

Polio Perspective
April 2015

Editor Millie Malone Lill

Publisher Wilma Hood

In This Issue

An article From Terry “Beating Post Polio” in Munich

Fainting and Fatigue: Coincidence or Causation?

By Richard L. Bruno

Fun House Mirrors

by Millie Malone Lill

**INTRAVENOUS IMMUNOGLOBULIN (IVIG) DOES
NOT TREAT PPS**

by Dr. Richard L. Bruno

Web Corner

A Little Bit of Humor

This is reprinted with permission from Terry's blog. Terry is from Munich, Germany.

Although nobody asked after me, where I stay or how I was doing, I would like to tell you what happened to me. A few days ago was the beginning of spring and everyone talked about the solar eclipse. I also looked several times without goggles despite all the warnings or perhaps because of them... For what reason should I keep my eyesight? In order to deal every day with such people I don't need it!

Actually, I was quite cheerful. The day went normal so far or as always with the difference that the sun was shining and when the sun shines, I'm always in a good mood. After I had done all my errands in the city, it was time for me to go home because my boys were waiting for me.

At a central station, where bus, train and metro encounters, I met a friend who also sits in the wheelchair due to a motorcycle accident. I meet him often at this stop because I live nearby and he works in the vicinity. After we had greeted us and exchanged a few words, I noticed that he often looked behind me. Suddenly he said, "Wait a minute, Terry !" He drove past me to the direction of the elevator that leads to the subway platform. I could hear him saying to the people who crowded into the elevator if they could kindly use the stairs or the escalator. Most people pretended they wouldn't understand him at all. Although he has a speech impediment caused by the accident, those who want to listen will manage to understand him.

There were some who first wanted to let him go into the elevator, but he didn't want to use the subway, he merely wanted to encourage people to think about the fact that for a possible defect of the Elevator, he as a wheelchair user or disabled person, has not the choice simply using the escalator or even stairs, but tediously drive along the surface until he reaches the next station and hope to find a working elevator there.

In the winter, such an action for a person who can't move, quickly leads to hypothermia. He tried to make people understand that he has lived in Munich for 13 years and spent a total of 2 years during that time trying to find alternatives to get from A to B, because the elevators are more often faulty than functional. He spoke mainly to young people, as we were near to some schools. But no one listened to him when he argued that the failures of the Elevators are mainly caused, as they are too often used by people who don't really need them. But no one really reacted, so the only possibility to attract attention was blocking the elevator door with his wheelchair and only let other wheelchair users, mothers with prams and elderly people pass. I decided to help him. As an annoyed teenager by walking away said to him that he was rightly sitting in a wheelchair, only because she had to take a few steps to the next escalator with about 16 years.

This situation was still relatively harmless compared to what would follow. We continuously tried to raise awareness. I helped as best I could so that no one could abuse his speech disability as an excuse to ignore him. While we were talking about which world we actually live in a middle-aged woman slipped into the elevator. We also pleased her to use the escalator. She refused and said she was already too late and would now like to go at last. She would have no problem with the fact that a wheelchair user would come into the elevator, but she don't want to walk! The escalators at that station are less than 20 meters away from the lift. She became more and more restless and threatened after about 10 minutes she will call the Police, if we wouldn't leave the elevator, immediately! She pressed the alarm button and called the subway agent, who also appeared in a few minutes.

So far we firmly believed that our action even wasn't officially registered as a demo, but maybe a good

thing to get the attention of people to the daily problems of disabled people, that normal people usually don't have to deal with. In this regard, we have been disabused now.

We should please keep clear the elevator for the good wife and I should keep my mouth shut. "Even if you're sitting in a wheelchair you haven't the right to do that!"

But that was still not all. Meanwhile, a second woman at the same age had arrived, which also vigorously pursued wanted and did not have time to discuss any problems of disabled people. The subway agent had now brought reinforcement to make us clear that each elevator in whole Munich, has to be available for everyone, regardless of age. In addition, we have already made us punishable! While the subway agent discussed with us, the elevator was so far free again, so that the two ladies who were so apparently in a hurry, could easily go toward their goal. Instead, they called now the police to create this thing to a giant balloon, of course encouraged by the already mentioned statement that all elevators have to be available for everyone. By the way now already about 1 hour, was passed. During this time they would have made their way to work, home or wherever else 10 times.

For the next situation, I must even mention that I have encouraged the two ladies to call the police. I've never been a friend of the police, I've often had made the experience that disabled people are not much worth there. Small note in passing. At accented demos where right and left groups meet, the police usually protect the nazi groups, although they are officialy "illegal" in Germany since 1945. But at that time I hadn't such thoughts, I actually always look optimistic into life and therefore assumed that this situation would practically resolve by itself.

