

POLIO PERSPECTIVE

June, 2016

Millie Malone Lill, Editor

Wilma J. Hood. Publisher

IN THIS ISSUE

A Cautionary Tale of ‘Stem Cell Tourism’

by GINA KOLATA

I GO THE DISTANCE

a poem by Glenda Crawford

TREATMENT FOR OSTEOPOROSIS

By Dr. Richard Bruno

A BLOOD TEST FOR POST POLIO MUSCLE PAIN?

By Dr. Richard Bruno

THREE MORE

By Millie Malone Lill

WEB CORNER

OTHER POLIO NEWSLETTERS

A LITTLE BIT OF HUMOR

A Cautionary Tale of ‘Stem Cell Tourism’

NY TIMES

By GINA KOLATA

JUNE 22, 2016

The surgeon gasped when he opened up his patient and saw what was in his spine. It was a huge mass, filling the entire part of the man’s lower spinal column.

“The entire thing was filled with bloody tissue, and as I started to take pieces, it started to bleed,” said Dr. John Chi, the director of Neurosurgical Spine Cancer at Brigham and Women’s Hospital in Boston. “It was stuck to everything around it. I had never seen anything like it.”

Tests showed that the mass was made up of abnormal, primitive cells and that it was growing very

aggressively. Then came the real shocker: The cells did not come from Jim Gass. They were someone else's cells.

Mr. Gass, it turned out, had had stem cell therapy at clinics in Mexico, China and Argentina, paying tens of thousands of dollars each time for injections in a desperate attempt to recover from a stroke he had in 2009. The total cost with travel was close to \$300,000.

A growing number of clinics, often in places like Russia or China, but also in Europe and elsewhere, say on websites that they can treat, even cure, diseases like muscular dystrophy, Alzheimer's, Parkinson's, and spinal cord injury as well as strokes, by injecting patients with stem cells that, in theory, could develop into a missing nerve, a muscle or other cells and repair damage from an illness or an injury.

Reports by injured athletes of seemingly miraculous results have contributed to a growing interest among desperate patients. Estimates are that tens of thousands of patients around the world have had such treatments and that the industry is worth hundreds of millions of dollars.

The clinics, which are unregulated, have websites with glowing testimonials from patients, some of which, Mr. Gass's sister-in-law discovered, have financial interests in the clinics. The clinics often claim to be doing clinical trials, giving a veneer of legitimacy to their work.

Academic researchers say stem cells hold enormous promise, but they are proceeding cautiously with clinical trials because stem cells divide rapidly and can form tumors in laboratory animals. In lab studies, stem cells also can quickly accumulate mutations like those in cancer cells.

While there have been reports in medical literature of patients who developed tumors after stem cell injections, few patients have been as open about their quest for a cure, the money they paid and the tragic consequences as Mr. Gass, a 66-year-old former chief legal counsel for Sylvania who lives in San Diego, has been.

After the stroke, Mr. Gass lived independently although his left arm was useless and his left leg weak. Now, however, with the foreign body in his spine, he is paralyzed from the neck down, except for his right arm. He needs a hoist to move from his bed to a wheelchair, and his doctors do not know how to stop the tumor from growing.

The doctors wrote about his case in a letter published on Wednesday in *The New England Journal of Medicine*. Experts who have written articles in medical and scientific journals bemoaning "stem cell tourism" said this case could make a difference.

"We scientists and clinicians say, 'Don't do this,'" said Dr. Jaime Imitola, a neurologist and stem cell researcher at Ohio State University Wexner Medical Center who has written about the dangers of stem cell tourism. But, he said, their warnings often do not resonate.

Dr. Imitola said that Mr. Gass "puts a human face to a tragedy." Patients might see what happened to Mr. Gass "and say, 'Oh my God, that could be me.'"

"This is a really cautionary tale," said Timothy Caulfield, research director of the Health Law Institute at the University of Alberta, who wrote a recent commentary on stem cell clinics. Mr. Gass's problems began on May 10, 2009, when he woke with a terrible headache. He tried to get out of bed and fell to

the floor, unable to move. He'd had a stroke. Two years later, he was able to walk only with a leg brace and a cane.

"I began doing research on the internet," Mr. Gass said. He was particularly struck by the tale of the former football star and professional golfer John Brodie who had a stroke, received stem cell therapy in Russia and returned to playing golf again. So Mr. Gass contacted a company, Stemedica, that had been involved with the clinic, and learned about a program in Kazakhstan. When Mr. Gass balked at going there, the Russian clinic referred him to a clinic in Mexico. That was the start of his odyssey.

Mr. Gass's doctors and his sister-in-law, Ruth Gass, tried to dissuade him. Ms. Gass called the clinics and demanded evidence that their treatments worked.

