



Bruno “Bytes”

May, 2019

From Dr. Richard L. Bruno, HD, PhD
Bits and Tidbits from the Post-Polio Coffee House

On the topic of a Central Registry for Polio Survivors (5/3/2019)

Original Post: Has anyone looked for their hospital records from the 50's? I think I know the right hospital name and town, but I can't seem to get any further.

Dr. Bruno's Response: Unfortunately, there is no central registry, or even a state registry, for polio survivors' records.

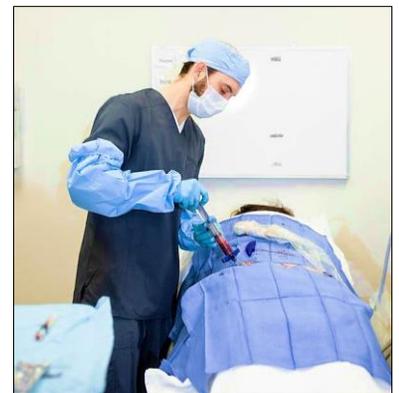
On the topic of Modafinil for PPS Fatigue (5/4/2019)

Original Post: I've been so tired lately that I don't have the strength to hold a conversation. I'm considering Modafinil to help me feel less tired.

Dr. Bruno's Response: A large, double-blind, placebo controlled study showed that Modafinil had NO effect on fatigue in polio survivors!

On the topic of Stem Cell Treatments (5/14/2019)

Dr. Bruno's Original Post: STEM CELLS - THE NEW SNAKE OIL. Most researchers, including those at the National Institutes of Health, think that efforts to sell therapies involving adult stem cells, which can develop into different types of cells to replenish tissue, have gotten way ahead of the science. Rogue clinics offering other kinds of procedures have flourished, accused of blinding people by injecting cells into their eyes, mixing stem cells with smallpox vaccine to treat cancer or causing severe infections by administering contaminated blood from umbilical cords into patients' joints or spines.



Stem Cell Treatments Flourish With Little Evidence That They Work

The F.D.A. has taken an industry-friendly approach toward companies using unproven cell cocktails to treat people desperate for relief from aging or damaged joints.

By Denise Grady and Reed Abelson May 13, 2019 (Article abbreviated for space). The complete article is available at <https://www.nytimes.com/2019/05/13/health/stem-cells-fda.html>

A surgeon recommended a hip replacement, but Kenneth Cevoli said no thanks. “They're really quick to try to give you fake joints and make a bunch of money off you,” he said.

At 71, Mr. Cevoli, a high-school guidance counselor in Teterboro, N.J., coaches cross country, teaches mogul skiing, surfs and works summers as a lifeguard on Cape Cod. Despite pain in his left hip and knee, he questioned the need for major surgery, worrying it would sideline him for too long. Instead, he tried an increasingly popular treatment, in which stem cells are extracted from a patient's own bone marrow and injected into worn or injured joints to promote healing.

Many people have become captivated by the idea of using stem cells to fix their damaged joints, and some claim to have been helped. But there is no clear evidence that these treatments work, and their safety has yet to be established. Most researchers, including those at the National Institutes of Health, think that efforts to sell therapies involving adult stem cells, which can develop into different types of cells to replenish tissue, have gotten way ahead of the science.

Even so, hundreds of clinics have popped up around the country to meet the demand. Some of the clinics also inject joints with platelet-rich plasma, a solution of platelets extracted from the patient's own blood. A few employers have even agreed to provide insurance coverage for the treatments.

There is almost no regulatory oversight of orthopedic procedures using bone-marrow extracts or platelets, which are regarded as low risk. While the Food and Drug Administration insists that [it does have the authority](#) to regulate stem cell treatments, it adopted an industry-friendly approach in 2017 by giving companies a three-year grace period in which to describe their products or treatments so the agency can determine whether they meet the criteria of drugs that would require agency approval. So far, few companies have submitted any information.

In the meantime, rogue clinics offering other kinds of procedures have flourished, accused of blinding people by injecting cells into their eyes, mixing stem cells with smallpox vaccine to treat cancer or causing severe infections by administering contaminated blood from umbilical cords into patients' joints or spines. In some of the worst cases, patients had already been harmed before the agency took any action, and the patients took legal steps themselves, suing the clinics that injured them.