The exact opposite was the case. 4 policemen and 3 metro agents were now against us. The whole thing now became the extent of a questioning during the Third Reich. We didn't have the right to explain our situation nor to refute the alleged insults against the two women. We just had to keep our mouth shut and only respond if we were asked. It got much worse when I tried to turn around to help my friend getting his papers from his backpack. One of the "very intelligent" police officers rated this as an escape attempt and grabbed me very painfully by the arm and pushed me so hard as I was a felon who must be stopped.

I screamed he should take his hand off me, that hurts !!! Then he tartly said : I should shut my mouth he would have only touched my jacket! He 'd know how to deal with such ... disabled, strong throw out of the wheelchair, then everything would be over, quickly! He isn't squeamish with such... like us. With my eyes I tried to get help by the passers and could not believe my ears, said: "I 'm sure you can!" At least now all sorts of images of newsreel reports shot in my mind. Suddenly I felt now even the same helplessness, of the people in that time on my own. In documentaries on television you are always shocked by the fates but when you are affected by yourself a paralyzing anger sets, that won't disappear for a long time.

A few minutes before we had to listen from the two ladies, with this action we only intend to unload our frustration, on normal people which we have due to our disability. What should it then be what they exert on us? I noticed very well that the two ladies enjoyed the whole situation. At least now, someone with a conscience would have said, " it's enough now, let us forget" or something like that, Instead, they took advantage of the fact that they had the attentions from everyone and never become tired to say, we have offended them. By the way they were two foreigners, I mention this because otherwise in a similar situation the foreign part often makes the bad deal but here we were the worthless part and we

get strongly felt that! We were humiliated , insulted and ridiculed. But what shocked me more about the whole thing, was that nobody else has interfered in any way or even said a word. Everything seemed to be OK.

Finally, the officials and the two "nice ladies" formed a circle, as you may know from a tactical meeting before a football match. Then the ladies demanded an apology from us, which should be like this: In the future, we should never come up to the idea of blocking any elevator in whole Munich, or asking anyone if he could kindly use the stairs or something like that ...To avoid us/my friend further more troubles (I had to reassure him often because he was shaking due to the excitement , therefore he was ridiculed even by the ladies and the police)I finally apologized exaggerated ironic that I was even born, that I'm sitting in a wheelchair and that I'm a disgrace for the society. Only then everyone seemed to be satisfied and let us go. Otherwise, we would get a complaint for assault and insult. That's what they threatened us. Meanwhile, I also could no more, it was cold, I had to pee and I also had a huge anger!

I only said to my friend: "Come home safely please and thank you for this experience! In the future, I won't go through the world as until today, on the contrary , despite of my disability and all difficulties I'll try everything to turn my back to this country!"

FAINTING AND FATIGUE: Causation or Coincidence.

By Dr. Richard L. Bruno

As the former autonomic nervous system fellow at New York's Columbia-Presbyterian Medical Center, and in mycurrent incarnation studying chronic fatigue in polio survivors, I have read with special interest the reports from Johns Hopkins University describing neurally mediated hypotension (NMH) in adults and adolescents with CFIDS.

In June 1995, we presented a paper to the American Congress of Rehabilitation Medicine describing several of our post-polio patients who have had episodes of vasovagal syncope. One patient with a 10-year history of severe, chronic and disabling post-polio fatigue had a history of frequent fainting 35 years before she ever experienced fatigue.

The 1995 North American Post-Polio Survey

Because of fainting episodes in our patients, we included questions about fainting and late-onset fatigue in the 1995 North American Survey of Polio Survivors conducted last Fall. We have recently analyzed data from the first 1,000 respondents to the survey. As was seen in our two previous National Post-Polio Surveys, chronic fatigue was the most frequent symptom in polio survivors; the daily fatigue rating was reported as "moderate" or higher in 76 percent of the 665 polio survivors, versus 29 percent of the 406 non-disabled controls.

An equal number of polio survivors and controls (44%) reported at least one fainting episode during their lifetimes. The causes of fainting - from physical trauma to emotional stress - were identical in polio survivors and controls. However, the occurrence of even one fainting episode was significantly related to having a daily fatigue rating of moderate or greater in both polio survivors and in controls. Polio survivors who passed out at least twice in their lives had a 14 percent higher daily fatigue rating and controls had a 31 percent higher daily fatigue rating as compared to those who never had fainted. These finding suggest that there may be a relationship between fainting and fatigue in polio survivors and the general population, as well as in people with CFIDS.