Some of the clinics hung up, saying they would not talk to a terrified relative, she said. Websites often had data but it did not hold up to basic analysis, Ms. Gass said, and when the data was published, it appeared in vanity journals. Other clinics simply told her, "People get dramatically better."

She raged against the clinics, telling them: "You ought to be ashamed for charging \$40,000 a shot. You prey on people like my brother-in-law who is desperate for help."

Then came her kicker: "I said, If what you are saying is true, you should get the Nobel Prize. If not, you ought to go to hell. Shame on you."

But Mr. Gass was undeterred. He was willing to spend his money and go anywhere. What did he have to lose? The worst that could happen, he thought, is that he would have no improvement. He went from clinic to clinic, ending up back in Mexico for an injection of fetal cells shipped from Russia. Six months later, his walking improved. But the improvement did not last long, so he had another injection. Then something disturbing happened.

"I felt pain when I would lie down, like I was lying on a tumor," Mr. Gass said. "I started to lose my ability to walk and I fell down a lot." He was in Thailand at the time, a place he likes to visit. Doctors at a hospital there tried to do a spinal tap but told Mr. Gass that something was wrong. There seemed to be no spinal fluid.

He returned to the United States, to Boston, where he had spent most of his life and where his brother and sister-in-law lived and asked the doctors at Brigham and Women's Hospital for help. They did a magnetic resonance imaging scan of his spine and were aghast when they saw the image. "The entire lower portion of his spinal column was filled with a mass," said Dr. Aaron Berkowitz, director of the hospital's global neurology program. The only option was to operate.

But now that the doctors knew what the mass was, they were left with another problem: How could they stop it from growing? If it had been an infection, they could have used antibiotics. If it had been cancer, they could have used drugs to target it. This mass, though, was unique.

They decided to try radiation. It seemed to slow the mass's growth a bit, maybe even shrink it. But recently, Mr. Gass has had another scan in San Diego, and doctors told him that the mass was growing again.

Asked what he would like others to learn from his experience, Mr. Gass said, "Don't trust anecdotes."

His sister-in-law had a different reply: "If something sounds too good to be true, it is.

I Go the Distance *by Glenda Crawford*

***I want to run so fast I feel the wind tug against my face.
I want to go the distance, I want to keep the pace.
Like a marathon runner I am driven to win,
I push and I try with all my strength and then.
Suddenly limp and weak I hit that wall.
Barely able to move; not able to finish at all.
I yell and I scream why does my body do me this way?
Why does it refuse to cooperate and obey.
My body responds and I am shocked at what I hear.
I go the distance you abuse me, my dear.
You push me beyond what I am able to do.
You refuse to listen when I talk to you.
Polio attacked us and left us weak and paralyzed.
When do you accept. When do you realize.
A block for me is another's mile.
I go the distance. I go my mile.***

Treatment For Osteoporosis *by Dr. Richard Bruno*

There have been a number of Coffee House members asking about treatment for osteoporosis. Here's one e-mail I received:

Q: I have both osteoporosis and acid reflux. I just read that the anti-reflux drug I'm taking may cause my bones to get thinner. I already am taking Fosamax, which I also read can cause my jawbone to die! Should I stop both these pills?

A. Polio survivors are finding themselves between drugs and a soft place, that soft place being their bones. Osteonecrosis -- bone death -- was reported in the jaws of 63 patients taking bisphosphonates, drugs that are given to increase bone density. Fifty-seven patients received intravenous bisphosphonates as treatment for cancer. But, six took Fosamax, the well-known oral anti-osteoporosis medication. Dentists across the country have reported about fifty cases of jaw osteonecrosis. Given that about three million women take Fosamax, fifty is a small number of cases. Even if you assume that only about one percent of problems caused by a given medication are reported, jaw osteonecrosis would occur in only two-tenths of one percent of women taking Fosamax. Still, if it's your jaw that's dying, who cares about percentages? So, the FDA now wants labels on all bisphosphonates to warn about the possibility of osteonecrosis.

If drugs to treat osteoporosis aren't causing enough worry, in late 2006 a study of nearly 150,000 people over 50 year-old found that taking proton pump inhibitors (anti-acid reflux drugs like Nexium) for

more than a year increased their risk of a hip fracture by 44 percent. The higher the dose and the longer the drugs were taken, the risk of a hip fracture, especially among men, rose nearly 200 percent. The increased risk of fracture may be caused by proton pump inhibitors interfering with your body's ability to deposit calcium inside your bones to increase their strength. This unfortunate side effect of proton pump inhibitors is a two-headed dragon for polio survivors.

The first head is that polio survivors with paralysis, both female and male, have osteoporosis more frequently because they either haven't been "pushing" on their bones by standing on their legs (the result of using a weight-bearing brace, crutches or a wheelchair) or because their weak or paralyzed muscles haven't been "pulling" on bones. It's the pushing and pulling that makes calcium bind inside bones so they won't become brittle.

