

Joe's story how he learned about Dupuytren's and RT

Hi. Are you wondering what others have done about this strange disease, well here is my story. I am 58 year old male and want to share with you some of my experiences. When I was in my mid-twenties, I was diagnosed with Dupuytren's Contracture.

I was in for a physical, plagued with sinus infections, one after the next as long as I could remember. I was sent to an infectious disease specialist. At that time I had been working sanding hardwood floors for nine years. I was hoping for a cure for the sinus issue but when I was examined, he noticed "the bumps" on my hands. I thought they were blisters and what he was talking about was nodules. There was speculation that the vibrations from the equipment may have stirred up the Dupuytren's Contracture.

I was asked if I would be a participant in a trial. I saw photos of what I was in store for and said yes. I was treated with standard X-rays and then a new machine called an e-beam machine. Despite my wife's (she was a nurse) advice I completed what is now considered the "standard" treatment. I also gave up sanding floors except for friends. Now, for what you are wondering about, the side effects and results.

Side effects were minimal verses what the disease was going to do. I experienced some hand & joint pain & my fingernails grew with ridges. My hands remained a bit more sensitive and the weather caused minor aching. Would I do it again? YES! I was followed by the group that ran the test asking about my treatment results by phone for years then no more calls. I forgot about all the treatment until about 18 months ago when the nightmare began.

Here is my continuing story.

I was working with my hands, tightening a bolt with a ratchet wrench and noticed a sharp pain in my right palm. My thought were, don't do that again! I looked at my palm and thought to myself I was working so hard I had a blister... A few weeks later I noticed pain again when I was using a wrench.

I laughed because I was being treated for a plantar's wart and now my hand hurts worse than my foot.

I had a doctor's appointment and mentioned that my hands were hurting. My dermatologist and family doctor both said it was Dupuytren's Contracture. Their thoughts were ... DON'T DO ANYTHING.

About 8 months later I saw my family doctor and he freaked from the speed the DC was progressing. He contacted a surgeon and had me see him that afternoon. He did the basic hand on the table test, but never felt for nodules and told me to come back when the contracture was about 15 to 20 degrees and he would perform surgery. Hand surgery was the best way to deal with it. Until then, don't worry about it, nothing can be done.

About 4 months later I saw my family doctor and he sent me for x-rays and then to a rheumatologist. After waiting a few weeks to see him I was told I needed Enzyme injection (collagenase) but he would need to clear it with insurance company and then he schedule me. He called me a few weeks later and

told me I would need to see another rheumatologist that was approved to do the injections, but they may not do them because there are no contractures, just nodules.

Yes, I said I got my hand x-rayed and the Dupuytren's Contracture seemed to slow. If the treatment worked the first time it should work again, right? No one in our area had heard of R/T treatment. With the internet I could research Dupuytren's Contracture and found that R/T is a common treatment in Germany. Some people are saying it doesn't work but it did for me. There is so much information everyone should be able to become educated then be comfortable with the direction of treatment they take. I am not sure how initially I missed this site.

I spent days calling cancer centers, oncologists and surgeons with no luck unless I wished to travel to Germany. I was checking into costs for plane fares... I could see a cord in my RH index finger. The disease is actively accelerating. It was now or never!

One last shot to find a doctor. I called my local orthopedic doctor, they are well known leaders, and I was told by the scheduler that they use R/T to treat Dupuytren's Contracture. They could see me in 3 weeks. I asked her to verify they use R/T. How could I have missed our local practice? I waited the 3 weeks and with high spirits waited an hour after my scheduled appointment time to see the doctor. I gave him my background and asked if he would do the treatments. His response... No they don't do R/T ... it does not work. There are no documented cases of any improvement. Any radiation used to treat any disease other than cancer would increase the odds of developing cancer in the future. He basically refused to believe that R/T was effective and it worked on me 30 years ago! He was the specialist. I gave up, leaving upset and knowing I had wasted 3 more weeks; and now another doctor to pay for nothing. I am more knowledgeable on early treatment of Dupuytren's than he was.

Back to the internet, one last shot and yes I found this site. Doctor Hayman at the University of Michigan Hospital was listed. Until I talk with him, in person, I don't want to get build up to be shot down again. The nodules are bigger, cords are becoming more visible... time is running out for R/T.

