

## My story begins: No NA in Canada

Born in 1945 I've had Dupuytren's nodules in my right hand (RH) for decades, then took Glucosamine/Chondroitin for arthritis about 5 yrs ago, and that coincided with an aggressive startup of Dupuytren's in the LH. This quickly surpassed the RH. I tried some cold laser therapy here in Toronto (recorded in the forum here in 2009) which little success. Now (year 2010) I have about a 90 degree contraction in my little finger LH and the RH is starting to catch up too. I'm a musician (keys) and do a lot of woodwork so of course this condition is quite challenging ... as it is to all of us who have it. I have also developed a painful (related) 'frozen shoulder' condition on my left side that has made sleeping difficult in the last few months.

I've been asking my GP for a referral to Dr. Binhammer (Toronto) for quite a while and he finally agreed that it was time. I knew from this forum that Dr. B. was the guy in my area for NA, (only 2 cities in Canada listed). When I received the referral acknowledgement from Sunnybrook (his hosp), it said Dr. B. had a waiting list of between 6 mths to a year! It was quite a setback to find such a long wait time before I could even SEE him.

I did send him an email with a hand picture and he was good enough to reply and say that from the pic, it would seem I was a good candidate for NA.



I then tried the private clinic in Vancouver, (Cambie Ctr), which also said I would be a candidate for NA consultation (from the same pic), and this seemed to be available anytime, but the cost would be \$1900/hand plus \$500 for the consultation. The NA procedure is actually covered by the medical insurance in Canada, if done in a regular hospital, but not at this clinic.

Then I tried Dr. Boyle, also in Vancouver (from the list on this web site), and he looked at the same picture of my finger and suggested that I would probably NOT be a good candidate for NA and so it

might be a waste of time to come out there. I called the office and also sent him a letter to ask WHY he thinks this ... just asking for a helpful explanation, but had no response at all.

From there I had a referral to a Dr. Morhart in Edmonton, Alberta, who seems to have good references and was recommended by the office in Vancouver. I contacted him and he also thinks I would be a candidate for NA and he's booked me for a consultation in Jan/11 and possible surgery next day .. on BOTH hands! It seems that Vancouver is less busy than Toronto, and Edmonton is less busy than Vancouver. But Edmonton is not really on the map for NA so far.

I thought I'd put a post up here as this site has been very helpful to me and I thought that there may be other people in Canada who might be interested in options in the cold North! Also as Dr. Morhart is not yet on your (Web) list of doctors in Canada, if it works out, perhaps he might be a good addition. If anyone has had any experience with Dr. M, I would like to hear about it.

And finally, I have wondered about starting up a small group of Dup people if there are any in Toronto that would be interested in getting together to talk. I have never met anyone else in person who has this (except my father!), but I know that there are many people who have it. I have joined a few discussion groups in the past and found them very helpful. We may even be able to do a little 'lobbying' if we can see ways to help with the process or distribute useful information. Also we may be able to gather useful info about travel options, costs, treatments in other locations that would be helpful to other people in this area.

## **NA in Florida, January 2011.**

After almost a year of trying to see a specialist, and a great health system that would cover all the costs of a visit and the NA, I have not been able to see a single surgeon.

I have had replies from them directly in some cases, while the nearby Toronto office of Dr. Binhammer has completely ignored me and will not communicate with patients at all until they rise to the top of their waiting list and are ready to be invited for a visit. They will not even give any indication of when this might happen other than repeating that their waiting list is from 6mths to a year. This is in spite of a direct request from my GP that my situation was urgent. It seems there is no getting around his office which controls all communication (or lack of it) about bookings and appointments.

There are only a few doctors in Canada who do the NA and they are all overwhelmed with work, apparently. All of the offices that I contacted were more responsive than Binhammer's office at Sunnybrook Hospital. However none of them do NA exclusively, so it must be a general overloading of other surgeries and duties that is the problem. Sometimes the surgeon himself took the time to exchange an email or two with me.

During the past year, my left hand has gone from being able to go flat on a table to a 90 degree contraction of the little finger. I have given up trying to play much serious keyboard music now but find I can still play the recorder which doesn't use the little finger of the LH.

I have done my best to cover all the bases in Canada and did manage to get an appointment in January with Dr. Morhart in Edmonton, Alberta. He and his office were far more approachable than

the office of Dr. B. in Toronto (of course). However, Dr. Morhart only does surgery once a week and so would have to do both my hands in a single day, which is not recommended.

