

Mornington Peninsula Post-Polio Support Group

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The aims and objects of our group are to gather and disseminate information on Post-Polio Syndrome and the Late Effects of Polio, and in any way we can to act as a support to each other. Any opinions expressed in this Newsletter are those of individual writers. We are not, and do not purport to be medically qualified. The information is only offered as a help to all in trying to understand "This Strange Beast" that has overtaken us. Please consult your Doctor before trying any non-prescription medication, or new form of exercise. Give any relevant information to your Doctor, and help them to help us! We do not necessarily endorse any products or services mentioned herein.

The next meeting will be held on Saturday November 14th. at 11-00am
at the Information Office, Mornington.

(Corner of Main and Elizabeth Sts. At the rear of the building.)

Polio Day at Darebin was worth attending. Dennis and I zoomed up Eastlink, listening to Audrey and I on the radio - terrible quality recording but Audrey was brilliant. The three of us who went to Warm Springs were keynote speakers and each gave a quite different interpretation of the trip. I told how I went looking for a magic bullet for us all and instead found that the information and well being came from us polio survivors. We are the ones who have found how to manage our conditions and how to support each other through the flashbacks and discomfort. Shirley Glance (Bayside) spoke about coming to terms with needing more aids such as wheels and about the wonderful support from carers. Liz Telford (PAC) gave an overview of the retreat while Mary-Anne spoke about the conference.

After lunch the pain management session by Steve de Graaf was packed, not everyone found it useful and decamped to the seat exercise session. There were free massages by students which were fantastic. Dennis and I shot through early to beat the traffic and made it home in good shape. Overall, hope next year more people will come. Eastlink has made a big difference to the journey. Having polio survivors as presenters attracted a big crowd - and that was most rewarding. – Fran.

At Saturday's meeting Fran and Audrey told about their experience of being interviewed by Disability Shop presenter Keith Horner for a polio day broadcast on radio 3RPP (fm 98.7 or 98.3 in parts of Frankston). Audrey told Keith about her childhood, of getting polio in 1929 and being away from home for many years. As the eldest of 10 children, when she finally returned home, there were siblings she had never met. Of course she talked about her mission to educate doctors about polio and post polio without much luck, but at 83, she is still trying. They both spoke about the late effects of polio, the symptoms and the benefits of coming together for polio day to exchange management tips. Fran spoke about children in India and Africa getting polio and how there appears to be little new treatment for them.

Discussion moved to Double Thomas splints. As usual we asked who was Thomas? About five members said they had been in Double Thomases. Dennis said children whose limbs hadn't been in plaster or splints twisted later as his did, requiring surgery. Dennis said he was treated in Manchester during the war, (1941), and the hospital was full of war casualties increasing the difficulty of getting focussed treatment.

Members talked a lot about being strapped or even padlocked into Double Thomases - this would be regarded as child abuse today. Audrey said she was shut in the bathroom for the day for escaping from hers. No wonder we are rebels today!

VALE JUNE MIDDLETON



Polio survivor June Middleton, who spent more than 60 years in an iron lung died on October 31 at her Thornbury care home, at the age of 83.

A family friend, Robyn Butterworth, told ABC Radio that June was an inspirational woman.

"She went through a lot but she had a great sense of humour, liked to tell a joke," she said.

"She just loved life, whatever was given to her she lived it day by day."

June marked 60 years in the iron lung on April 5, ever remembered in the Guinness Book of Records.

She celebrated with friends and with her devoted care dog Angel.

At the time, she described life spent in an iron lung for 16 hours a day in matter-of-fact terms, according to the Sydney Morning Herald on November 1.

"It's hard to explain but it's what you gotta do, make the most of it, get over the obstacles on the way," she said.

"It doesn't pay to be miserable," she said.

Her passion for dancing was one of the biggest blows dealt by the disease, she told the SMH.

But that wasn't as hard as letting go of Noel, the love of her life whom she was to marry the same year she was diagnosed.

He stood by her for five years, eventually marrying and having children.

