Bruno "Bytes" – March, 2017

(Bits and Tidbits from the Post-Polio Coffee House)
Available through a "link" from www.postpolioinfo.com
(or) directly through http://www.papolionetwork.org/bruno-bytes.html

On the topic of Lack of Energy (3/15/2017)

Original Post: I am having a difficult time keeping my energy levels up. Is PPS responsible for this?
Dr. Bruno's Response: Always remember that PPS is a "diagnosis of exclusion". This sounds like a good time to see your physician.

On the topic of "Allergies" to medications (3/18/2017)

Original Post: Have any of you discovered that you are allergic to a lot of pain medications or any kind of other medication that has been prescribed to you? I am allergic to so many.
Dr. Bruno's Response: Remember: "Allergic" is not the same as "adverse reaction."

- Allergic is when your body responds to a bee sting or peanut allergy and could kill you.
- Adverse reaction is when a medication causes symptoms, like muscle pain (statins), reflux (Celebrex).

Additional Post: When I take any Sulfa Drug – I get itchy all over and my face swells up.
Dr. Bruno's Response: *That* is an allergic reaction.
Additional Post: Why is it that when we go to the doctor or the pharmacy they ask " Are you allergic to any medications" vs asking the question " Do you have any adverse to any medication"?
Dr. Bruno's Response: We should be asked both about allergies AND Adverse reactions.
Additional Post: Benadryl makes my legs "restless" for several hours, makes me want to do anything to stop the sensation. I began listing my allergies to include Benadryl since no one ever asks about "sensitivities". This causes repeated statements about how I cannot possibly be ALLERGIC to benadryl since it "helps" allergic reactions.
Dr. Bruno's Response: This is a sensitivity (a bad side effect of the drug), not an allergic reaction. Unfortunately, you have to list it as an allergy.

On the topic of Medicare Requirements for Power Wheelchairs (3/18/2017)

Dr. Bruno's Original Post: There have been questions about power wheelchairs recently. Here are the Medicare requirements. Note: The Requirement is now Upper Extremity Function NOT Strength! Therefore, pain and limited range of motion that limit function (and make pushing a manual wheelchair inappropriate) would qualify you for a power wheelchair. Talk to your Rehabilitation Physician.
https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/downloads/pmd_DocCvg_FactSheet_ICN905063.pdf

On the topic of Exercise and Chronic Fatigue (3/19/2017)

Dr. Bruno's Original Post: This article from the NY Times discusses the issue showing that Progressive Exercise Does NOT Reduce Chronic Fatigue. Daily Activities Can INCREASE Fatigue. Although this article is about Chronic Fatigue Syndrome, the physiological and symptom similarities seen in our and other's research (see http://www.postpolioinfo.com/lib_fatigue.php) suggest that there is similar damage done to the brain activating system in both.
Certainly, "progressive exercise" hurts in CFS just as in PPS.

SundayReview | OPINION

Getting It Wrong on Chronic Fatigue Syndrome

By JULIE REHMEYER and DAVID TULLER MARCH 18, 2017

What are some of the treatment regimens that sufferers of chronic fatigue syndrome should follow? Many major medical organizations cite two: psychotherapy and a steady increase in exercise. There's just one problem. The main study that has been cited as proof that patients can recover with those treatments overstated some of its results. In reality, the claim that patients can recover from these treatments is not justified by the data.

That's the finding of a peer-reviewed preliminary re-analysis of previously unpublished data from the clinical trial, the largest ever for chronic fatigue syndrome. Nicknamed the PACE trial, the core findings of the British study appeared in The Lancet in 2011 and Psychological Medicine in 2013. Patients battled for years to obtain the underlying data, and last spring, a legal tribunal in Britain, the General Regulatory Chamber, directed the release of some of the study's information.

The impact of the trial on treatment options for the estimated one million chronic fatigue patients in the United States has been profound. The Mayo Clinic, Kaiser Permanente, WebMD, the American Academy of Family Physicians and others recommend psychotherapy and a steady increase in exercise.

But this approach can be harmful. According to a 2015 report from the Institute of Medicine, now the National Academy of Medicine, even minimal activity can cause patients prolonged exhaustion, muscle pain, cognitive problems and more. In severe cases, a short conversation or a trip to the bathroom can deplete patients for hours, days or more. In surveys, patients routinely report deterioration after a program of graded exercise. The psychotherapeutic intervention also encourages patients to increase their activity levels. Many patients (including one of us) have remained ill for years or decades with chronic fatigue syndrome, also known as myalgic encephalomyelitis, or ME/CFS. It can be triggered by a viral infection, resulting in continuing or recurring immunological and neurological dysfunction. The Institute of Medicine dismissed any notion that it is a psychiatric illness.
Proponents of these therapies argue that these very sick patients harbored "unhelpful beliefs" that they had an organic illness that limited their capacity to exert themselves. According to this theory, patients are deconditioned from too much rest and can recover if they overcome their fear of activity and get back into shape.
But as the new re-analysis by an academic researcher and three patients showed, the promise of recovery using the two treatments appeared to be an illusion. When the study's findings were first published, patients and some scientists noted a stunning problem: The investigators had weakened their outcome measures from their trial protocol so much that participants could actually deteriorate on physical function and still qualify as "recovered." Thirteen percent entered the trial already having met the definition of "recovered" on that measure. The investigators have argued that this didn't matter since participants also had to meet additional recovery criteria.

