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The Night the Mothers Marched on Polio

by Tom Hoover

The evening of January 16, 1950, you would have noticed nothing out of the ordinary. It was an average Monday evening in Phoenix. At 6:59 p.m., all was quiet. But at the stroke of 7, Phoenix suddenly became a city possessed.

Every fire engine was rolled out in front of the station house and the sirens turned up to full shriek. Huge searchlights came on. Filling the darkening sky. They came together to form a cone of light over the city. Almost at the same instant tens of thousands of porch lights flicked on, the whole city was a glow.

To a casual visitor all this must have seemed very strange behavior on the part of a normally well-ordered town.

But there was a reason for all this commotion. It was the story of a community responding en masse to a great host of mothers and a community opening its heart in a way in which few communities ever had before.

On January 16th, Mothers spread out throughout the valley and collected nearly \$48,000 in one hour. In 1952, the Mother's March on Polio had become a national fundraising event. And that year over \$10,000,000 dollars were raised to fight polio. In 1954, Jonas Salk developed the vaccine for polio.

On January 16, 1950 a community fought back. Mothers fought back. Phoenix fought back. Shortly, after the success of the first Mother's March, a 16mm black and white film was developed that recreated the first Mother's March.

(Continued on page 3)

POLIO ECHO

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Tom Hoover

BOARD MEETINGS

All meetings are open to the public. Anyone wishing be on the agenda should notify the president, Brad Dowden, at (480) 987-2571 in advance.

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

2011 MEETING SCHEDULE

Tuesday, September 20—Board Meeting at the DEC.

Tuesday, October 18—Board Meeting at the DEC.

Saturday, October 22—Joint Meeting with Polio Epic in Casa Grande "Mimi's" Restaurant at 11:30 am

Tuesday, November 15—Board Meeting at the DEC.

Saturday, Dec. 3 — 11:30-2:30 pm The Annual Holiday Luncheon / Meeting at DEC

This film was then distributed across the United States to show people how to organize their communities.

Tom Hoover is the son of Charley Hoover, creator of the Mother's March on Polio. Tom contracted polio shortly after he arrived in Phoenix in 1945. Currently living in Tempe, AZ, he owns a marketing company. He graduated from the University of Arizona and Thunderbird International Management School. He has been involved with several non-profits among them Phoenix Youth at Risk, Habitat for Humanity Valley of the Sun and Educational Endeavors.

Tom Hoover will be the featured speaker at Polio Echo's Annual Meeting in December.

Post-Polio Wellness Retreat

Big Bay, Michigan

Sept. 12—17, 2011

Our own President, Brad Dowden, will be attending and we're looking forward to his report when he returns.

Robert J. Lynch, F.AIA and Architectural Accessibility

I am an example of "the right person in the right place at the right time" during the beginning of Accessibility, back in the '50s and '60s. For that, I was elected to the College of Fellows of the American Institute of Architects in 1977, "for the pioneer work he spearheaded in creating national standards of Accessibility through the AIA, resulting in the creation of the federal Access Board and the federal laws: The Americans with Disabilities Act of 1990 and the ADA Accessibility Guidelines of 1991."



Your editor of the Polio Echo newsletter asked me to recount: "How did I become an architect starting from inside the iron lung?" and "What brought about federal laws requiring Architectural Accessibility?"

Just after my ninth birthday I contracted

To contribute news to Polio Echo News call (480) 820-3358 or E-mail: ringhofer@aol.com

Polio, was paralyzed below the chest. This was before the Polio vaccine and before Sister Kenney's treatment. The standard treatment was to put both legs in full-length plaster casts for several months. Later, while receiving daily therapy, my parents arranged for me to go back to public school by hiring a full-time attendant. He dressed me, carried me down to breakfast then drove me to school, carried me to class, drove me home for aquatic therapy and exercises, then put me to bed. This was my routine from the 5th grade until I was graduated from high school. Before World War II, wheelchair accessibility in public buildings was virtually non-existent - especially in public schools, so being carried was essential.