I met with Doctor Hayman. He is a nice, well-educated and a doctor with the patients' well-being in mind. Our talk went well and he has agreed to take me on as a patient even though I was treated once before. His hope is to stop the progression. My hope is to have the nodules shrink over the next 18 to 24 months after the treatment ends. I will be traveling back to Michigan as soon as the insurance company gives the hospital the ok. I will have both hands casted then return the following week to begin the treatment.

I will fast forward to the 5th treatment. The staff has been wonderful. The treatments have been on time and the Doctor Hayman and his staff has been available to answer any and all questions. They are not sure but I am getting tired quicker than normal but it doesn't seem to be a concern. By 2 or 3 o'clock in the afternoon I wanted to rest for thirty minutes or so. There were a many evening, after work, where I would sleep in the car for a few minutes before making it to the couch. (The tiredness lasted for the next 5 weeks.)

Let me talk about my hands. They are not overly dry but my hands feel swollen after the third treatment. This has not gone away yet. My hands are achy but don't hurt. The treatments seem to have made the DC angry. The nodules are white and the pain seems to be increasing specially at night. I am sleeping on my hands to prevent them for tightening up and they are waking me up during the night.

My loss of extreme fine motor control is getting worse but I refuse to let it control me. Riding the motorcycle bothers my hands (the heated grips help a little if it is cold enough to use them). The pain from using a wrench to tighten a bolt HURTS! I need to start my second course in a week and I am not sleeping more than an hour at a time without my hands waking me up and I am exhausted. I went to my pain management doctor and he gave me some pain meds... the first time I slept thru the night. (I am only taking pain meds at night.)

The pain has stopped at night to the point I don't need the meds and the treatments start tomorrow. I have read that the pain indicates the R/T is working and there is a change happening.

I spoke to the Doctor Hayman about what was happening and he said it is unusual to be having these side effects. The question: Could it be because I was treated some 30 years before?

My thoughts are the pain is a good sign as it means the disease is reacting to the treatments.

With the minor side effects Doctor Hayman agreed to continue with the treatment.

Everyone is great and I have made the right choice and I am hoping for the same results as 30 years ago!

I brought my pain meds but I haven't needed them this week. I have one more treatment tomorrow. My hands feel like they are slightly swollen and the treatment area look like I had picked up something hot. The "puckering", cords, and nodules are very pronounced and the skin is tender. My hands are not swollen and the palms appear to be sunken. I will continue to use hand cream and my gloves at night until the redness is gone.

I am not tired like I was with the first set of treatments. I am assuming the new vitamins are helping.

The treatments are done and I have a certificate of completion.

I am home and now it is the wait to see what happens. My index finger on my right hand is tight. It appears that the treatment has made the DC angry again. I just noticed a nodule that is that is flat and long running to the bottom of my hand. I guess that is why my index finger is tight. How could this change so quickly.

I will update this every few weeks. Don't give up. Do your research and educate yourself. You need to take control of your health care. Most health providers are overworked and they don't have the time to become educated on everything. Do you part and help educate them.

I can't say if the success will be as good as the first time for myself but I don't want to think how much my life would have been changed if I wasn't part of the "test group" thirty years ago.

It has been almost 3 weeks since completing my second set of treatments. The large cord on my right hand index finger is very noticeable but no contractures. I can also see 2 smaller cords in both my right and left hands. Every night I put on moisture gloves to keep the hand cream from getting all over. You can see the "bumps" thru the gloves. I am not sure why but in the morning they don't appear to be so pronounced thru the gloves.

My hands are very tender and I have noticed I do not have as much strength in them. I am a bowler and have been noticing I cannot "feel" the ball when rolling it. The bowling seems to force the index finger to be straighter. I can also gauge the beginnings of the contracture of my index finger.

I have lost the feeling of fine motor skills. I have all the normal motor skills but I can no longer manipulate a small screw into a nut and tighten it. I catch myself wrapping a towel around a bottle cap or pill bottle in order to loosen it. Only certain tasks are affected but it is very frustrating when it does. Living alone is now starting to have additional challenges.

The pain is now only at nights and if I do an activity that bumps or compresses a nodule. I am not sure why the pain seems to affect me more than others that have posted.

In today's world, of wanting an instant fix, with this disease, it is not going to happen. I am hoping that the treatment will just cause the disease to regress.

Feel free to follow me over the next few years or write me. And thank you to all that are posting.