The second dragon's head is that our 1985 Post-Polio Survey found that gut problems, including ulcers and acid reflux, are between six and fifteen times more common in polio survivors than in the general population. To make things worse, sleep apnea, which we have found in 25% of Post-Polio Institute patients, may increase reflux.

Oh, and another "head" has just reared its ugly self. A 2007 study of 5,000 adults 50 year-old and older found that daily use of the newer antidepressant medications (selective serotonin reuptake inhibitors -- SSRIs -- like Prozac) decreased bone density by as much as four percent and doubled the chance of breaking a bone. What's more, the higher the dose of an SSRI, the risk of falling increased by fifty percent.

So, what's to be done about your belly, your brain and your bones? All female polio survivors, and males who have muscle weakness or paralysis, should have a DEXA bone density scan to determine if they have osteoporosis or osteopenia, a lesser decrease in bone density that still increases your risk of fracture. If you have decreased bone density, ask your doctor if you could try to increase calcium, vitamin D and protein before starting a bisphosphonate. If you need medication, ask about using calcitonin, a hormone that also increases calcium inside your bones, or the non-bisphosphonate drug Evista.

If you are taking a proton pump inhibitor or an SSRI, ask your doctor if increasing calcium would be helpful in combating these drugs' unwanted effects on bone density and falling. And, Postmenopausal women should talk to their gynecologist about whether hormone replacement is an appropriate treatment.

Unfortunately, fatiguing exercise or walking to "push and pull" on bones is not a treatment for osteoporosis or osteopenia in polio survivors, since exercise can cause muscle weakness and exactly what you're trying to prevent: a fall and a fracture.

A BLOOD TEST FOR POST-POLIO MUSCLE PAIN?

By Dr. Richard Bruno

Q: Recently I had arm and chest pain. I went to the ER. The only abnormal blood tests showed high C-reactive protein and high creatine kinase. My blood pressure and cholesterol are normal, I have never smoked and I'm thin. My EKG showed that I hadn't had a heart attack. Could high CRP and high CK be related to PPS?

A. C-reactive protein is a blood marker for inflammation somewhere in the body. High CRP can be

seen with type 2 diabetes, autoimmune diseases and cancers. Could inflammation somewhere in your body, as indicated by your elevated CRP, be related to PPS? Fifty consecutive patients evaluated at The Post-Polio Institute had CRP measured. The patients were on average 59 years old and 55% were women. Thirteen percent had an elevated CRP, 66% of whom were men. CRP was on average nearly three times the normal value. However, there was no significant difference between those with high and normal CRP on self-ratings of daily fatigue, difficulty with self-care or ability to perform activities inside or outside of the home. So, there is no evidence that elevated CRP or inflammation is related to PPS, either to post-polio fatigue or difficulty in functioning.

Recent studies have found that elevated CRP is related to having a heart attack or stroke. The theory is that a bacterial or viral infection (although definitely not a poliovirus infection) somehow inflames arteries and causes them to clog. Our 1985 National Survey found no more heart disease or high blood pressure in polio survivors than in the general population. But two studies found that 5% more male post-polio patients had abnormally elevated cholesterol as compared to the general population. In one of the studies, only 33% of those with high cholesterol had been given a cholesterol screening test by their doctor and not even 25% were on cholesterol-lowering medications, like the statin drugs such as Lipitor, Pravachol and Zocor. This is not good, since reducing “bad” cholesterol reduces heart attack risk. and may increase survival even after having a first heart attack. But, as you know, statins can and do cause muscle pain and can cause muscle breakdown so several may been to be tried before finding one that helps (see CHOLESTEROL DRUG article in the POST-POLIO LIBRARY <http://www.PostPolioInfo.com> .

Statin drugs provide a connection between CRP and CK --in polio survivors. CK is an enzyme released when muscle is damaged. One half of one percent of anyone taking a statin develops muscle breakdown, which causes muscle pain (especially in the calves), muscle weakness and an increase in CK. Even without muscle breakdown or an elevated CK, some polio survivors report muscle pain or weakness when taking a statin, usually one of the older statins like Lipitor.

And polio survivors can have an elevated CK without taking a statin. Two studies found that 40% of polio survivors had abnormally elevated CK, with men having significantly higher CK than did women. In one study, CK increased with the number of steps polio survivors walked in a day. In our fifty Post-Polio Institute patients, 21% had abnormally elevated CK levels (on average about 33% higher than normal) with men also having higher CK than did women. But, as with CRP, there was no significant difference between those with high and normal CK on self-ratings of daily fatigue, difficulty with self-care or the ability to perform activities inside or outside of the home.