My attendant, Walter Burke, had a profound influence on me - as it proved years later - because he had just finished several years in the "CCC," the Civilian Conservation Corps. He described how they learned to build wood bridges from trees they chopped down, how they made stone retaining walls out of available stones, how the discipline of the Corps had such good influence on these kids during the depression, and how working to make a better environment made for a better society. During summer vacations in my college years, my hobbies became making my own wood furniture, making stone retaining walls and shaping flagstones to make walks and patios while sitting on the ground. Years later, at the University of Notre Dame,

I took courses in the graduate school of sociology, studying Community Planning, and this reinforced the things Walter shared with me.

When I became an architect I tried to marry my interest in Community Planning with Architecture, resulting in my adopting Accessibility as my specialty, making buildings more convenient for people with disabilities - a natural for me.

By coincidence, a month before high school graduation in 1944, my balance and strength developed to where I could lift myself up and down stairs wearing hip-length steel braces and using crutches. At the same time, Walter was drafted into the army (World War II), and I was without help. My father wanted me to go to college but I was obviously not ready. He bought me a motor scooter to get around and sent me to a prep school to learn to live on my own, "sink or swim." That year was so difficult that I found college a lot easier. Not easy, just easier.

I chose the University of Notre Dame, thinking the mid-west was all flat land and probably had few steps. How wrong I was! The old buildings had a flight of stairs up to the first floor and 29 steps to each floor, and most of my classes were on the second or third floors. In those days college buildings did not have elevators, and I needed great strength to get to classes in different buildings each hour, so I took up weightlifting, and soon became a

champion in my weight class, bench-pressing nearly 300 pounds! I was lifting more than twice my body weight!

By the end of my third year in Arts and Letters at Notre Dame, majoring in Philosophy, I began to wonder what I would do when I graduated, so I went to the career-testing department and they assured me that I was talented to be an architect. On their recommendation and with my father's approval I signed up. The registrar said "By the way, starting next year Architecture will be a five-year course."

Clearly, I was just doing what my parents expected of me - study and work hard. My father's viewpoint was "For someone so disabled, he should become super-educated." So that's what I did. I had 22 1/2 years of formal education, not counting Kindergarten. I was now able to earn a living doing what I was physically able to do - work at a drawing board - and mentally, to develop my talent. This is the message I share with any disabled kids I encounter: "Do what you can, and work hard at it!"

Why did I choose Accessibility as my niche? At first, I didn't choose it, didn't even think of it. After graduation I got a job as draftsman at one of Boston's finest architectural firms, a 49 year-old company that had only one client in all that time - the Catholic Church. In those days the Church had lots of money and wanted only the best architecture with the best materials and art work and de-

tails, and this is how I learned to design.

During my interview for the job, the head of the firm told me they didn't need any architectural draftsmen; what they needed was structural draftsmen. I told him that I also took all the courses leading to a degree in Architectural Engineering, but that they canceled the entire curriculum in my last semester. I worked for one year as a structural draftsman and designer. Then I was moved to the architectural department.

But to get to work in Boston I had to park close to the office building, and put a quarter in the meter every hour. This was unrealistic, so I asked the metermaid to overlook my violations because "staying at my drafting board was a condition of my employment." Soon we got a new metermaid who mailed a ticket home every day until I had 33 tickets and a summons to court. I lost my case, but a group of disability advocates took up my cause, and we wrote a bill for the state legislature to create the Massachusetts Architectural Barriers Board, and the bill passed! The bill we wrote simply asked to create an Access Board with the power to write and enforce its own regulations. This proved to be revolutionary, and led to compliance boards across the country, with state and federal laws to enforce them. I was appointed to serve on the Board as its only architect, and I was soon voted its Chairman. We had legal and enforcement power over all construction in Massachusetts, with Subpoena power,

authority to fine violators of our Regulations \$1,000 a day, and even to withhold an architect's license if necessary to achieve compliance. We were occasionally challenged, but our attorney was the State Attorney General. As Chairman I conducted the public hearings of complaints. By the time we had completed 1,000 cases I re-wrote our Regulations to reflect the decisions of the Board.

