

# **THE POLIO PERSPECTIVE**

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## **Polio-like illness mystifies California doctors**

A small number of children in California have contracted a polio-like illness since 2012, and doctors and public health officials don't yet know why.

Dr. Keith Van Haren, a pediatric neurologist at Stanford University's Lucile Packard Children's Hospital, told the Los Angeles Times that the illness is not polio, noting that all of the patients he studied had been vaccinated against the disease. However, Van Haren noted that in five cases he had studied, all of the children developed paralysis in one or more of their arms or legs, and none had recovered limb functions after being diagnosed.

The first case was reported in the fall of 2012, when a doctor requested polio testing on a child who had developed a severe paralytic illness. California health officials did not release to the Times the total number of cases reported. Van Haren told the paper that he was aware of approximately 20 cases in total. The median age of the children diagnosed is 12 years old.

The symptoms sometimes occur after a mild respiratory illness. Carol Glaser, leader of a California Department of Public Health team investigating the cases, said a virus that is usually associated with respiratory illness but which has also been linked to polio-like illnesses was detected in two of the patients. Other cases were reported in children who suffered symptoms that could not be linked to known causes like West Nile virus or botulism.

Glaser also told the Times that scans of the patients' spinal cords revealed damage patterns similar to those found in polio sufferers. Two children tested positive for enterovirus-68, which is usually associated with respiratory illness, but has been linked to polio-like illnesses as well.

Glaser encourages local physicians and health officials who are aware of similar symptoms in children to report the cases to her team.

## WHEN "POLIO ISN'T 'POLIO'.

*By Dr. Richard Bruno*

Do doctors learn nothing in medical school, nothing about the history of medicine or what's happening in other countries that can affect Americans?

Remember "polio" merely means "gray" in Greek and refers to neurons NOT covered with insulation (myelin). So "poliomyelitis" simple means inflammation of "gray neurons " in the spinal cord, not the CAUSE of the inflammation.

In India, as cases of "poliomyelitis" due to the 3 polioviruses decreases, the number of cases of "poliomyelitis" caused by other viruses -- e.g., Coxsackie viruses that damage the brain, spinal cord and HEART and Enterovirus 71 that some call poliovirus Type IV because its effects are so similar to the 3 polioviruses -- have skyrocketed to 60,000 cases a year! So, polio vaccination has traded 250,000 cases of paralysis due to the 3 polioviruses in India for 60,000 cases of paralysis due to Coxsackie and other enteroviruses. So, the anti-polio campaign is getting rid of a virus for which we have a vaccine but allowing to run rampant viruses that paralyze and kill at 4 time the rate of the polioviruses for which there will never be vaccines.

So there are many polioviruses other than our friends polioviruses Types I, II and III that cause spinal cord and brain neuron damage plus additional symptoms different than Types I, II and III. These California and UK cases are apparently due to Enterovirus 68, (which causes a respiratory illness plus spinal cord damage.

By the way, British researcher the late Betty Dowsett has evidence that Chronic Fatigue Syndrome (or ME in Canada and the UK) is cause by a Coxsackie virus damaging the brain activating system, as does the poliovirus.

Check the Post-Polio Library at [postpolioinfo.com](http://postpolioinfo.com) under FATIGUE for more information about "polio-like viruses" (as Albert Sabin used to call them) and the damage they cause.

## **My Recollections of Having Polio**

*By Robert W. Hamilton*

It was 1949, and parents were panic stricken over the threat of Polio. The Sister Kenny Foundation, and the March of Dimes, were looking for new methods of treatment, and raising money to fund research. At that time, it had not even been established that Polio was caused by a virus. Major Medical insurance had not been “invented”, but insurance companies were selling policies called “Dreaded Disease Coverage”. These policies covered “the top ten” cancer, leukemia, polio, and 7 other illnesses folks were getting to die. They provided \$100,000. In coverage over one’s Blue Cross. Dad was in the insurance business, and prudently made a \$25.00 investment. By the time I was through, the limit of this policy had not been exhausted.