"We had our day job clearly cut out for us," said Dr. Scott Gottlieb, who was the F.D.A. commissioner until April. There is, he added, a lot of "really bad stuff."

Dr. Gottlieb spoke in an interview after leaving office. A spokeswoman for the agency said current officials declined to be interviewed. But she said the agency had taken about 45 enforcement actions against stem cell businesses in the past year, including two court cases and various types of warning letters. Many scientists are skeptical about the treatments being offered, and have called for stricter oversight. "I believe strongly that it isn't ethical to charge patients for unproven therapies like these and raise what are likely to be false hopes," said Paul S. Knoepfler, a stem cell researcher at the University of California, Davis. He said that some properly conducted studies on platelet-rich plasma suggested it might help, but others did not. As for stem cells extracted from bone marrow, Dr. Knoepfler said well-controlled studies were even scarcer, also with mixed results. Rigorous studies are essential, because symptoms from arthritis and injuries can wax and wane, making it hard to determine whether treatments work.

In part because of the scant data, no stem cell or platelet treatments are approved by the F.D.A. for orthopedic problems, and most insurers don't cover them. Still, many patients pay thousands of dollars out of their own pockets.

Mr. Cevoli was treated in December by a doctor in Wayne, N.J., affiliated with a company called Regenexx, one of the boldest players in the growing industry. Based in Des Moines, the company has dozens of affiliated clinics around the country, specializing in treating orthopedic problems with patients' own platelets or stem cells from their bone marrow. And Regenexx has persuaded some large, self-insured employers to cover its treatments.

The doctor in Wayne injected stem cells and platelets into Mr. Cevoli's knee, fitted him with a brace and sold him a vitamin supplement made by Regenexx to promote healing. The procedure cost \$6,900, and was not covered by insurance. Four months later, Mr. Cevoli said he thought the procedure was helping. He skied during the winter, and has begun running a few times a week.

"There was pain involved, and there is still swelling," he said. "The strength is starting to increase significantly in that left knee. I'm advised that there will be more of an improvement to come in the next couple of months." Although he's been told that the stem cell treatments are less successful in hips than in knees, he hopes to have his hip treated anyway, maybe in late summer or early fall.

Navigating the existing guidelines

Some stem cell businesses have carefully navigated F.D.A. rules to stay just inside the lines. The agency regulates cell and tissue products, but treatments that use a patient's own cells do not require the agency's approval if the cells are "minimally manipulated," meaning that they have not been cultured or multiplied in a lab, and no drugs or other substances have been added. (Section abbreviated)

Needed: Real data

Scientists say that research on stem cells does hold tremendous promise for treating many diseases. But those goals are years away.

"There's not a whole lot you can say definitely about whether these therapies are efficacious," said Scott Noggle, the senior vice president of research at the New York Stem Cell Foundation, a nonprofit scientific group. "Until you do well-controlled clinical trials showing it works in humans, the question is still up in the air."

Bone marrow contains many different types of cells, and unless the extracts used to treat patients are analyzed, it is not clear which cells they are receiving, Dr. Noggle said. (Section abbreviated)

[On the topic of Bracing for Polio Survivors](#) (5/14/2019)

Dr. Bruno's Original Post: We have lots of questions about bracing to keep walking. Read "[Bracing and Polio Survivors](#)" in the [articles](#) section of the Encyclopedia of Polio and PPS.

Remember: To walk can be painful, to roll is divine!

[On the topic of Forgetting Words \(5/14/2019\)](#)

Original Post: I had a neuropsychological exam and one of the test results is verbal memory loss, meaning wherever is said to me the next minute is gone. I understand now why I was forgetting everything said to me. So, I have to write everything now.

Dr Bruno's Response: Since word finding is a Post-Polio Sequelae, polio survivors should not be given a quickie verbal memory test for dementia since false positives will result.
(Abbreviated From [Medscape](#) by Megan Brooks 11/2018) -

Three Common Dementia Screens Faulty, Inaccurate

"Three brief cognitive assessments often used in primary care settings to identify patients with cognitive impairment who could benefit from a full diagnostic workup for dementia are often inaccurate, new research shows. The three tests are the Mini-Mental State Examination (MMSE), which assesses orientation to time and place and the ability to remember words; the Memory Impairment Screen (MIS), which focuses on the ability to remember words; and Animal Naming (AN), which involves naming as many animals as possible in 60 seconds.