I then went to Washington to ask the American Institute of Architects' Board of Directors to adopt Accessibility as a national issue. The AIA agreed by creating a committee of 55 architects to study this new issue and to produce the AIA standards for building accessibility. I was appointed their Chairman. We researched and wrote the first national standards which were published by the American National Standards Institute (ANSI), called "A-1 17.1-1980." It has now been improved and expanded to become their 2008 edition.

To become effective, the standards had to be adopted into law by each state. When every state had an official standard of accessibility, but which differed slightly from other state standards, Congress created the federal Access Board to research and write the definitive standard, and authorized the Department of Justice to enforce the "Americans with Disabilities Act" - called the ADA law (of 1990), and the ADA Accessibility Guidelines (updated 2010). Making buildings accessible by invoking the Guidelines became my avocation, and it all started with my

33 parking tickets in 1954.

Compliance with the ADA law requires architects to design in full compliance with the ADA Guidelines. I soon realized that architects, as a group, do not understand the Guidelines well enough to protect themselves legally, so I taught a college course for nine semesters, until finally including my lectures in a 625-page book with more than 700 photos, entitled "EASY ACCESS, the Encyclopedia of Accessibility."

Robert Lynch is a long time member of Polio Echo who lives in Phoenix and has served in many capacities in the group.

Taking Pains after Surgery **Polio Tips 'N' Techniques**

by Dr. Richard Bruno

Polio survivors' most troublesome problem after surgery is pain control. Studies have shown that surgical patients are often under medicated for pain.

Under medication is a serious problem for a post polio patient since two studies have shown that polio survivors are twice as sensitive to pain as those who didn't have polio, increased pain sensitivity apparently being caused by poliovirus killing the body's own morphine-producing cells.

So, while for Anesthesia the "Rule of 2" is that polio survivors need the usual dose of anesthetic divided by two, the "Rule of 1" for Pain is just the opposite: Polio survivors need two times the dose of pain medication for twice as long.

This rule applies to dental procedures, too, since polio survivors may need two or more times the dose of Novocain. After surgery, polio survivors should have a PCA pump that delivers pain medication on demand when the patient pushes a button. And, doctors need not worry that polio survivors will become addicted to pain medication. Polio survivors are known to be extremely stoic and are not likely to abuse or become dependent upon pain meds, even narcotics.

There is also a "Rule of 2" for recovery after surgery. Polio survivors need at least twice as long to recover as other patients. In keeping with insurance companies' and HMO's wanting to get'em up and move'em out, there is a tendency to get polio survivors up and walking almost immediately after surgery. This is not a good idea. When polio survivors reach the nursing floor, they may still be very sedated. Since polio survivors need a very clear head to be able to control their polio-affected muscles to stand and walk, a fuzzyheaded polio survivor is at serious risk for falling.

Even with a clear head, anesthetics or other drugs may have temporarily weakened or even paralyzed the cut muscles (like abdominal muscles) that substitute for muscles paralyzed by polio that allow polio survivors to stand and walk. Polio survivors may also have low blood pressure after surgery that could itself cause light-headedness, fainting and falls.

Polio survivors should get up slowly, first sitting up in bed, than sitting with feet dangling, then getting into a bed-

side chair with assistance, then standing with assistance and finally walking with assistance and appropriate assistive devices. Gentle physical therapy is helpful to maintain range of motion and for stretching, since polio survivors are prone to developing painful muscle spasms if they are not moving. Physical and occupational therapists need to know that polio survivors have learned to be very aware of what their bodies can and can't do. They are the best judges of when they can safely move, stand and walk.

All hospital staff need to be aware that many polio survivors have emotional difficulty merely being in the hospital, having insomnia, anxiety and even have panic attacks. These symptoms are easy to understand when it is remembered that as young children, polio survivors were ripped away from their families and admitted to rehabilitation hospitals for months or even years. Post-polio children underwent multiple surgeries and painful physical therapy, procedures administered often without explanation and certainly without their consent.