Physiology of Fainting and NMH

The question raised by our data and those from Johns Hopkins is: why do fainting, NMH and fatigue appear to go together? The answer may lie in the physiological mechanisms that regulate blood pressure and actually trigger NMH.

NMH has been said to result from a "miscommunication between the heart and the brain which causes blood pressure to lower when it should rise." Actually, NMH is a survival mechanism, hard-wired into the brain, that turns on when the autonomic nervous system (ANS) is unable to stop blood pressure (BP) from falling. If BP falls for any reason (e.g., loss of blood from a cut artery) pressure detectors in the carotid arteries of the neck (the baroreceptors) stop firing. The silence of the baroreceptors is "heard" by BP regulation centers in the solitary tract and dorsal vagal nuclei, which release the brake on heart rate that is normally provided by the cardiodepressor center of the reticular formation. The BP regulation centers also trigger the release of vasopressin and norepinephrine, neurochemicals that constrict blood vessels and make the heart beat harder and faster, and should help to increase BP. However, if these measures cannot stop BP from falling, the amount of blood returning to the heart will decrease. If the heart continues beating hard and fast even though it is nearly empty, the heart muscle will be damaged. Stretch receptors in the heart detect that it is "beating on empty," and send a signal to the dorsal vagal nucleus to protect the heart by stopping its beating for a few seconds. With the heart stopped, BP falls to zero and causes the faint of NMH.

But, even fainting has a protective function (if you don't knock yourself out falling to the ground). Lying flat, your brain will be at the same level as your heart. Without gravity pulling blood toward your feet, the heart will have an easier time increasing BP, pumping your remaining blood to your brain and (hopefully) waking you up again.

A Physiological Link Between Fainting and Fatigue.

If we assume that the heart itself is normal, there must be something wrong with the BP regulation centers in the brainstem that causes fainting in our post-polio patients and NMH in people with CFIDS. In the case of polio survivors, damage done by the poliovirus to the brain suggests that fainting should be expected. The poliovirus frequently and severely damaged the brainstem, especially the reticular formation. The RF contains the cardiodepressor center that is responsible for "putting the brake" on heart rate. Of those with acute "bulbar" polio ("bulbar" meaning associated with the brainstem) 73 percent had hypertension and rapid heart rate and five percent died of cardiovascular collapse.

Importantly, the RF is not only responsible for heart regulation, but also brain activation, keeping us awake and allowing us to focus attention. Using MRI of the brain, we have found lesions of the RF and its connections to the cortex, as well as clinically impaired attention on neuropsychological tests, in polio survivors with chronic fatigue. Recently, Costa, et al. found that decreased perfusion of the brainstem on SPECT was the only physiological finding that differentiated people with CFIDS from patients with depression, neurological disease and controls. These data support our hypothesis that damage to the brainstem "reticular activating system" may be a cause of chronic fatigue in polio survivors and in patients with post-viral fatigue.

Outside of the RF, but in the same area of the brainstem, lie the other cardiovascular control centers. The dorsal vagal nucleus, responsible for activating the stomach and slowing the heart, was damaged in 55 percent of those who had bulbar polio, as were the vestibular nuclei. Nausea, reported by 70 percent of those who have NMH, was seen in 27 percent of those with acute polio and attributed to poliovirus lesions in the vestibular nuclei.

Also outside the RF but damaged by the poliovirus, were the nucleus ambiguus and solitary tract nuclei, the main centers for blood pressure regulation. These nuclei "communicate" with the heart via the vagus nerve, regulating blood pressure by sensing and altering the force and rate of the heart's contraction.

The Chemistry of Fatigue, Fainting and NMH.

Recent research has also found chemical abnormalities that may be related to fatigue and fainting in polio survivors and CFIDS and NMH. We found a marked blunting of adrenocorticotrophic hormone (ACTH) release in polio survivors that was correlated with daily fatigue severity. The secretion of corticotropin releasing hormone (CRH), which stimulates ACTH release, had already been found to be decreased in patients with CFIDS. CRH is secreted by the paraventricular nucleus (PVN) of the hypothalamus, which is known to be damaged by the poliovirus. Both ACTH and CRH are brain activating hormones, and their decreased secretion could cause symptoms of fatigue.

The PVN of the hypothalamus also produces the vasoconstrictor neurochemical vasopressin, the secretion of which is also impaired in people with CFIDS. Thus, the PVN may be damaged in polio survivors and people with CFIDS, causing impaired brain activation and faulty BP regulation in both groups.