These critiques received little attention until 2015, when Virology Blog, a science site, published a 15,000-word investigation of PACE written by one of us. This led dozens of scientists and clinicians to demand that The Lancet seek an independent review.
In December, the journal Fatigue: Biomedicine, Health and Behavior published the re-analysis of some of the data. The PACE investigators claimed in the journal Psychological Medicine that 22 percent of those undergoing either psychotherapy or graded exercise "recovered" from their illness. But that was not based on the study's original definition for recovery but on the looser one adopted by the researchers after the trial began.
Using the original definition, the re-analysis found that 7 percent or less had "recovered" with no statistically significant differences between those who did and did not receive the treatments. In their response, the investigators argue that there is no "generally agreed-on measure of recovery."
Last week, Virology Blog posted an open letter to Psychological Medicine, which one of us helped draft and which was signed by more than 100 clinicians, scientists, experts and patient groups, requesting the retraction of the PACE recovery study results to "protect patients from ineffective and possibly harmful treatments." The journal has said it has no plans to retract the study but is open to publishing a re-analysis of data in any papers it has published.
In The Lancet, the trial also claimed that around 60 percent of patients in the exercise and psychotherapy arms "improved." But according to the investigators' own recent re-analysis of their data, using their stricter protocol measure of improvement rather than the looser one they used for The Lancet, only about 20 percent receiving each therapy in addition to medical care "improved" — and half of those would have improved with specialized medical care alone.

Even that limited finding is questionable. The improvement rates and other reported findings were based largely on patients' subjective self-ratings, which are vulnerable to bias. In contrast, none of the trial's objective measures supported the claims of treatment success.
In short, this episode has damaged public trust in science.
Doctors and medical organizations must stop recommending these two therapies for ME/CFS as treatment options. Next, the disputed findings must be retracted. Finally, health agencies must ramp up funding for medical research to develop accurate diagnostic tests and pharmacological treatments.
A million Americans are waiting.
https://www.nytimes.com/2017/03/18/opinion/sunday/getting-it-wrong-on-chronic-fatigue-syndrome.html?ref=todayspaper

Additional Post: My mother (who was a physician) thought that at least some of the Chronic Fatigue Syndrome patients were people who had a very light case of polio, (maybe were even unaware they had it), and experienced the post-polio symptoms we are all so familiar with.
Dr. Bruno's Response: You have a very bright mother. The physiological and timing of polio outbreaks and outbreaks of chronic fatigue are remarkable. That is why it came to the attention of our ICPE. I cover this in detail (throughout multiple chapters) in *The Polio Paradox*.

On the topic of Polio Survivors and Pain (3/26/2017)

Dr. Bruno's Original Post: This study, "to describe the frequency, intensity, and impact of pain in persons with postpoliomyelitis syndrome (PPS)", is from the US National Library of Medicine – of the NIH. Although I feel that the number of subjects is too small, the findings are useful.
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2651567/

On the topic of Power Wheelchair (and Equipment) "Scams" (3/28/2017)

Original Post: It's so good to know I'm going to be mobile. I've been approved for a motorized chair and a company called Aeroflow has been calling. They say they got Medicaid/Medicare approval for a chair for me. It is a portable indoor/outdoor chair called Cobra and I had no choice of other power wheelchairs. I was concerned because Aeroflow wanted my bank info to "secure" it. I said no, I don't want to do that. Aeroflow plan to bring it to me but I think I should maybe call Medicaid and find out just what they approved.
Dr. Bruno's Response: WARNING! Never give out your bank information!
No choices? No way!!! They're going to bring you a portable indoor/outdoor chair called a Cobra? That is either a Cobra GT4, a Heavy Duty Power Scooter (https://www.hoveround.com/mobility-solutions/mobility-scooters/four-wheel/cobra) that's far from "portable" without a crane and not intended for in-home use as Medicare requires or a Chinese-made power wheelchair (http://www.cobra-wheelchair.com))
Aeroflow told you they want your bank info to "secure" it. If they are asking for your bank account information, they don't have approval. You have to go through the steps for Medicare and meet requirements for Medicaid. Did your doc write the Rx and describe your wheelchair evaluation in his notes, as Medicare requires? Were you fitted by a Medicare-certified therapist for the chair as Medicare requires?
Aeroflow is using high-pressure sales. Don't ever deal with any company that forces ONLY ONE device on you, and doesn't allow you to try multiple pieces of equipment. Also, never buy a wheelchair from a company that doesn't have a vendor in your state and hopefully close to you.
Additional Post: I've been going through the correct process of getting a new wheelchair, with the doctor, PT etc. I wish I had known this before. The first chair I got was through the Scooter Store and it was a horrible experience. The chair did NOT work for me! Since Medicare and my insurance helped pay for it I wasn't eligible for another chair for 5 years. I am so happy you are warning people about these scams.

