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Information and Support for the ME/CFS/FM Community
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INTRAVENOUS FLUID AS A TREATMENT FOR ME/CFS

Upcoming Conference: The International Association for Chronic Fatigue Syndrome (IACFS) will be having its bi-annual conference in Ft Lauderdale, FL co-hosted by the Patient Alliance for Neuroendocrine-immune Disorders Organization for Research and Advocacy (PANDORA). This conference will be held at the ocean-front Bahia Mar Resort. The patient conference will be January 10th and 11th, and the research conference will be the 12th, 13th, and 14th. The patient conference will be an overview and review of the science and geared for patients and family of patients; the research conference will be technical and fast paced.

I think this is an excellent conference for patients and their families to attend. They should come a day or two early and stay a day or two to relax and talk with new friends afterwards. It is nearly impossible for patients with ME/CFS to have a vacation, but give it a try. It is even possible that you could learn something. If you are a patient, plan the trip carefully, and PANDORA may be able to give you some help and tips. More information at www.aacfs.org or www.pandoranet.info.

Introduction

The newsletter today is my first discussion of intravenous saline as a treatment agent for ME/CFS. I have now been using this treatment for nearly six years and wish to share my thoughts. While I plan to be open, honest and even blunt about this treatment, I will not compromise the confidentiality of the

patients treated. I have nothing to sell, and I am not encouraging this treatment as it has not been rigorously tested. However, I do not think I am witnessing a placebo response, and all things considered, it is the most effective treatment for severe ME/CFS that I have found in my 21 years of looking. But it has serious drawbacks and risks.

Background

My first exposure to this treatment was nearly twenty years ago when a patient I knew was seeing a nutritional MD and receiving vitamins in intravenous fluids. This patient reported that she would get a “lift” for a day or so after the treatment. But taking huge doses of vitamins orally did not give her the same response.

A few years later came the intravenous gamma globulin trials, and some people had a temporary response after the IVIG. But at a thousand dollars a treatment this could not be continued. I wondered why the IVIG worked better than intramuscular injections.

Infection with an antibiotic-sensitive bacteria was always a hot topic and I undertook a trial with three weeks of high dose intravenous antibiotics. Patients had an improvement during the treatment which was assumed to be due to the antibiotic. Some people had a reaction called a “Herxheimer” reaction consisting of chills, fever and shaking that was assumed to be an allergic reaction to killed microorganisms in the blood stream. More on that later.

First Trials

The first patient to use this treatment had a very severe case of ME/CFS; she had been disabled for years and bed-ridden for nearly two years. She had been having nearly constant syncope and pre-syncope and had been admitted to a first rate hospital for nearly six weeks. They then concluded that these were “pseudo-seizures” and that she was a fruitcake and sent her home without a follow-up appointment.

I knew her and her family well and we had lengthy discussions about a trial of intravenous saline to increase her circulating blood volume which we had measured to be low. She agreed and with the first bag of saline the “pseudo-seizures” stopped and did not return. At three months of daily infusions of 1 liter of normal saline, she was able to be up and around the house for several hours a day. At six months of treatment she was able to volunteer at her church for three hours a day. At one year of infusions she returned to full time work and has remained working for nearly five years.

She has had the severe complications of this treatment. On four occasions she has had an infection of the indwelling catheter (PICC line or Mediport), and on each occasion the line was surgically removed and treatment was started with antibiotics. She remained without the IV fluids for several weeks and on each occasion she would slide down toward her previously disabled state. She has elected to

continue the IV saline despite the serious infection risks as she can lead a nearly normal life with the indwelling catheter.

There are several important things to consider: 1) the IV saline has not cured anything, it has merely improved the orthostatic intolerance and fatigue, pain, and other symptoms; 2) with the saline infusions she can work full time and lead a nearly normal life; 3) with the saline infusions she has severe blood stream infections that require urgent removal of the intravenous line and high dose antibiotics; 4) she feels that the risks and drawbacks of the treatment are justified by the improved activity and decreased symptom intensity.