In my searching I kept coming across Dr. Eaton's name who was the pioneer of NA in North America. He has devoted his whole practice to this and set up a clinic in Florida which is dedicated to this procedure. They were also very responsive when I contacted them. Many of the surgeons in Canada have taken a training session with Dr. Eaton (including Dr. Morhart). They were also able to offer me an appointment in January, even earlier than the Edmonton booking. And I could have each hand done on consecutive days, as people seem to recommend.

So I decided to choose this option. It is sooner, Dr. Eaton is apparently one of the best, certainly one of the first, and Florida is a lot warmer than Edmonton, Alberta! He's also less expensive than the private clinic I found in Vancouver and charges \$600/finger. I realized that I would probably have to pay for everything myself, but if it comes to saving my hands, it's worth it.

I applied to the Ontario Health Insurance Policy (OHIP) to see if they would cover the costs, anyway. They refused, stating that the clinic in Florida is not 'an approved health facility' and also that the procedure is available in ON and I would not suffer either death or 'irreversible tissue damage' if I waited a year or more for treatment (they should take a look at my hands).

They gave me a few more names to try and suggested I ask my GP to contact Binhammers office again. I tried all the other docs and asked my GP to contact Binhammer. The other docs were equally busy and Binhammer's office continued its policy of non-communication, telling my GP only that I was 'on the waiting list'. In other words, although the system here is theoretically set up to cover this procedure, in fact it is so overloaded that it can't respond. Since writing this, Binhammer's office has stopped taking ANY new patients.

The good news (in the big picture) is that I have just returned from a 3 day visit to Florida and the office of Dr. Charlie Eaton. My thread of NA in Canada has crossed the border and become NA in the US.

Dr. Eaton mentioned to me that when he started offering this procedure he had a long lineup of patients and some had extreme conditions and some had been actually lobbying for him to go to France and bring the technique back to the US. Several patients had been waiting hopefully for quite a while for this to happen, rather than going for the old hand surgery. Because of this, he started out with a kind of trial by fire where he worked on some very difficult and advanced cases right away.

So in the end he had no trouble with my rather advanced condition and I think that perhaps he was able to proceed where other surgeons might fear to go. And by the time I got there, the finger was several degrees worse than in the picture above - beyond 90 dgs.

I must say that this is not a really fun thing to have done and I have always hated needles, but if it is possible to have some fun with this, then Dr. Eaton is the GoTo guy! He is a wonderful man, highly skilled, humorous, completely unassuming and on a buddy basis immediately. It's almost impossible NOT to enjoy your time with him. He's a great listener and of course has many stories to tell himself.

He encourages you to talk during the procedure as this requires diverting some mental energy away from what's happening to your hand. This really does work, so I babbled on non-stop during the process and he made a great show of being interested and responding while doing amazing work on

my hand. I found it quite surprising that you can really feel the releases as he does them. Sort of like losing a tension you didn't know you had, until it goes away. This part is not painful (although quite dramatic) and you know it is really helping your hand so it feels good (I think!).

He measured angles of 75 and 35 degrees in the PIP joint and hand/knuckle joint before surgery. After surgery it was 20 and 0 degrees. Although my little finger is not completely straight (pretty close though), the improvement is huge.

There are so many little things that I can do easily again, such as putting on gloves, washing my hands etc. Also my reach on the keyboard has improved to an octave plus 2, (was down to an octave, and I could reach further with my 4th finger before) and now I can actually use the little finger again rather than just aiming it like a stub. The end joint was just wobbling with no control before, but now it is functioning as it used to. The Doc says that it may even get a little better in the next while and I am using a splint to help it along.

This is my hand 3 days after the needle fasciotomy:



The next day, he did my right hand which was not nearly as far gone as the left, and this also had a very good result (went from 40 and 15 degrees to 10 and 0 degrees).

I noticed in a forum posting here that someone mentioned a great restaurant in this area, called Moir's Food Shack. Well Barb and I found that it was in walking distance from the place we stayed, La Quinta, and we had a very delicious meal there. I recommend the "Sweet and Spicy".

And compared to winter in Toronto, the weather was also great. These were a few days I will not forget.



*Together with Dr. Charles Eaton, after my NA.*

## **NA and RT in Germany (May 2011)**

Having FINALLY dealt with the contractions and 'got my hands back' in good working order, I was highly motivated to stop further contraction by going for Radio Therapy (RT). I read all about it online here and figured this was my best option.

It quickly became clear that it is not available in Canada and most Canadian doctors will not recommend or even support it. I was advised from Germany not to have it in North America at all.

The choices were the UK, France or Germany. It seemed that the cost is about 3 times higher in the UK than Germany and as I have a school friend living in Frankfurt, I decided to go to Germany.