On the topic of Depression during Menopause (3/30/2017)

Dr. Bruno's Original Post: Although major depression is not more common in polio survivors, it does occur. Ladies, take note please…

"First-of-its kind study finds number of traumatic experiences and when they first occur significantly affects the risk of depression during menopause."

http://www.newswise.com/articles/trauma-and-stress-in-teen-years-increases-risk-of-depression-during-menopause-penn-study-shows

Penn Medicine

TRAUMA AND STRESS IN TEEN YEARS
INCREASES RISK OF DEPRESSION DURING MENOPAUSE.

Newswise — PHILADELPHIA – Although depression is common during a woman's transition to menopause, understanding who is at-risk of experiencing major depressive disorder (MDD) during this period of hormonal fluctuation were previously unknown. Now, a new study shows that women who experience multiple traumatic events during childhood or adolescence have a significantly increased risk of depression in the years leading into menopause (known as perimenopause). In particular, women who experienced their first traumatic event in their teens are especially susceptible to depression during perimenopause, even if they had previously never had depression. Conducted by researchers at the Perelman School of Medicine at the University of Pennsylvania, the study is the first to focus on the role of childhood adversity in the onset of MDD during the menopause transition, and how the onset of MDD might be affected based on when the traumatic event occurred. Results are published in The Journal of Clinical Psychiatry.

"Our results show that women who experience at least two adverse events during their formative years – whether it be abuse, neglect, or some type of family dysfunction– are more than twice as likely to experience depression during perimenopause and menopause as women who either experienced those stressors earlier in life, or not at all," said lead author **C. Neill Epperson, MD**, a professor of Psychiatry and Obstetrics & Gynecology at the Perelman School of Medicine at the University of Pennsylvania, and director of the Penn Center for Women's Behavioral Wellness. "This suggests that not only does early life stress have significant and long-lasting effects on the development and function of the regions of the brain responsible for emotions, mood, and memory, but the timing of when the event occurs may be equally as important."

In the study, 243 women between 35 and 47 years old at enrollment (all deemed premenopausal with normal menstrual cycles) underwent behavioral, cognitive, and endocrine evaluations at predetermined intervals from 1996-2012. Over the 16 years, each woman also completed roughly 12 assessments for cognition and mood, as well as blood samples to measure hormone levels. "Following these women for so many years allowed us to track the significant changes many of them experienced with the onset of the transition to menopause" said **Mary Sammel, ScD**, a professor of Biostatistics in Penn's Center for Clinical Epidemiology and Biostatistics, and a co-author on the study. Between study years 14 and 16, phone interviews were conducted to assess menopause status, and in year 16, researchers used an Adverse Childhood Experiences Questionnaire (ACE-Q) to assess the relationship between stressful or traumatic events experienced in adolescents and health outcomes.

In the sample, 39.5 percent, 22.2 percent and 38.3 percent of women reported having experienced 0, 1 or 2 or more ACEs, respectively. The most commonly reported ACE were emotional abuse, parental separation or divorce, or living with someone with alcohol or substance abuse. Most ACEs had occurred before the onset of puberty, suggesting that these traumatic and stressful events typically begin quite early in development.

Results of the study showed that 52 women (22.4 percent) were diagnosed with MDD prior to experiencing any menstrual irregularity (premenopause), while 48 (20.7 percent) experienced their first MDD during perimenopause. Notably, women who reported two or more ACEs after the onset of puberty were 2.3 times more likely to have their first experience of MDD during perimenopause, compared to those who did not experience any ACEs, but were not more likely to have been diagnosed with MDD previously.

The authors say the finding suggests that the hormonal changes that occur during menopause may unmask previously undetected risk for depression in women who experienced ACEs, particularly when the events occurred after puberty.

"There's clearly a strong link between childhood adversity and risk of depression, throughout a woman's life, but particularly during the transition to menopause," said senior author **Ellen W. Freeman, PhD**, a research professor of Obstetrics & Gynecology at Penn, noting that dramatic changes in hormone levels are experienced during both puberty and menopause. "Our study points to the need for more research examining the long-term brain effects of childhood adversity, particularly around the time of puberty."

The authors say that although the study is based on nearly 3,000 assessments, further research is needed to determine the effects of frequency and severity of ACEs, and the potential impact of hormone therapy on the risk of MDD during menopause.

Other Penn authors on the study include Mary Sammel, Tracy Bale, Deborah Kim, Stephanie Scalice, Katharine Freeman.

Funding for the research was provided by the National Institute of Mental Health and Office of Research on Women's Health (P50MH099910), the National Institute on Drug Abuse (K24 DA030301 and R01 DA37289), and the National Institute on Aging (R01 AG048839 and R01 AG012745-15).

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