June attended Polio Day at Government house in 2006 and at Darebin in 2007.

She was able to get out a bit and had several holidays on the peninsula.

Vale June, a brave woman, free at last.

Frances Henke

POLIO TIPS AND TECHNIQUES: Bad Research Part II–Publishing by Press Release

By Dr. Richard L. Bruno

Last issue, I described a 2006 Mayo Clinic article presenting a 15-year follow-up study of 38 polio survivors in which the authors omitted data from their own two previously published articles, which found progressive muscle weakness and loss of ability in those very same polio survivors, and concluded “our polio survivors did not age any differently than a normal population.”

There is a more dangerous issue than the publication of twisted, truncated and tortured data in a little-read medical journal. The bigger problem is that the authors “published” their findings in a press release. So, when the media got hold of the distorted data, the headline generated was a dismissive, “People who survive polio in childhood will not suffer further effects later in life.”

Unfortunately, “publishing” research findings in media press releases is the new trend in medicine. Forget peer-reviewed medical journals. Just put your findings in a press release and wait for the reporters to start calling.

Drug companies, universities, hospitals (frequently, the Mayo Clinic), national medical associations-even the Corn Refiners Association- distribute press releases about unpublished medical research to reporters.

Research presented at medical conferences that frequently is never published is also distributed to reporters by press release. A recent release from the American Urological Association conference begins, “Young researchers presented innovative, early-stage research.” I don’t know about you, but I’d like to wait until older researchers actually publish late-stage research before deciding what I should do with my urological system.

The latest study involving polio survivors was released to the press on August 26, 2008: “Pharmalink AB today announces positive results from a...study of Xepole, its candidate for the treatment of post-polio syndrome (PPS). The data has shown the candidate to be effective and well tolerated with no serious adverse events attributed to the product being reported in the treated patients. Xepole, the first medical

PPS treatment, is an injectable biologic product, administered once per 9-12 months. This novel treatment modality for PPS (caused) a significant reduction of symptoms of PPS while also showing that Xepole is safe and well tolerated with few or no side-effects. Full results are to be published in a peer review journal.”

Having reviewed, consulted on and performed studies of drugs to treat post-polio symptoms, believe me I know the difficulty of designing and conducting drug studies. The biggest issue with PPS treatment studies is that data on symptoms must be collected daily-not weekly, let alone monthly or at the beginning and end of a study-because polio survivors’ symptoms change daily, if not hourly. I want to see the specific details of the design and execution of the Xepole study when “full results” are indeed “published in a peer-review journal,” and not take the word of the drug company’s press release that Xepole is “the first medical PPS treatment...effective and well tolerated.”

As my last column showed, it’s not hard to get crummy research published, especially in infrequently-read journals. But, for researchers to go over the heads of all peer-reviewed medical journals and just “publish” their findings in the media leaves us all open to unsubstantiated claims that can promote incorrect beliefs about our bodies, emotional upset and possibly dangerous behavior. If polio survivors believe that they do “not age any differently than a normal population” or that Xepole will cure treat their PPS symptoms, and they keep overusing their poliovirus-damaged neurons, polio survivors will deteriorate, as studies of thousands of polio survivors-not just the Mayo 38-have shown.

Much of the research reported by the media turns out to be crap. Medical “facts” presented by the media change from week to week. Chocolate causes obesity, then fights cancer; a daily glass of red wine causes

alcoholism, and then prevents heart disease. So, it's vital, in this age of the 24 hour news cycle and the Internet, that we are extremely cautious when medical research is "published" via press release and the media. Again, be it PPS or any medical condition, we need to read the actual published research studies, not just listen to stories on TV and radio or read newspaper articles or press releases, to understand what's happening to our bodies and really know how to take care of ourselves.

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. E-mail rbruno@unitedspinal.org.

It got crowded in heaven, so, for one day it was decided only to accept people who had really had a bad day on the day they died. St. Peter was standing at the pearly gates and said to the first man, "Tell me about the day you died."