I returned from summer camp, and started the 4<sup>th</sup> grade in September, 1949. I was 9. A few weeks into the school year, the family took our 1939 Plymouth to visit Grandpa and Grandma Gonnoud in Bay Ridge, Brooklyn. I don’t remember anything prior to the ride home, but I distinctly remember riding on the floor of the rear of the car on the way back, and not being unable to stay awake. When we got home, I was unable to keep my head up to watch Howdy Doody, and my dad carried me to bed. The next day, the Doctor came, (they still made house calls in those days), and after an examination, I was on my way to Bergen Pines, the County Hospital.

The Polio ward was building 5 of Bergen Pines. Initially, I was put into a private room, and given a Spinal Tap (lumbar puncture). This is a 2” long needle, which to me looked like 6”, inserted through the spine, to check for the disease. The first spinal tap didn’t work, and I heard the nurses plotting to return for a second stab. I remember crawling out of the bed and hiding in the closet, but they got me anyway, and confirmed my affliction. This entitled me to full admission to the polio club.

Building 5 was a 2 story building with patients on the second floor. The grade floor had, in addition to building services, physical therapy rooms, whirlpool baths and a swimming pool (for therapy). Initially, I was in a 4 bed room, but the building quickly became overcrowded. We ended up with beds in the solarium, beds in the hall, and extra beds in all the rooms. Visitors were not allowed in the building to see you. There was a balcony around the perimeter of the second floor, and when you had a visitor, your bed was rolled over to the screened window, and you chatted.

I always thought that the description of paralysis was a misnomer. Polio attacked the nervous system, and killed muscles. You were paralyzed in the sense that you couldn’t move, but not because you were rigid. You were just tired, and you had no muscle power. You are left with muscles that are literally gone, and other muscles that are

partially there, but cannot be built back up. I guess you could say that they are partially dead.

Although I did not know it at the time, shortly after I was hospitalized, my sister Cathy, age 8, was admitted. She had a form of Polio known as Bulbar, affecting the ability to breathe, and requiring the use of an "iron lung". This pressurized tank was supposed to allow the patient to breathe. Unfortunately, Cathy didn't make it, and passed away a few days after admission. Then my friend, Torkiele Petersen, came down with it, and Cathy's friend Joan Eisley. As far as I know, they both came through unaffected. At some point both my parents were admitted for observation, and, my dog, Ginger, was put to sleep.

They closed Kenilworth School, for two weeks, and Miss Alburty's class (my class) got a 6 week holiday.

I remember the "treatment"...oh, do I remember the treatment! Blood tests were required twice a day. The nurse would come in with this little gun, which shot a spike into your finger. Not really so bad, but once they used up your fingers; they started on the toes...then after the fingers healed, repeated the process.

Then there were the "HOT PACKS", an invention of Sister Kenny. I think they used this because water boarding had not yet been developed. I assure you that no one who has experienced these will ever forget them. Here's the deal. They roll a pressure cooker to your bed side, containing 16 x 16 squares of raw wool. They are steaming, hot to the point of scalding you. The nurse, using tongs, takes them out of the cooker, and, starting at your toes, wraps the squares around your entire body. This proceeds up to and around your neck. Then she leaves, and goes for a cigarette (they didn't have joints then), and waits for them to cool. Your body lays there in cold wet wool, and you can't scratch, because you do not have mobility in your limbs. She waits until you are as uncomfortable as possible, then returns with a new set of squares, heated in the cooker, and exchanges the packs. You actually root for her return and exchange, because the cold ones are more uncomfortable than the hot ones. I may be exaggerating, but, I believe this went on and on for hours.