Many post-polio patients have had multiple experiences of psychological, physical and even sexual abuse at the hands of hospital staff. Questions or complaints about painful and frightening therapies were not infrequently met by staff anger or punishment. Necessary nursing care could be withheld for no apparent reason. Patients report having been locked in dark closets overnight when they asked questions, spoke out or cried.

(Continued on page 10)

CHAPTER NEWS

PHOENIX CHAPTER (Central Valley) meets on the second Thursday of each month in the Mesquite Branch of the Phoenix Public Library in Paradise Valley Mall, 4525 Paradise Village Parkway North, in Phoenix. The meetings usually begin at 1:00 pm and conclude around 3:00 pm. The meeting room is near the entrance to the library.

The next meetings will be on Thursdays, September 8th, 1-2 pm and October 13, 1-3 pm.

EAST VALLEY CHAPTER meets, and eats, at 1:00 pm on the third Wednesday of each month at selected restaurants throughout the east valley, which are designated in the newsletter and by electronic mail, if you have notified Jane Crawford to send reminders.

On Sept 21, members will meet at The Egg and I 2625 W Queen Creek Rd UNIT 101, Chandler, AZ, 85248. This is on the S side of Queen Creek Rd between Dobson & Price.

On Oct 19, members will meet at Islamorada Fish Co. located inside the Bass Pro Shop at 1133 N Dobson, Mesa.

To make reservations, or get more information, contact Joan Derenzis (480) 895-8238, or Jane Crawford, (480) 899-5857.

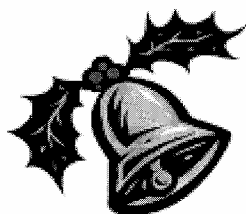
SCOTTSDALE CHAPTER meets on the first Thursday of each month, from 11:30 to 1:30, usually at the Scottsdale Public Library at 3839 N. Drinkwater Blvd. in Scottsdale in the Gold Room.

Carol Pranka is in the hospital at press time so chapter meetings are yet to be determined.

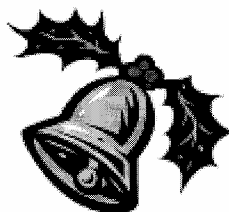
POLIO ECHO HOLIDAY LUNCHEON / ANNUAL MEETING AGENDA

Dec. 3, 2011

- 11:30 -11:55 am Registration/Socializing
- 11:55 -12:00 pm Welcome / Opening Remarks
- 12:00 -12:45 pm Meal Service
- 12:45 -1:15 pm Speaker: Tom Hoover
"History of the Mother's March of Dimes in Phoenix"
- 1:15 -1:20 pm Spirit of Polio Echo Award Presentation
- 1:20 -1:35 pm Annual Business Meeting
 - Financial Report
 - 2012 Director/ Officer Nominations
- 1:35 -1:45 pm Door Prizes
- 1:45 -2:00 pm Socializing



Holiday Luncheon



and Annual Meeting

Join us

Nina Mason Pulliam Conference Center
of the Disability Empowerment Center

5025 East Washington Street

Phoenix , Arizona 85034

Dec. 3rd 2011

11:30 AM

Choice of

Traditional Turkey dinner

**Sliced roasted Turkey (all white meat)
with Giblet Gravy.**

Or

Baked Ham with Sweet and sour Glaze

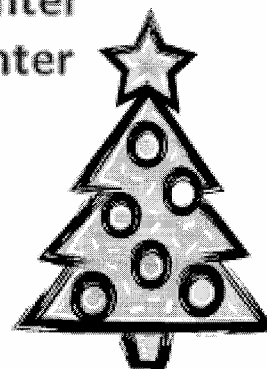
**Cornbread stuffing, Green Beans Morocco, Mashed
Potatoes or Sweet Potatoes**

Roasted Red Potatoes

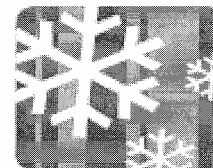
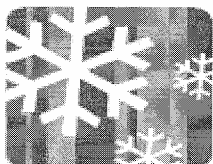
Tossed green salad and Bakery fresh rolls