The man said, "Oh, it was awful. I was sure my wife was having an affair, so I came home early to catch her with him. I searched all over the apartment but couldn't find him anywhere. So I went out onto the balcony, we live on the 25th floor, and found this man hanging over the edge by his fingertips. I went inside, got a hammer, and started hitting his hands. He fell, but landed in some bushes. So, I got the refrigerator and pushed it over the balcony and it crushed him. The strain of the act gave me a heart attack, and I died." St. Peter couldn't deny that this was a pretty bad day, and since it was a crime of passion, he let the man in.

He then asked the next man in line about the day he died.

"Well, sir, it was awful," said the second man. "I was doing aerobics on the balcony of my 26th floor apartment when I twisted my ankle and slipped over the edge. I managed to grab the balcony of the apartment below, but some maniac came out and started pounding on my fingers with a hammer. Luckily I landed in some bushes. But, then the guy dropped a refrigerator on me!" St. Peter chuckled, let him into heaven and decided he could really start to enjoy this job.

"Tell me about the day you died?", he said to the third man in line.

"OK, picture this, I'm naked, hiding inside a refrigerator...."

BY BARBARA BOXLEITNER Special to Florida Weekly

Dan Smith's daily routine is easier these days. Afflicted with post polio syndrome and confined to a wheelchair, the North Port resident had his home remodeled to make it easier for him to manoeuvre.

Carole Ponzio, who owns Design Solutions! of Southwest Florida, designed the retrofit, which required Mr. Smith to live elsewhere for months during the process. "It's much better," said Mr. Smith, who lived in the home 14 years before the changes were made. "It looks more livable." Ms. Ponzio and medical experts, notably therapists, report seeing a steady need to improve living quarters for the disabled, geriatric and multigenerational households.

The National Association of Home Builders Remodelers TM Council, Research Center and Seniors Housing Council and the American Association of Retired Persons developed the Certified Aging-In-Place Specialist national designation program. "I think it's more to the forefront here in Charlotte County," said Ms. Ponzio, who is CAPS certified and serves on the Charlotte-DeSoto Building Industry Association

board of directors. She said she started thinking about designs for homeowners with limitations after visiting an acquaintance whose husband was in a wheelchair. The home's layout made her envision ways to improve residences.

"Her home was just so open and airy," Ms. Ponzio said. "That made me want to look into it more." The remodels have become special to her. "It challenges me to figure out ways to help people get around easier. You kind of have to figure out how this particular person can use this home. Every job you go into is totally different. It's really appealing to me," she said. "It really feels good for me to do something special." Some family units have several generations — elderly to young children — while others are single homeowners. The scope of need is vast, depending on the type of limitation, whether an occupant has lost the ability to walk or has experienced diminished capacities, such as in mobility, strength or sight.

Santo Garcia, MOTR/L (masters of occupational therapy, registered and licensed) was Mr. Smith's occupational therapist. He assisted in getting Mr. Smith and Ms. Ponzio to consult about a retrofit. "I realized that while there's so much I can do, there's so much more he can use," Mr. Garcia said. "It's just amazing the difference, his ability to move about."

Many improvements can enhance the quality of life for people with disabilities, the experts said. For instance, kitchen appliances and drawers can be placed at a lower level to accommodate those in wheelchairs. Pullout drawers, not reach-ins, make it easier to retrieve items.

There are cutting boards that have high edges and a nail on which to place a piece of food to be cut. "It's not like these are difficult things to do or to find," Ms. Ponzio said. Shower bars help people hold themselves up, and elevated toilet seats aid those with weak legs. A tub with a swing door allows people to enter and exit at ground level. "Now you don't have to step up," Mr. Garcia said, noting that a special seal keeps the water in.

People with diminished eyesight can get their home fitted with special lighting. "It really doesn't matter what the disability is, there is a fix for the house," Ms. Ponzio said.

Mr. Smith lives in an older house in a single-family development. He was on disability retirement and was still able to walk when he moved into the home. Over the years, his condition grew worse and he has been unable to walk for eight years. "Everything was too small," he said, noting that he wasn't able to maneuver a wheelchair in the hallways without banging into walls. "Even as it was being built, my arm strength continued to diminish. Even so, I can still manage around the house."