Sign in for the complete article: <https://www.medscape.com/viewarticle/905800>

Please read the articles under "Fatigue" and "Word Finding Difficulty" in the [Encyclopedia of Polio and PPS](#) for information you can share with your physician.

[On the topic of Electrolyte Levels \(5/19/2019\)](#)

Original Post: I have trouble keeping my electrolyte levels - iron, potassium, sodium, vitamin B, calcium etc, where they're supposed to be. Is this polio related?

Dr. Bruno's Response: This is not a polio issue but certainly needs tending!

[On the topic of Gabapentin for Pain \(5/21/2019\)](#)

Dr. Bruno's Original Post: Gabapentin, et al: Do they even provide a placebo effect?

"In many well-controlled studies they found there was less than a one-point difference on the 10-point pain scale between patients taking the drug versus a placebo, a difference often clinically meaningless. Despite the limited evidence of benefit, Dr. Johansen found that the number of people taking gabapentinoids more than tripled from 2002 to 2015."

Millions Take Gabapentin for Pain But There's Scant Evidence It Works.

By Jane E. Brody N.Y. Times May 20, 2019

"There is very little data to justify how these drugs are being used and why they should be in the top 10 in sales," a researcher said.

One of the most widely prescribed prescription drugs, gabapentin, is being taken by millions of patients despite little or no evidence that it can relieve their pain.

In 2006, I wrote about [gabapentin](#) after discovering accidentally that it could counter hot flashes. The drug was initially approved 25 years ago to treat seizure disorders, but it is now commonly prescribed off-label to treat all kinds of pain, acute and chronic, in addition to hot flashes, chronic cough and a host of other medical problems.



The F.D.A. approves a drug for specific uses and doses if the company demonstrates it is safe and effective for its intended uses, and its benefits outweigh any potential risks. Off-label means that a medical provider can legally prescribe any drug that has been approved by the Food and Drug Administration for any condition, not just the ones for which it was approved. This can leave patients at the mercy of what their doctors think is helpful.

Thus, it can become a patient's job to try to determine whether a medication prescribed off-label is both safe and effective for their particular condition. This is no easy task even for well-educated doctors, let alone for desperate patients in pain.

Two doctors recently reviewed published evidence for the benefits and risks of off-label use of gabapentin (originally sold under the trade name Neurontin) and its brand-name cousin Lyrica (pregabalin) for treating all kinds of pain. (There is now also a third drug, gabapentin encarbil, sold as Horizant, approved only for restless leg syndrome and postherpetic neuralgia, which can follow a shingles outbreak.)

The reviewers, Dr. Christopher W. Goodman and Allan S. Brett of the University of South Carolina School of Medicine, found the drugs, called gabapentinoids, wanting in most cases for which they are currently being prescribed. As Dr. Goodman said in an interview, "There is very little data to justify how these drugs are being used and why they should be in the top 10 in sales. Patients and physicians should understand that the drugs have limited evidence to support their use for many conditions, and there can be some harmful side effects, like somnolence, dizziness and difficulty walking." Furthermore, for patients prone to substance use disorders, like an opioid addiction, the gabapentinoids, although they are not opioids, are potentially addictive, he said.

The gabapentinoids are symbolic of three currently challenging problems in the practice of medicine: a deadly national epidemic of opioid addiction prompting doctors to seek alternative drugs for pain; the limited training in pain management received by most doctors; and the influence of aggressive and sometimes illegal promotion of prescription drugs, including through direct-to-consumer advertising.

Gabapentin and Lyrica, both sold by Pfizer, have been approved by the Food and Drug Administration to treat only four debilitating pain problems: postherpetic neuralgia, diabetic neuropathy, fibromyalgia and spinal cord injury. Even for these approved uses, the evidence for relief offered by the drugs is hardly dramatic, Drs. Goodman and Brett reported in *JAMA Internal Medicine* online.