Several times a week, I was rolled down for physical therapy. First they limbered me up. If you had lost the muscles in, say, the front of your thigh (quadriceps), then the muscles in the back would contract, and it was necessary to stretch them. For this they used two female sumo wrestlers. Initially, I was placed on a gurney, and made to touch my toes, without bending my knees. That was stage one. Stage two, was to touch my nose to my knees, and finally, stage three, to touch my nose to the gurney between my knees (assisted by 440 lbs of Amazonia). It is a shame I couldn't walk, because I probably had the requisite training for the ballet. This stretching was effective, because

well into my 40's I could still touch my nose to my knees with no difficulty. After the stretching, the gurney was wheeled to a figure 8 whirlpool tank, and I was lowered in with an electric hoist. The warm water was agitated with small outboard motors, and it was heaven. I don't know if any of these treatments did any good, but, I vote for the whirlpool tank.

We had some fun in the Ward. My parents gave me an ant farm. Really neat! The ants build their tunnels, I watched them, then everyone got to look for them after a nurse knocked the farm on the floor, and the room was infested. Oh well...no more ants allowed. Before polio, I was an athletic kid, and the sense of competition never failed. We had wheelchair races down the hall, and I was the horse to bet on.

And, after about 9 months I decided it was time to see the world. My bed was against the screen, and the screens were screwed to the window frame from the inside. I plotted my escape, as I removed all the screws. At this point I could sit up and crawl, but not walk. I got the screen off; the bed was at the same height as the window sill, and the catwalk just below the sill. I made it! Well, not really. I got about 100' and was nabbed. I think that led to the hospital staff's decision that I was cured enough to leave.

They called in Mr. Schuster, the brace maker. It took about a month to make a brace to fit my leg. It consisted of two steel rods with locking knee joints, strapped to the leg with leather bands, and inserted into a reinforced heel in my shoe. I was up and walking in no time.

Post polio, I have lived an active life. I didn't play most of the school sports, but I played golf, hiked, was a boy scout, and later a scoutmaster. Most of the people I know who had polio, while unable to do certain things, have not been held back by their disabilities. Dr. Bruno, a post polio guru, maintains that polio has made neurological impacts on the brain, altering the survivors personality to heighten the tendency to type A. True or not, I can attest that, while frustrated by my deficiencies, I have never been prevented from doing what I desire, and I am a Super Type A.

After leaving the hospital, I returned to school in the 5<sup>th</sup> grade. I wore my brace until the 8<sup>th</sup> grade, and then did fine without it. I caddied at Ridgewood Country Club, I set pins at Ridgewood Lanes, I worked before school at Ronnies Stationary store. I started riding my bike, with the brace, almost immediately after release.

About 20 years ago, I started having trouble with my leg. I went to the Kessler institute, and ended up with a new brace. I can walk without it for limited time, but it quickly becomes tiring and painful. Even with the brace, I continued to play golf for a few years, but, now, one day of golf, equals 3 days of exhaustion and pain, so that is out. I was principally affected in my right leg and left arm. My arm strength is absent in several areas, but not in others. Over the past few years, I believe that there has been

further deterioration of the arm. At 73, I am tired all the time, and physically tire very easily, but who knows how much that has to do with my polio.

In 1950 there were about 60,000 cases of polio worldwide. This is the number of reported cases, and only about 1% of those hit with the virus, actually come down with it. In 1954, Jonas Salk developed the “dead” vaccine, and in 1956 Dr. Sabin developed the “live” vaccine for polio, and since then there has been a concerted effort to eradicate the disease. I understand that in 2012, there were 233 cases worldwide....so, in truth, I am a dying breed.

Robert W. Hamilton

Ringwood, NJ

2-18-13

## **Energy Tokens and How They Can Help Manage Our PPS Lives.**

*By Hilary Hallam Boone*

First you have to work out how much each task that you do each day takes you. We are all different so whilst you can look at what someone else has done you will still need to do it for yourself and I can now do less per token than I could when I first started this idea.

Start listing the tasks that you have to do each day, like getting up and going to bed, getting dressed and undressed, whatever you need to do to eat meals, etc. Here are a few ideas.