Ms. Ponzio made significant changes to most of the home except his bedroom. One bathroom was designed with a single commode and adjacent handrail, and the shower has a custom seat. Floor bumper bars prevent the wheelchair from hitting the walls.

Because Mr. Smith did not want the washer and dryer in the garage, a European one-piece washer and dryer was installed to the left of the sink area. "It automatically dries after washing," Ms. Ponzio said.

In the kitchen, she designed an oblong island. One side has room underneath for him to pull the wheelchair and use the countertop to eat, write and read. On the other side of the island are an undercounter microwave and an induction cook top. A pullout board at the end of the island enables him to easily transfer food from the nearby oven. The sink and other appliances are easily reachable from the wheelchair.

Mr. Smith said a double dishwasher features upper and lower drawers. "As you use them, you put them in the other drawer," he said. "It minimizes the transportation of the dishes." All the doors were widened, Ms. Ponzio said, and the exterior doors now operate by remote control. Windows were upgraded to hurricane resistant and sun filtered, he said.

In the hallways, which were widened, carpet was attached to the lower half of the walls, with a horizontal rail along the top of the carpet. "After awhile, the bumping of the wheelchair into the wall tended to make the doors, walls and everything else look really bad," Mr. Smith said. "If you accidentally bump into the wall, it keeps the wall from getting scuffed." The back lanai was closed in to create an office space, and a new driveway was installed.

A wide pad leading from the driveway around to the back of the home facilitates access through the rear.

Mr. Garcia said many illnesses, such as multiple sclerosis and Parkinson's disease, zap patients' energy and mobility. Any adaptive aids "that make their life the slightest bit easier, it means all the world to all the people," he said. Depending on the changes needed, projects can range from one month to six months, Ms. Ponzio said.

For information about the Certified Aging-In-Place Specialist designation program, visit the National Association of Home Builders online site at www.nahb.org.

Carole Ponzio's online site, www.designsolutions-fl.com, has information and links about CAPS and remodels. †



[LIFE](#)

Friday, Oct. 09, 2009



Motorcyclist helps fight against polio

By Lisa Millegan

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 E-Mail  Print

Comments (0)

Text Size:  

Bob Mutchler is riding full throttle against polio. Though his legs are weakened because of a childhood bout with the virus, the 62-year-old Folsom resident is an avid motorcyclist who has traveled all over the world. Thursday, he was in Modesto to raise money for the Rotary Club's Polio Plus program, which is working to eradicate the disease.

"I will continue to talk, to ride, to raise awareness until we have immunized the last child on Earth," Mutchler said to sustained applause from nearly 200 Modesto-area Rotary Club members.



Bob Mutchler, "Motorcycle Bob", spoke to Modesto area Rotary Clubs Thursday about Rotary's drive to end polio.

Mutchler contracted the polio virus when he was 9 months old, years before the polio vaccine was available. His parents were told he never would walk. He spent three years in an iron lung in a children's hospital.

When he got out, his parents treated him like any other child, including him in all the usual activities.

Mutchler married, had two children and became a piano tuner and technician.

He got interested in motorcycles at age 38, shortly after a divorce and before he married again, when doctors diagnosed him with post-polio syndrome. Nerves and muscles previously attacked by polio began to break down. Three neurologists told him he had only two more "productive years" before he would end up in a wheelchair.

Mutchler decided to make the most of his time left, bought a motorcycle and started taking long rides. Asked why motorcycling became his passion, Mutchler cited "the absolute freedom. The understanding that most people assume I could never do it. Knowing I could not only do it, but excel at it."

Riding across America

Though he's been a Rotary member since 1970, it wasn't until about a decade ago that he began going on motorcycle rides for Polio Plus. Since childhood, he hadn't told people he had polio because he believed there was a stigma attached to the disease. Mutchler, who can walk only with leg braces and crutches, would lie and say he'd been in an accident or tell people it was none of their business.