The Coincidence of Fainting and Fatigue

Taken together, these findings suggest that polio survivors may be predisposed to fainting because of poliovirus damage to their brainstem cardiodepressor and blood pressure regulation centers and PVN. However, it is important to note that many viruses besides polioviruses (e.g., the Coxsackie viruses) are also known to frequently and preferentially damage the brainstem, especially the reticular formation. People with post-viral fatigue may have similar brainstem and hypothalamic damage as is seen following poliovirus infection, as Costa's finding of decreased brainstem perfusion in CFIDS suggests. Thus, damage to cardioregulatory centers could be responsible for NMH in people with CFIDS. But what of the coincidence of fainting and fatigue?

Since the cardioregulatory centers are either part of or lie close to the reticular activating system, it would be surprising if fainting and fatigue did not occur together. Damage to the RF alone could both decrease brain activation and impair BP regulation. The question that remains is whether NMH is the "cause" of chronic fatigue or if it is just coincidental in those who have chronic fatigue. At this early stage in the research, the answer to both of these questions appears to be "yes."

The Johns Hopkins team reported that 47 percent of their adult CFIDS patients and 57 percent of their adolescent patients with NMH had "complete or near complete resolution of all symptoms" after receiving blood pressure elevating therapies. Could the resolution of fatigue symptoms in CFIDS patients whose NMH was treated have resulted from elevated BP increasing brainstem perfusion, thereby enhancing the functioning of the reticular activating system, or by elevated BP directly increasing perfusion of the brain? SPECT scans in people with CFIDS whose symptoms disappear when their BP is increased could answer these questions.

But what of the nearly 50 percent of patients whose CFIDS symptoms did not respond or were only "somewhat better" after NMH treatment? Could NMH in these individuals just be a coincidence of generalized damage to the brainstem, including the BP regulation centers? Could fatigue symptoms in these individuals actually result from damage to the brainstem's reticular activating system, or the hypothalamus or the immune system? Only blinded, placebo-controlled trials of treatments for NMH,

combined with SPECT scans of the brainstem, measurement of CRH, norepinephrine, and vasopressin, and assessment of the individual blood pressure and heart rate regulation pathways to and from the brain stem will provide answers to these important questions.

Dr. Richard L. Bruno is chairperson of the International Post- Polio Task Force and director of The Post-Polio Institute and The International Centre for Post-Polio Education and Research at Englewood (New Jersey) Hospital and Medical Center.

Fun House Mirror

by Millie Malone Lill

One of my favorite pastimes is listening to an audiobook on my mp3 player. Mostly, I enjoy fiction, especially mysteries, but I happened to load a book by Diane Keaton titled Lets Just Say It Wasn't Pretty. She was talking about people's odd perceptions of beauty. Someone had compiled a list of The Ugliest Celebrities. I was expecting to hear about people who were truly not good looking. Guess who was on the list. Angelina Jolie, and, among others, Diane Keaton.

These people are ugly? No! They are beautiful. But it got me thinking about our own self-images. In my case, I have always been self conscious about my appearance. My mother was a tiny little woman and in her mind, anyone over 5' tall and weighing more than 100 lbs was huge, obese and lazy. Lazy was the absolute worst thing she could think of to call anyone. She thought that I was enormous at 5'3" tall and about 120 lbs. I think, now that I look back, that she was really just embarrassed that the daughter she'd waited for so long was not perfect. She seemed to feel that my having contracted polio was something that reflected badly on her. She never forgave me for it.

I've spoken to many polio survivors over the years and to my complete astonishment, my mother was not unique in her attitude. Lots of polio mothers were angry with their children for getting what was at the time considered a dirty disease. How could they hold their heads up when their children had gotten something that was similar, in those days, to the way AIDs is perceived now? Their houses were quarantined, the siblings of these children were shunned in some cases. Looked at in that light, I can forgive my mother to some extent for withholding her love and acceptance.

However, I have always believed that what a child learns in his first seven years is what remains in his mind the rest of his life. I have looked back at some of my pictures taken when I was in my 30s and 40s. I was not fat! I was actually quite slender. Some old school pictures showed me not as the largest and bulkiest child in my class but almost the smallest. I bet a lot of my women readers have had the same reaction. Compliments embarrass me because I see them as false, as people being nice to me because they want to make me feel good.

We need to erase those old fun house mirror images of ourselves. The beauty of a person is not the outward appearance, anyway. As Fred Sanford use to say, "Beauty may be skin deep, but Ugly goes clear to the bone." I am working on trying to see myself in a better light. It is hard to accept that my mother's opinion had really very little to do with me personally. It was her failure to provide a perfect child that colored her perception of me. She did everything she could to "perfect" me, all the exercises, the braces, the trips to Iowa City for doctor's visits, and then I blew it all by getting PPS.