In many well-controlled studies they found there was less than a one-point difference on the 10-point pain scale between patients taking the drug versus a placebo, a difference often clinically meaningless. For example, among 209 patients with sciatica, Lyrica did not significantly reduce the intensity of leg pain when compared with a placebo, and dizziness was more commonly reported by the 108 patients who took the drug. But when patients complain of pain related to conditions ranging from sciatica and osteoarthritis to foot pain and migraine, clinicians often reach for the prescription pad and order either gabapentin or the more costly Lyrica.

Following the approval of Neurontin, its producer at the time, Warner-Lambert, engaged in what the government determined was an illegal marketing campaign that resulted in sales exceeding \$2 billion a year before its patent expired in 2004. Still, the campaign succeeded in bringing gabapentin to the attention of many doctors who treat patients with persistent life-disrupting pain.

It's not that there are no other alternatives to opioids to treat chronic pain, among them physical therapy, cognitive behavioral therapy, hypnosis and mindfulness training. But practicing clinicians may be unaware of the options, most of which require more effort for the doctor than writing a drug prescription and are not as easy or accessible for patients as swallowing a pill.

As Dr. Michael E. Johansen, a family doctor in Columbus, Ohio, put it, "I use gabapentin clinically and try to stay close to the approved indications, but occasionally we run out of options when faced with patients who hurt. It's rare that these drugs eliminate pain, and I don't tell patients their pain will go away. If there's any benefit, it's probably marginal."

Despite the limited evidence of benefit, in [a study published in *JAMA Internal Medicine* in February](#), Dr. Johansen found that the number of people taking gabapentinoids more than tripled from 2002 to 2015, with more than four in five taking the inexpensive generic, gabapentin.

In 2016, 64 million prescriptions for gabapentin were dispensed, up from 39 million in 2012, [Drs. Goodman and Brett reported in *The New England Journal of Medicine*](#). They believe that the opioid epidemic partly fueled this increase. "While working in inpatient and outpatient settings," they wrote, "we have observed that clinicians are increasingly prescribing gabapentin and pregabalin for almost any type of pain."

Dr. Johansen cited several serious concerns about overuse of gabapentinoids, including "a dearth of long-term safety data, small effect sizes, concern for increased risk of overdose in combination with opioid use, and high rates of off-label prescribing, which are associated with high rates of adverse effects."

Contributing to the frequent misuse of gabapentinoids is how doctors interpret the term "neuropathic pain" for which the drugs are commonly prescribed. It is defined as pain caused by a lesion or disease of the

nervous system, leading clinicians to assume that if a drug is effective for one type of neuropathic pain, it is effective for all types, regardless of the underlying cause, Drs. Goodman and Brett suggested.

Dr. Johansen pointed out that "there is no recipe book" for treating pain with gabapentinoids. "Doctors need to work with one patient at a time and figure out what works and what doesn't work," he said. He noted that many times pain resolves with "the tincture of time" but patients and doctors may attribute improvement to the prescribed drug. For those taking a gabapentinoid, he suggested that patients' doctors readdress its use after two or three months.

But, Dr. Goodman cautioned against going off the drug cold turkey because there can be unpleasant withdrawal symptoms.

<https://www.nytimes.com/2019/05/20/well/live/millions-take-gabapentin-for-pain-but-theres-scant-evidence-it-works.html>

[On the topic of Legs Feeling like they are on Fire](#) (5/21/2019)

Original Post: Why would my legs feel like they are on fire with every step?

Dr. Bruno's Response: I often say "Feeling the burn means nerves are burning out." This is a metaphor, not what really happens, when you overuse muscles. But there could be any number of causes for burning sensation. See your doctor and rule out the others, please.

[On the topic of Vaccine Hesitancy](#) (5/23/2019)



Dr. Bruno's Original Post:

Exposing vaccine hesitant to real-life pain of diseases makes them more pro-vaccine.

22-May-2019

Newswise — The re-introduction of measles, mumps and other previously eradicated diseases to the United States is nothing short of a public health crisis. Since Jan. 1, a staggering 880 individual cases of measles have been confirmed in 24 states -- the greatest number of cases since 1994. Measles was declared eliminated in the U.S. in 2000.

The outbreaks have been attributed to an increasing number of Americans who choose not to vaccinate themselves or their children. Overcoming this "vaccine hesitancy" is a major concern for government and health agencies, which have tried a variety of approaches to convince anti-vaxers to change their minds, including mandating vaccinations in some communities.