At the invitation of a friend, he decided to ride across North America in 1998 to give speeches about the Rotary's drive to end polio. The trip succeeded beyond his wildest dreams — he was interviewed by television and radio stations across the country and was the subject of a 90-minute TV documentary.

Since then, he has ridden in three "Iron Butt" motorcycle rallies, where invited participants ride 11,000 miles in 11 days throughout North America — in 2001, 2005 and this summer. The Iron Butt Association has supported Polio Plus with donations.

In the recent ride, he crashed in Oregon and was under his bike on the side of a road for half an hour before two women rescued him. He said it didn't discourage him at all. "I was thinking what a great ride I had," he said.

Mutchler said he is driven to continue supporting Polio Plus because the eradication of the disease is an attainable goal. When Rotary started the program, 122 countries had cases of polio. Now, there are only four countries left — India, Pakistan, Afghanistan and Nigeria. Last year, fewer than 2,000 cases were identified.

Since 1985, Rotary International has contributed \$800 million to end the disease and immunized 2 billion children around the world. The Bill and Melinda Gates Foundation has contributed a \$335 million challenge grant toward the effort.

"Children do not deserve to suffer," Mutchler said. "That is not an option."

For more information about Mutchler, visit <http://www.polioplusride.org/>. Text the word "polio" to 90999 and \$5 will be added to your phone bill with proceeds going to Polio Plus.

Bee arts writer Lisa Millegan can be reached at lmillegan@modbee.com or 578-2313.

Polio: Forgotten, but not gone

By CHRISTOPHER TUFFLEY

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SEBRING -- Polio. There was a time that word struck the kind of terror the word AIDS does now. A virus that particularly strikes children, it killed and paralyzed thousands. The iron lung was invented to save polio sufferers who could not breathe on their own. There was no known cure. There still isn't. Being a virus, polio created epidemics. According to the Polio History Timeline, in 1934, an outbreak occurred in Los Angeles. In one four-month period, one hospital treated almost 2,500 cases. In 1952, about 58,000 cases were reported nationwide; in 1953 about 35,000.

With the development of vaccines and robust immunization programs the disease was brought under control in the United States by the end of the 20th century, leaving nearly 2 million survivors. But Richard Bruno, the organizer of the International Post-Polio Task Force, as well as the director of The Post-Polio Institute at the Englewood (N. J.) Hospital and Medical Center, warns the threat of a polio outbreak remains very real. There have been seven reported cases in the U.S. since 2005, resulting in one death.

He is serious enough about the dangers that despite being confined to a wheelchair he travels to educate the general public. It is the reason he was in town for the Sebring Noon Rotary luncheon Oct. 6. Unlike smallpox, Bruno told the group, the polio virus is alive and well. New cases are reported every year, especially in Third World countries. With the ease of international travel, he added, and the fact that roughly 70 percent of individuals who carry the virus show no symptoms, the danger of contagion is real.

This is one reason October has been designated Polio Awareness Month. The only protection against the virus, Bruno said, is immunization. But a group must have at least 95 percent of its members immunized for the whole to be considered safe. Florida meets the 95 percent threshold, one of only eight states to do so. Highlands County does even better, with 98 percent of individuals inoculated.

The United State as a whole, however, only has a 93 percent average, and eight states less than 90 percent, Bruno said. Part of the problem is because the polio vaccination is not required and 20 states allow parents to refuse immunization simply because they believe it is dangerous. For example, some parents believe inoculations cause autism, but Bruno said 16 "huge studies" have shown there is no correlation between the two.

The standard protocol, he said, is to vaccinate children at two months, four months and between six and 18 months, with a booster at four years. Bruno recommends a booster for adults travelling to areas where polio has been reported recently. He wants people to remember what a terrible disease polio is.

Simplified, the disease destroys neurons, so muscles no longer receive messages from the brain. Paralysis often results. Without the nerve stimulation muscles atrophy, although patients retain feeling. But the original onset of the disease is only part of its devastation. With the passage of time polio survivors have found themselves dealing with a secondary condition called post-polio syndrome.