Get up out of bed and going to bed at night

Dressed/Undressed – look at stages of dressing and undressing as well. Washing self, having a shower or bath, washing hair, shaving face and other bits if necessary

Shopping for and making and eating meals.

Any housework items that you have to and still need to do.

Driving to and doing appointments.

Attending Church or other club outings.

Take an average day of normal everyday stuff and you have 10 x your currency. \$10 or £10. So try spreading the funds out across the day...

Might be 50 pence/cents to get up and dress.

£1 or \$1 to drive in easy traffic for an hour but if you went on winding country road then 15 mins.

Take ironing how many items can you iron before you really should sit down and take a break. Say four items and then for you how many cents/pence can you spare out of your average day for that.

Once you have a basic idea of the length of time you can do each activity that you do over a week or month if you add in medical appointments then you can start charting.

7 days x 24 hours – you may have to get up a few times at night so you have to factor this in if you do. If not then just start from normal getting up to going to bed time.

First I start with the things I have to do like medical appointments. I block them in and then think how long will I need to rest before and after to cope with that. Block that out as resting time. Then add in the normal daily stuff. Now we all know we have to be clean to go to medical appointments but do we have to do it that morning? Should we have a bath or shower early evening the night before and just wash the bits they are going to look at on that morning. ;-)

Blocking times out to do and to rest soon shows you that if you want to do something that there is no room for can you modify what's already there. Can you ask someone to help you do all or part of another task?

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## **CURING VS HEALING**

*By Millie Malone Lill*

There is a difference between being 'cured' and being 'healed.' Being cured means your illness is gone. Being healed means you are now whole. Are you with me so far? Then let's apply this to PPS. It is incurable, so curing is not gonna happen. Healing? I think we can do that. I think we have done that!

Let's use myself as an example. I no longer have polio, so in that sense I guess I'm cured. However, I'm left with PPS so, in that sense, I am not cured. But am I whole? I think I am. Can I do whatever I want to do? Yes and no. Many times I can do it, but the cost is prohibitive in terms of repercussions. For instance, if a lightbulb goes, I can climb on a chair or stepladder and replace it. Chancy, because my hip is unreliable and so are my legs. Change that sentence to this: If a lightbulb blows, can I get it replaced? Oh, put it that way and the answer is yes. I call our maintenance man or, before I had access to a maintenance man, I could call one of my kids, grandkids, or neighbors. The result as far as the lightbulb is concerned is the same.

I could be bitter about not being able to dance, being tired all the time, not being able to be spontaneous. If I felt that way, while the polio is cured, I would not be healed. But I can still dance, if I find the right partner, one who is willing to stand in one spot and sway to the music or take a risk and dance with me in my power chair. As for being tired, I can take a nap whenever I want, sleep in as late as I like, and as far as planning ahead, I did that before PPS, too. So, looking at it that way, I am healed.

My children and grandchildren grew up with a disabled mother. No one gave it a thought. They were taught to offer help when they saw the need for it. My sons are tall...well, taller than my 5'2"...so they willingly got things for me that I couldn't reach. They did not expect me to suddenly become 6' tall, they just accepted that this was Mom and nothing wrong with that. They accepted my disability in the same way. If I couldn't do it, they could. If they couldn't do it, perhaps I could. We were a team. My grandchildren have also accepted me. My youngest grandson and I frequently went for 'walks' when we lived close together. He walked, I rode in my power chair. The dog went with us and none of us thought that I was not whole. I am whole. So are you. We don't need a faith healer to put his hands on our heads and pronounce it to the congregation. We can just accept that we are healed.

If we can accept ourselves as is, if we can remember that everyone has some limitations, we can be healed. I can't run, but my friend who can run cannot write a column on PPS. I can do that, but I can't sing. (I sing like a bird, but unfortunately, that bird is a crow.)

Everyone has something they cannot do. Everyone. The trick is to find that which we can do and go with it. Adapt. Accept ourselves as the imperfect human beings that we all are. Give ourselves credit for being survivors. We lived through polio when many did not. We are here, we can thrive, we are healed.