New research from Brigham Young University professors Brian Poole, Jamie Jensen and their students finds there is a better way to help increase support for vaccinations: Expose people to the pain and suffering caused by vaccine-preventable diseases instead of trying to combat people with vaccine facts.

"Vaccines are victims of their own success," said Poole, associate professor of microbiology and molecular biology. "They're so effective that most people have no experience with vaccine preventable diseases. We need to reacquaint people with the dangers of those diseases."

Poole and his team designed an intervention for college students in Provo, Utah -- a city which ranks sixth nationally for under-vaccinated kindergartners -- with the hope to improve vaccine attitudes and uptake among future parents. The experiment was carried out with 574 students, 491 of which were pro-vaccine and 83 being vaccine hesitant, according to a pre-study survey.

For the study, half the students were asked to interview someone who experienced a vaccine-preventable disease such as polio, while the other half (serving as the control group) interviewed someone with an autoimmune disease. Meanwhile some students were also enrolled in courses that contained intense immune and vaccine-related curriculum while others were enrolled in a course with no vaccine curriculum. One student interviewed a member of their church congregation who had shingles, recalling, "The pain was so bad that she ended up at a pain management clinic where they did steroid shots into her spine. The pain meds didn't even touch her pain, even the heavy ones. For months, she couldn't leave the house." Another student interviewed her

grandmother, who suffered from tuberculosis. The student said of the experience: "I dislike the idea of physical suffering, so hearing about someone getting a disease made the idea of getting a disease if I don't get vaccinated seem more real."

Researchers found nearly 70 percent of the students who interviewed someone with a vaccine-preventable disease moved from vaccine hesitant to pro-vaccine by the end of the study -- even when they had NO vaccine curriculum. Overall, 75 percent of vaccine-hesitant students increased their vaccine attitude scores, with 50 percent of those students moving fully into pro-vaccine attitudes.

The researchers also found all vaccine-hesitant students enrolled in a course with intensive vaccine curriculum significantly increased their vaccine attitude scores, with the majority of them moving into the pro-vaccine category.

"If your goal is to affect people's decisions about vaccines, this process works much better than trying to combat anti-vaccine information," Poole said. "It shows people that these diseases really are serious diseases, with painful and financial costs, and people need to take them seriously."

Poole and coauthors hope other universities and government agencies will see their findings and consider using similar methods to improve vaccine attitudes.

<https://www.newswise.com/articles/view/713317/?sc=mwhn&fbclid=IwAR19yTQteb7p7FSV04g9CS4BDRBZsvj6jHdQ2XVEtqC45ZogYkkeCV78okE>

[On the topic of Power Chair vs Scooter](#) (5/23/2019)

Original Post: Why are power wheel chairs better for us than a scooter?

Dr. Bruno's Response: Scooters are tough on the arms when steering and your posture is terrible because you're bending over to steer. The tillers can be heavy and therefore strain your muscles while MOVING the tiller!

[On the topic of Retaining CARBON DIOXIDE](#) (5/23/2019)

Original Post: Do all polio survivors retain carbon dioxide?

Dr. Bruno's Response: Not all polio survivors retain CO2 while they are sleeping, but CO2 must be measured during pulmonary function studies and sleep studies in polio survivors! I always recommend [Dr. John Bach, MD](#) for these issues.

[On the topic Polio after the Vaccine](#) (5/23/2019)

Original Post: I was vaccinated for Polio about 6 months before I got it. In that time in between I got the Measles, then a very bad Tonsillitis before getting Bulbar Polio in July 1958. Parents who don't allow their children to be vaccinated are causing more harm than just exposing their child to a "harmless" childhood disease.

Dr. Bruno's Response: Most likely you got a bad batch of "Salk" vaccine and the tonsillitis made you vulnerable to bulbar infection by the poliovirus. The "Salk" vaccine was released in 1955 and there were still 10,000 cases of polio in the US in 1959! A 1960 commission found the "Salk" vaccine was only 72% effective and batches contained live poliovirus.

Additional Bruno "Bytes" are available for you to share in the Encyclopedia of Polio and Post-Polio Sequelae.

Go to: <http://www.papolionetwork.org/bruno-bytes.html>

Scroll down the page (through the Current Month posts).

Previous months are located there, in easily printable PDF format and are available by "clicking" on them,

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