The results of PPS are overwhelming fatigue, muscle weakness, muscle and joint pain, sleep disorders, heightened sensitivity to anesthesia, cold and pain as well as difficulty swallowing and breathing. These symptoms typically manifest themselves about 30 years after the virus first strikes, and affect roughly 75 percent of those who suffered paralytic polio and 40 percent of non-paralytic polio survivors.

"The polio virus-damaged neurons are now failing and dying from overuse, causing the debilitating symptoms," Bruno said, explaining that PPS is not a recurrence of the original virus. "PPS is caused by the body tiring of doing too much work, for too long, with damaged neurons." Roughly 110,000 polio survivors live in Florida, there are estimates that about 700 of them live in Highlands County.

Deanna Pieretti, another polio survivor, founded Handicapped Americans Love of Life Organization here in Sebring partly as a support group for people with PPS.

For more information call 385-1196.

Having a bad day? Just remember, it could be worse...

The average cost of rehabilitating a seal after the Exxon Valdez oil spill in Alaska was \$80,000.. At a special ceremony, two of the most expensively saved animals were being released back into the wild amid cheers and applause from onlookers. A minute later, in full view, a killer whale ate them both.

Still think you are having a bad day?

A woman came home to find her husband in the kitchen shaking frantically, almost in a dancing frenzy, with some kind of wire running from his waist towards the electric kettle. Intending to jolt him away from the deadly current, she whacked him with a handy plank of wood, breaking his arm in two places. Up to that moment, he had been happily listening to his Walkman.

STILL think you're having a bad day?

Two animal rights protesters were protesting at the cruelty of sending pigs to a slaughterhouse in Bonn, Germany. Suddenly, all two thousand pigs broke loose and escaped through a broken fence, stampeding madly the two hopeless protesters were trampled to death.

What?! STILL having a bad day??

Iraqi terrorist Khay Rahnajet didn't pay enough postage on a letter bomb. It came back with "return to sender" stamped on it.. Forgetting it was the bomb, he opened it and was blown to bits. There now, feeling better?

From Mary-ann.

Services in The Home: Home and Community Care (HACC)

Home and Community Care (HACC) is one of a number of services funded by state and federal governments to enable older people to remain in their own home for as long as they are able and wish to do so.

Subsidised home-based services are provided by local government and other community agencies. Services may include:

- Food services, such as delivered meals, or a meal in a community facility, help with shopping
- Home help, such as cleaning, cooking, washing and ironing
- Personal care: help with bathing, and dressing
- Community respite: provides a break for carers
- Home maintenance or minor modifications, such as installing rails and ramps
- Social support, such as transport to group and social activities, and to appointments
- Health services, such as home nursing, podiatry, physiotherapy

WHO IS ELIGIBLE?

People living at home who

- have a disability;
- are older and are assessed as needing support;
- are carers of these people.

ASSESSMENT

An assessment by the service provider will determine eligibility, level of need, priority for service and individual cost.

COST

Charges range from minimal to full cost, according to ability to pay. *No person will be denied a service because they are unable to pay.*

WHO CAN REFER?

- self
- doctor
- family, friend or neighbour
- Aged Care Assessment Service (ACAS)

COMPLEX CARE NEEDS

People with high levels of care needs may still wish to remain at home and coordinated care, such as that provided through a Community Aged Care Package or Linkages Program, may be needed.

IF LANGUAGE IS A DIFFICULTY

Contact the Translation and Interpreter Service (TIS) on 131 450 and ask them to call the service provider or Seniors Information Victoria.

CONTACTS

Your local council's Aged and Disability Services Department, your local community health service, your doctor or SeniorsInformationVictoriaon1300135090

The real art of conversation is not only to say the right thing at the right time, but also to leave unsaid the wrong thing at the tempting moment.

The easiest way to find a lost thing is to buy a replacement.

Did you ever notice that the Roman numerals for 40 are XL.

And that's all for this month. Ed.