However, an elevated CK may mean that polio survivors are making their muscles work too hard and are causing them to break down. So, neither CRP nor CK is related to fatigue or loss of functional abilities in polio survivors. However, all polio survivors need to have their cholesterol and CRP measured to assess heart disease risk. And since an elevated CK indicates muscle breakdown, either from taking a statin or from muscle overuse, polio survivors should have CK measured before taking a statin. If you are worried about possible muscle weakness or breakdown with the statins, or the newer cholesterol-lowering drugs like Zetia and Vytorin, ask your doctor about using older medications like slow-acting niacin or bile acid sequestrants.

Besides medication, polio survivors need to eat high fiber foods, reduce saturated fat, treat high blood pressure and stop smoking to keep their tickers ticking.

THREE MORE

By Millie Malone Lill

Certain scientists, (OK, it is just me) have discovered three new diseases that polio survivors are likely to contract. The first is:

THE GREAT RELUCTANCE: Symptoms include a slightly nervous feeling, difficulty in getting motivated, tiredness and a sore throat from yelling at someone else to do whatever needs to be done. There is no known cure, and worse news, it can progress into:

THE DON'WANNAS. Symptoms of this ailment are much like those of The Great Reluctance, but more severe. Dishes may pile up in the sink, clutter may abound. Your behind develops an attachment to the seat of your recliner that is difficult to ignore. Things may then progress to a third stage:

NOTGONNAS. While the first two of these ailments can be sometimes be overcome by consistent nagging on the parts of others in your household, the side effects usually result in the Notgonnas which can be identified by a complete and utter refusal to leave that recliner.

Treatments varies depending on whether or not you are a polio survivor. If you are not, then vigorous, even loud discussions and threats sometimes work. Eye rolling on both sides of the discussions can occur along with loud put-upon sighs. Sometimes hefty bribes are involved. However, if you are a polio survivor, the only known treatment is rest. Just give in, wait for some able bodied person with low tolerance to finally give in and do the dishes, clear up the clutter or hire someone to do it for you.

All three of these ailments are often caused by the polio survivor smacking into the Polio Wall, a very substantial edifice made of Overdoing and Peer Pressure and, yes, Stubbornness, and Type A Personalities.

My advice is to avoid that darn Wall whenever possible by slowing down, resting before you are wiped out, learning to delegate chores and to conserve to preserve. You may even have to lower your standards for a clean house, especially if, like me, your roommate is only a small dog with extremely low standards and a high tolerance for clutter.

On the bright side, resting often helps relieve the symptoms of all three ailments as well as bringing on boredom. Eventually, you will feel like tackling it again. Remember, as my mother always told me, if you don't want to clean up a mess, don't make one!

WEB CORNER

People with disabilities do Live Boldly

<http://liveactionnews.org/people-with-disabilities-do-live-boldly-and-theyre-not-better-off-dead/>

Five ways to live well with chronic pain

<http://www.everydayhealth.com/columns/therese-borchard-sanity-break/ways-live-well-with-chronic-pain-illness/>

India to vaccinate 300,000 children after polio strain found in sewage

<http://www.everydayhealth.com/columns/therese-borchard-sanity-break/ways-live-well-with-chronic-pain-illness/>

Non invasive test for colon cancer:

<http://www.cologuardtest.com/>

New plant-based vaccine trials

<http://www.labnews.co.uk/news/new-plant-based-vaccine-investigation-21-06-2016/>

Dr. Richard Bruno's interview on Dancing on our Disabilities

<http://www.myragoldick.com/5979/post-polio-sequelae-known-as-pps/>

Seven things you can do to prevent drug interactions

<http://www.health.harvard.edu/staying-healthy/7-things-you-can-do-to-avoid-drug-interactions>

Polio Pioneer helps survivors hold on to strength

<http://www.npr.org/templates/story/story.php?storyId=103892252>

OGO, the new hands free power chair:

<https://www.facebook.com/RocketsAreCool/videos/907464282716437/>

How Bruce Burnham keeps growing where he is planted

<http://www.transfermaster.com/blog/view-post/He-Grows-Again-5>

OTHER POLIO NEWSLETTERS

Atlanta Post Polio Association

[http://www.atlantapostpolio.com/APPA News-2016-spring-final.pdf](http://www.atlantapostpolio.com/APPA%20News-2016-spring-final.pdf)

Pennsylvania Polio Survivors

<http://www.papolionetwork.org/>

Polio Place

<http://www.polioplace.org/>

A LITTLE BIT OF HUMOR

Spraying the Vegetables

My wife asked me to buy ORGANIC vegetables from the market. I went and looked around and couldn't find any. So I grabbed an old, tired looking employee and said, "These vegetables are for my wife. Have they been sprayed with any poisonous chemicals?"

The produce guy looked at me and said, "No. You'll have to do that yourself."