Results to Date

Over the past six years approximately twenty five other patients have had placement of PICC line or Mediport and daily normal saline infusions. Three patients could not tolerate the IV fluids because it made them feel more ill, and the fluids were stopped after several days. Three other patients used the IV saline for three months and then discontinued it because there was no benefit. It caused no harm, but it was just not doing any good. So overall, six of twenty-five (24%) did not respond, and 19 of twenty five (76%) have felt better with this treatment.

Two patients have had a line infection and have elected not to resume the fluids because of the risks. Both have said that the IV saline made them feel significantly better. Five or six other patients have had line infections but have resumed the saline treatment because they feel better and are willing to assume the infection risk. Some patients have returned to work, most have not, but all patients continuing the treatment have an improved quality of life.

It can be assumed that everyone with an indwelling IV line (PICC line) will have an infection sooner or later. A rough estimate is an infection rate of 20% per line per year. Usually a PICC line is placed for short term administration of antibiotics or chemotherapy for cancer. The line is changed every six weeks, but there is no data available for normal saline infusions. Because the blood vessels are not injured by the saline, the six week rule does not make sense and some patients have done well long term (over a year) without an infection. The key is to pull the line at the first sign of an infection and not wait, in hopes of saving the line.

It does not seem to matter how fast or slow the fluids are run in, everyone seems to develop their own preferences. A physician once called me and said the results were even better when albumin was added to the saline, but I have not tried that. I tried once weekly saline by a peripheral line but the results were one half a good day and six and a half bad days per week. No one has elected to stay with this approach. No one will believe that this treatment works until several double blind studies are run. But it is not possible to do a double blind study because you cannot have fake (placebo) intravenous line and saline. What an irony – after all these years the results are better with the usual placebo, normal saline!

I have no idea of why this treatment works. At first I thought it was because of correcting the low circulating blood volume, but we have been able to correct that with other measures (dDAVP) without

the same results. Whatever the saline is doing, it should be possible to reproduce the effects without intravenous fluids if we only knew the mechanism.

As for the “Herxheimer” reaction, the last patient started on the saline had these reactions without the antibiotics. Therefore it could not be that the body was reacting to dead microorganisms unless the saline somehow drown them. She is continuing the fluids because she is improving and described the reactions this way:

“As a CFS patient, I recently received a PICC line and administered my first IV infusion. Initially, I infused 1,000 cc's of normal saline from 12:00 until 4:00 p.m. My day was uneventful until 10:00 p.m. when for 15 minutes I was overcome with intense nausea and hot flashes. An overall feeling of sickness swept over me. The nausea and hot flashes subsided over a period of two hours. I then experienced a general feeling of sickness and mild nausea that continued throughout the night. I slept fitfully. Determined not to be discouraged and to try my utmost to make this treatment work, I resumed my infusion the next day.”

In conclusion, I feel that this treatment approach is a valid area of research, and urge researchers to attempt to understand the mechanism that appears to underlie this approach. I would be interested to hear from any clinicians/researchers concerning their experience with IV saline.

Question and Answer

Question....on people who develop CFIDS as a result of inoculation. I had one flu shot in my life, became terribly ill within 48 hours with what felt like flu. And it was the flu that never went away, eventually dx'd as CFIDS. From my years on online support groups, I know there are many more people who have reported the same occurrence.

Answer: There is no doubt that inoculations can set off the process. These shots are designed to stimulate the immune system in a way that can prevent a future infection with something like a strain of the flu virus. Therefore it is just like getting that particular flu virus strain and thus can set off the process. The vaccine that I have seen causing the greatest problem is the Hepatitis B. Maybe that is a coincidence, but.....

Question: Neither genetic susceptibility nor increased psychological stress answer this question (about increased incidence) to my satisfaction. That leads me to believe either there's a new pathogen about - or an old one acting in atypical fashion, or that the toxic overload in the environment has reached a critical mass, damaging either the brain, the immune system or both. I can't think of any other explanations. I'd love to be corrected if I'm wrong.

Answer: Because it has been ignored for so long, we really do not know if there is an increased incidence of this illness. If there is, I like the idea of a two hit process. It would go like this. Hit #1 would be silent, either with an infectious agent, a new agent, or a toxin. By itself it does not do

anything but sets the stage for hit #2 which would be the standard infection. Because of the silent first hit, the second hit causes ME/CFS. It would make a good science fiction/horror movie.

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