I think it would be helpful to try to see ourselves through the eyes of those who love us. My grandchildren love my face, they loved my soft lap when they were little, and one granddaughter is

flattered when people tell us that she and I are very much alike in personality.

Breaking that fun house mirror won't give us seven years of bad luck. It might, however, give us a few years of contentment and of acceptance of ourselves just as we are. I love my friends on the polio lists and to me they are all gorgeous. Because I met so many of them online before meeting them in person, I've learned to see them inside out. Not face first, but soul first. They have the most genuine beauty a person can have.

INTRAVENOUS IMMUNOGLOBULIN (IVIG) DOES NOT TREAT PPS

by Dr. Richard L. Bruno

I've been writing since 2004 about the failure of intravenous immunoglobulin (IVIG) as a treatment for PPS in spite of glowing "press releases" from the IVIG manufacturers (please see below).

Independent researchers have reviewed the published studies on IVIG in 508 polio survivors and have come to the same conclusion: There is no evidence that IVIG helps with any PPS symptom.

**INTRAVENOUS IMMUNOGLOBULIN FOR POSTPOLIO SYNDROME:
A SYSTEMATIC REVIEW AND META-ANALYSIS.**

Yao-Hsien Huang, et al. BMC Neurology 2015, Number: 39 March 22, 2015

SUMMARY

Background: Postpolio syndrome (PPS) is characterized by progressive disabilities that develop decades after prior paralytic poliomyelitis. Because chronic inflammation has been suggested as causing the development of PPS, immunomodulatory management, such as intravenous immunoglobulin (IVIg) administration, may be beneficial.

Methods: We performed a systematic review and combined analysis of 3 published randomized, placebo-controlled trials of 241 patients and 5 prospective studies of 267 patients that evaluated the effect of IVIg in managing PPS. Pain severity, fatigue, muscle strength, physical performance and, quality of life were measured before and after IVIg infusion.

Conclusion: The present review indicated that IVIg is unlikely to produce significant improvements in pain, fatigue, or muscle strength. Thus, routinely administering IVIg to patients with PPS is not recommended.

INTRAVENOUS IMMUNOGLOBULIN (IVIG) DOES NOT TREAT PPS.

Dr. Richard L. Bruno

Chairperson

International Post-Polio Task Force

and

Director

The Post-Polio Institute and International Centre for Polio Education

PostPolioInfo.com

Web Corner

Restless Leg Syndrome and Post Polio

<http://www.ahcmedia.com/articles/135155>

Bionic Power Trousers Could Help Us Get Up Stairs

<http://www.iflscience.com/technology/bionic-power-trousers-could-help-us-get-stairs>

For those who were treated by Dr. Ponseti at the University of Iowa Hospital in Iowa City, Iowa

<http://www.ponseti.info/about-us/ponseti-international/dr.-ponseti.html>

Pennsylvania Polio Survivor Network article on Where do we start when getting mobility aids?

<http://www.papolionetwork.org/wheelchair-power-chair-scooter.html>

Sunny Roller's Blog

<http://www.sunnyrollerblog.com/?p=3340>

Explanation of various vaccinations

<http://www.cdc.gov/vaccines/hcp/vis/current-vis.html>

Polio Australia newsletter

<http://www.polioaustralia.org.au/>

Check to see if this is available in your area: Home Instead, In home care for elderly/disabled

<https://www.homeinstead.com/>

Take action on Medicare therapy caps!

<http://www.spinalcordinjury-paralysis.org/blogs/16/2397>

A Little Bit of Humor

In case you needed further proof that the Human Race is doomed through stupidity, here are some actual label instructions on consumer products:

1. On a blanket from Taiwan - NOT TO BE USED AS PROTECTION FROM A TORNADO.
2. On a helmet mounted mirror used by US cyclists - REMEMBER, OBJECTS IN THE MIRROR ARE ACTUALLY BEHIND YOU.
3. On a Taiwanese shampoo - USE REPEATEDLY FOR SEVERE DAMAGE.
4. On the bottle-top of a (UK) flavored milk drink - AFTER OPENING, KEEP UPRIGHT.
5. On a New Zealand insect spray - THIS PRODUCT NOT TESTED ON ANIMALS.
6. In a US guide to setting up a new computer - TO AVOID CONDENSATION FORMING, ALLOW THE BOXES TO WARM UP TO ROOM TEMPERATURE BEFORE OPENING.

(Sensible, but the instruction was **INSIDE** the box.)

7. In some countries, on the bottom of Coke bottles - **OPEN OTHER**