French Strawberry Cream Cake

Coffee and iced Tea



Polio Echo



Polio Echo Holiday celebration
Fill out and mail with check by 11-15-2011 to:
Polio Echo Annual Luncheon c/o Roger Buel
4202 E. Greenway Lane
Phoenix, AZ 85032-8111

Please reserve the following number of tickets:

 ___ Number of Turkey Lunch(es)
 ___ Number of Ham Lunch(es)
 ___ Lunches Total @ \$15.00 = \$ _____

Check included made payable to Polio Echo. Do not send cash

Your Name _____
Phone Number _____
Names of your guests: _____

Nina Mason Pulliam
Conference Center
of the
Disability Empowerment Center
5025 E. Washington

Phoenix
Washington
202
143
Hohokam
Tempe
I-10

Many post-polio children were slapped and some were actually beaten with rubber truncheons by physical therapists to “motivate” them to stand-up and walk.

It is not surprising that polio survivors can be terrified of again becoming powerless “patients” who are at the mercy of hospital staff. Nursing staff’s appreciation of the childhood trauma polio survivors experienced at the hands of medical professionals, and taking a moment to actually listen and respond to the real needs—both physical and emotional—of the adult post-polio patient, will go a long way toward making the polio survivors feel safe and more comfortable during their hospital stay.

Dr. Richard L. Bruno is Chairperson 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 (NJ) Hospital and Medical Center.

Please take the time to complete the registration form below. If you cannot afford the membership fee, you can still receive the newsletter. We need everyone on our mailing list to send in their registration. Memberships are due in January for the current 2011 calendar year. If you have questions about membership status, contact the Treasurer, Roger Buel, at (602) 493-7242.

POLIO ECHO MEMBERSHIP REGISTRATION & RENEWAL FORM

Name: _____ Date _____

Address: _____ Zip: _____

Phone (____) _____ - _____ Cell (____) _____ - _____

E-mail address: _____@_____

Emergency Contact Name & Tel # : _____ () _____

I am enclosing \$10.00 for my 2011 dues donation.

I am sending an additional donation in the amount of \$ _____

I am enclosing \$2.00; please send me a membership pin.

I am unable to pay membership dues at this time, but would like to be a member and receive the Polio Echo Newsletter by mail.

I do not wish to be a member, but am sending a (tax deductible) donation of \$ _____

Please remove my name from the Polio Echo Mailing list. (The Polio Echo News is available on our web site: (www.polioecho.org))

Make checks payable to Polio Echo and send to:

Polio Echo, P.O. Box 61024, Phoenix, AZ 85082-1024

KEEP US INFORMED

If your Name, address, telephone number, or Internet address has changed, please up date your information with us. Either call Jane Crawford at (480) 899-5857, email her at janwec94@q.com, or use website www.polioecho.org.

Annual contributions help to educate the public and health care community concerning polio. We respond to the needs of individuals who suffer from post-polio syndrome, through group meetings, educational programming, newsletters and website. Polio Echo is a 501(c)3 non-profit Arizona corporation. All contributions and voluntary dues are tax deductible.



P.O. Box 61024, Phoenix, AZ 85082-1024

**FREE MATTER FOR THE
BLIND OR HANDICAPPED**

Address Service Requested



Funding of this Newsletter is made possible through a grant from the Phoenix Chapter of MARCH OF DIMES

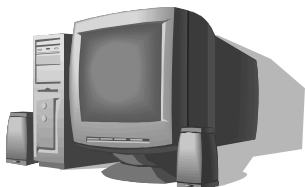
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Please address all correspondence to Tom Ringhofer, Polio Echo News, P.O. Box 61024, Phoenix, Arizona 85082. Telephone Number (480) 820-3358.

Polio Echo Website

<http://polioecho.org>

Newsletter available here



Polio Echo E-mail

polio_echo@polioecho.org



Information:

(480) 987-2571

If you have questions concerning projects or programs of the post-polio support group, please call our president Brad Dowden and leave a message. The person best able to serve you will call back.