

Good morning. My name is Deborah Waroff. I have a bachelors degree with honors in architectural sciences from Harvard College and a MBA degree with honors in finance and international business from New York University. Prior to becoming sick with ME/CFS at the end of July, 1989, I had two successful careers, the first in journalism, including some medical and science journalism, and the second as a Wall Street analyst of the oil and gas industries.

My sickness began with a flu-like illness. After a week, thinking I was pretty much well, I went back to my ordinary activities like tennis and my biking. A week later I was sick again. This repeated several times that summer until I soon got to a point where I was never well again. I had classic symptoms. After a little activity I would just collapse, totally fold up. I also had symptoms like fevers, dizziness, upset tummy, swollen lymph glands and a new type of frequent headache. I had cognitive problems embarrassingly often, including dysphasia – putting the wrong words in sentences. I was often too weak to even talk on the phone, or after five minutes of talking I would fold. When I tried to play squash or tennis I would totally collapse for two or three days after. I recall one particularly embarrassing moment when, waiting for a meeting to begin, I fell sound asleep in my chair.

I was luckier than most people in that I was diagnosed fairly promptly by talented doctors well-respected in their professions. After just a few months my primary care doctor said “I think you have this new syndrome.” In February, 1990 an infectious disease specialist seconded the probable diagnosis, though he also gave me a whopping dose of tetracycline as I could have had lyme disease, which testing in those days often missed.

I am here today because I realize the CDC is trending toward the British position that only CBT and GET are acceptable treatments. Virtually no work is being done about other treatments. This need not be the case. And we need not wait for further data on XMRV to start to relieve the suffering of the perhaps one million people now severely disabled by the disease.

Therefore, I would like to share my experiences – experiences at least partially successful – with treatments that have proved successful for me in terms of allowing me to increase the hours and days of productive work I have been able to perform as well as improve my functioning around the home – such as being able to make a salad -- and enable normal social interactions such as having a telephone conversation.

My aim is to generate interest in further studying treatments that have helped me, with two purposes in mind. One purpose is to study the mechanisms of these treatments to further understand the disease. The second is to relieve the suffering and increase the productivity of others who share the disease of ME/CFS. I include in this the thought of making pediatric patients able to attend more days of school and have normal human interactions to develop socially.

First, I want to note that the tetracycline intervention of 1990 succeeded in producing a roughly 70% remission for nine months. Why? This is a question to investigate. I improved in February and only crashed again on December 4<sup>th</sup>, 1990.

Second, following a train of investigative thought that began with amantadine, from 1992 my wonderful pharmaceuticals doctor worked out a series of interventions involving substances that are dopaminergic and substances that are norephiphinergic. A protocol using Wellbutrin as its base enabled me to work roughly 25 hours a week for 14 months producing the investor relations column for Institutional Investor Magazine. I was just filling in for a pregnancy leave, or it might have held up longer. In addition to regularly taking Wellbutrin I intermittently took Pemoline as needed. This would be replaced with methylphenidate after Pemoline was taken off the market.

I should mention also that I take thyroid hormones. This of course would be normal for anyone scoring low on thyroid tests. But I want to add that I take a mixture of a partial dose of cytomel and a partial dose of l-thyroxine – T3 and T4 both. The cytomel is more psychoactive and more helpful to the ME/CFS.

Then something terrible happened on September 16<sup>th</sup>, 2003. My CFS doctor said my immune system broke down. In any event, my health broke down suddenly, and instead of being able to function somewhat with my treatments I became absolutely unable to function. Immediately on September 16th, I could not muster the strength to write a fax to renew my about-to-become-overdue library books. More generally I would estimate I became about 90% disabled and essentially bed-bound. I couldn't shop, I couldn't prepare food, I couldn't think. clearly. I drifted from one nonexistent day to the next, my life now wholly taken away.

I had terrible cognitive dysfunction that winter of 2003-04. I was confused. I couldn't write. I lost track of all my bills. I left off paying my bills for months, which is totally uncharacteristic as I hate late fees. I lost all track of my financial life. I was lucky the stock market was okay then, because I couldn't have told you the difference. I lost all track of my financial life

The CFS doctor did some expensive tests. It turned out. I had the classic CFS immune system problems of not enough natural killer cell activity and too much activity of T cells, the kind of immune cells that put out the chemicals in your body make you feel sick when you have a flu.

I also had a lot of infections. I had exceptionally high titres of Epstein Barr antibodies. I had high HHV6 titres. I had Chlamydia – the blood cell kind, not the venereal kind

Nothing helped.

My life was essentially over from September 16<sup>th</sup>, 2003.

And then, in March of 2005, by the grace of God, I found my way to treatment with substantial intravenous infusions of ozone gas, made from and mixed with hospital quality oxygen. Three times every week I dragged myself across midtown Manhattan, usually having to resort to a taxi, to obtain my infusions at the doctor's office.

Now to the uninitiated this may sound very peculiar, and even wacko. Or quacko. But it's not. Ozone of course is a widely used and recognized antiseptic, valued for its germ-killing properties in liquid. Intravenous ozone therapy is commonly used against pathogen-caused disease in Russia, Poland, and Cuba – all places where economics mitigate against high priced pharmaceuticals. Many papers about this can be found in Medline, attesting to its efficacy. Most notably, IV ozone has been used successfully against antibiotic-resistant tuberculosis in Russia.

Ozone is legal in New York State – among very few states – because the late Robert Atkins, best known as the diet doctor but also an alternative physician, was able to fight a very long and very expensive battle in court to make it so. It was judged legal in NY. It should be legal everywhere.

Anyway, after twelve weeks of treatment, in June, 2005, life began again. I could walk several blocks, and with enthusiasm. I could talk on the phone. I could get out and about. I could write again, for the first time in 19 months. I finished my course of treatment in June, 2006. Unfortunately, by September I had relapsed.

I started treatment again in November and after a while began to function again. But this only lasted to June of 2007. By then, as I am a person with small and delicate veins, I had used up all my viable veins for infusing the ozone. I could no longer be treated.

In August, 2007, I collapsed again. I felt sick all the time; I could do nothing. I was desperate. I knew that what I needed to restore me to life was a PICC line, so I could get my ozone infusions again. But how?

For more than a year, no longer writing, socially isolated and helpless, I tried with ever spare ounce of strength to learn about PICC lines and how to get one. Finally, in November 2008 – after more than a year of living like a corpse – I managed to get a hospital to install a pick line. This I think also falls into the by grace of God category.

Starting in early February I began to function again. I now had the strength to sit up at my desk or a library table and write. I could socialize. I could shop. I could make and eat salads.

And here I am. Via Amtrak. Having just visited Egypt. Having done research trips to France in May and August. I'm alive and thriving.

By the way, I am not the only evidence for efficacy of ozone in ME/CFS. In January, 2007, during a public session of the IACFS conference in Fort Lauderdale, I asked the

prominent European clinician Kenny de Meirlier whether ozone works for ME/CFS. Yes, he stated to the audience, but only as long as you keep doing it.

It is worth doing it. It is vastly better than the living death of ME/CFS. While we wait to work out the properties and cures of XMRV we can do any number of clinical trials that will prove what I am saying. We cannot count on the pharmaceutical industry to do it – there is no profit in it for them. It is government funds that must be allocated to relieve suffering.