Tucson Post Polio Support Group, Polio Epic, Inc., beginning in the 80's and served the last 12 years as an board member. Charlie served as a member of the Soaring Society of America Board of Directors. He traveled across the country every summer and was well-known as a competition director, soaring contest worker and advocate for safety.

He is survived by his wife Michelle (Micki) Minner, and two daughters Melissa and Samantha Port-Minner. He will have a ceremony of Ashes scattered from a glider over El Tiro Gliderport in Marana, Arizona on May 21st. There will also be a ceremony May 24th, with Mass said at St. Rafael's in Long Island, New York, with a graveside service at the family plot in Holy Rood.



WE NEED EACH OTHER
From RICHES OF THE
HEART
by Steve Goodier

Many living things need each other to survive. If you have ever seen a Colorado aspen tree, you may have noticed that it does not grow alone. Aspens are found in clusters, or groves. The reason is the aspen sends up new shoots from the roots. In a small grove, all of the trees may actually be connected by their roots!

Giant California redwood trees may tower 300 feet into the sky. It would seem that they would require extremely deep roots to anchor them against strong winds. But we're told that their roots are actually quite shallow- in order to capture as much surface water as possible. And they spread in all directions intertwining with other redwoods. Locked together in this way, all the trees support each other in wind and storms. Like the aspen, they never stand-alone. They need one another to survive. People, too, are connected by a system of roots. We are born to family and learn early to make friends. We are not meant to survive long without others. And like the redwood, we need to hold one another up. When pounded by the sometimes vicious storms of life, we need others to support and sustain us.

Have you been going it alone? Maybe its time to let someone else help hold you up for awhile. Or perhaps someone needs to hang on to you.

COME OUT TO YOUR NEXT SUPPORT GROUP MEETING.

(Source: Current Tides of the Atlantic County Post-Polio Support Group, January 2004)



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

Answers to the CON quiz

- | | |
|----------------|------------------|
| 1) Concentrate | 11) Conduct |
| 2) Conquer | 12) Conduit |
| 3) Concert | 13) Conflict |
| 4) Concern | 14) Confetti |
| 5) Conceal | 15) Condiment |
| 6) Concorde | 16) Conifer |
| 7) Conclude | 17) Condor |
| 8) Concur | 18) Congregation |
| 9) Condemn | 19) Congenial |
| 10) Condense | 20) Confiscate |