## **WEB CORNER**

For those who cannot afford vaccinations for their children:

<http://www.cdc.gov/features/vfcprogram/>

If you would like to share your polio story, Ray Jajko has the following to say:

We started a project here in New Jersey and I hereby (official type talk) extend an invitation to everyone reading this to play a role in making it bigger and better. Us Polio Survivors all have incredible stories of what we have gone through and accomplished.

Each of us has found ways of doing things by alternative means that we individually take for granted. We've adapted to life in ways that seem routine to ourselves but would surprise and even amaze many able-bodied people. Our feelings, thoughts, dreams, disappointments and other intangibles may seem unimportant to us as individuals, but describing these things in writing to others can be of tremendous help and inspiration. So, we started a website where your story can be posted for all to see. Please take a look at the website...a part of my own Polio life is there, as well as several others. I'd love to have each of you submit your own story...I promise we are not looking for pieces written by accomplished authors. Your own words express so much more than you may think. Finally, editing will be kept to a minimum...mostly taking out inadvertently included "bad" words. YOUR STORY IN YOUR WORDS. It can summarize your entire life or some little experience that had an impact on you. Anything from feelings to accomplishments...long or short. Please give it a look and submit yours (instructions are right there)... [www.mypoliostory.org](http://www.mypoliostory.org) You can hit the "skip" button, get right to the "Home" introduction and then to "Shared Stories". Photos via E-mail are welcome.

Living with Disability: Recognizing the Effects of Non-Polio Health Problems on Post-Polio Symptoms:

<http://www.cvppsg.org/library/livingwithdisability.pdf>

( If you do not already have Adobe reader on your computer, go here:

[http://download.cnet.com/Adobe-Reader-XI/3000-10743\\_4-10000062.html](http://download.cnet.com/Adobe-Reader-XI/3000-10743_4-10000062.html) and download it so you can read documents in PDF format. There is a version for iPads and Android tablets here: <http://www.adobe.com/products/reader-mobile.html>)

**The Spoon Theory:**

<http://www.butyoudontlooksick.com/wp-content/uploads/2010/02/BYDLS-TheSpoonTheory.pdf>

**How War and Terror Are Keeping Polio Alive Around the Globe:**

<http://thinkprogress.org/world/2014/02/19/3298081/war-terror-polio/#>

**The Olympics, Polio and the Medicine Wheel:**

<http://michaelwatsonvt.wordpress.com/2014/02/17/the-olympics-polio-and-the-medicine-wheel/>

Scientists Get Closer to Rejuvenating Aging Muscles:

[http://www.nlm.nih.gov/medlineplus/news/fullstory\\_144640.html](http://www.nlm.nih.gov/medlineplus/news/fullstory_144640.html)

Disabled people need preparedness for storms and such:

<http://news.shepherd.org/people-with-disabilities-need-preparedness-plan-for-storms-and-other-emergencies/#null>

Grow your own hip replacement in a decade:

<http://www.telegraph.co.uk/health/elderhealth/9858466/Grow-your-own-hip-replacements-in-a-decade.html>

## **A Little Bit of Humor**

### **That's My Story And I'm Sticking To It**

A man got really drunk one night in his local bar.

The bartender refused to serve him any more alcohol and told him he should be heading home.

The man thought this was a good idea so he stood up to leave but fell over straight away. He tried to stand up again but only fell over again. He thought if only he could get outside and get some fresh air he'd be fine.

So he crawled outside then tried to stand up and fell over again. In the end after falling over lots more, he decided to crawl home.

When he got back to his house he pulled himself up using the door handle but as soon as he let go he fell over again. He had to crawl up the stairs and managed to fall over onto the bed and fell asleep.

When he finally woke up the next morning his wife asked him why he was drinking all night at the bar.

He denied it but she said, "I know you were there..." he maintained his innocence until "...the bartender called to say you forgot your wheelchair again...."