I had originally intended to go to Hamburg to see Prof. Seegenschmiedt but then found that there is an excellent doctor (Herkströter, see below) providing the same therapy in Frankfurt (but with x-rays, Seegenschmiedt is using electrons). So I planned to stay with my friend Terry from where I could reach both of the hospitals in the Frankfurt area, one in Höchst and the other in Bad Homburg, that offer this treatment with Dr. H..

My grand plan was to go to the UK and Belgium to visit friends and relatives and then move on to Germany for Radiotherapy (RT) in Frankfurt in May. However, while I was still in the UK I realized with some apprehension that my little fingers were contracting again and that this might affect the decision to have RT.

I managed to see a very helpful radio oncologist in Surrey (Dr. Shaffer) who agreed that my hands were too contracted for the RT and he directed me to a hand surgeon. The hand surgeon agreed

about the contraction but felt that the PIP joint in my little finger was too difficult to perform N/A on without risking nerve damage and said she would only perform full hand surgery. This I was not prepared to undertake at that time.

I already had my ticket to Frankfurt for my appointment with Dr. H. so I decided to follow through with my original plans even if it meant returning home with no treatment at all. I thought the most likely scenario was that Dr. H. would send me back home to get N/A again (SOMEWHERE?!) and then I'd have to make ANOTHER trip to Germany for the RT!

I arrived in Germany by train and took an "S" train directly from the main station to see Dr. Herkströter at the hospital in Bad Homburg, a quaint old suburb of Frankfurt, on May 23, 2011. I walked to the hospital from the station lugging my bags, about 20mins.



*This is the Hospital in Bad Homburg (Bad means bath or spa in German by the way)*

Dr. Herkströter has Dupuytren's himself and is a very careful and compassionate man. He talks of Dupuytren's as an 'inflammatory disease' and laments the fact that more people don't take advantage of the radiotherapy in the early stages of D, before the contractions begin. He claims a success rate of around 80% for the RT compared with around 60% for the N/A.

Tragically, his own father has D. quite severely and has had several operations without great results. In spite of suggestions from Dr. H, he declined to have the RT because of the dynamics between father and son.

I wish I had known what I know now in the early stages of MY disease.

Dr. H. advised that if I had radiotherapy now it would probably arrest further progression after perhaps a further 10 degrees of contraction, but the best solution would be to have N/A again BEFORE the RT. He suggested a number of hand surgeons in the area that I could call for a consultation to see if N/A was even still possible.



*Dr. Markus Herkströter holding up a piece of lead shielding.*

My friend Terry, fluent in German, called all the suggested doctors within about 100 miles of Frankfurt and finally found Dr. Staub in Dossenheim who was able to see me in a couple of days, on Friday, at his clinic as a private patient.

After a thorough examination of my hands, Dr. Staub said (to my surprise) that he felt that both my hands were treatable with N/A and that he could do the most difficult one on the following Wed. He suggested that I should have the N/A asap as they were obviously contracting. Wow.

My flight back to Toronto was on Thursday so this required some thinking. Next day I called Dr. Staub again and asked if he could do my other hand as well, and he said he could do this next Friday. I then called Dr. H. who said he could begin the radiotherapy on both hands the following Monday, for a week. I therefore decided to cancel my flight home and rebook it later as this was a unique opportunity to have both the surgery and the RT and end up where I had hoped to be with straight(er) fingers and a completed session of RT before coming home.

My friend Terry drove me to Dossenheim on Wednesday, about an hour from Frankfurt. As well as Dr. Staub, I was lucky to have Dr. Albrecht Meinel present also. Dr. Meinel was one of the first surgeons to practice N/A in Germany, somewhat like Dr. Eaton in the States. He originally accompanied his brother who had Dupuytren's in his hands and went to get N/A in France. After observing the effectiveness of the procedure Dr. Meinel began to practice it himself.

In my session, Dr. Staub did most of the work with Dr. Meinel observing and there was much discussion in German. Then at one point they swapped positions and Dr. Meinel had a turn!

This is the team right after the surgery. I think I surprised them by hopping off the gurney and asking for a picture ... they didn't seem to mind though. The picture captures a great moment for me.



*Dr. Staub (left), Dr. Meinel (right) and an assistant, just after my NA.*

After the procedure, Dr. Meinel made a special splint for me out of silicon, moulded to my finger shape. It was to be worn every night, wrapped in with a special stretch/cling bandage. I'm still wearing it every night.



I now believe that the splinting is something I did NOT do well after my first surgery in Florida. I had made my own splints and had been wearing them before (and after) the surgery but they were

'tension' splints which attempted to straighten my fingers. I wasn't able to wear them overnight as they became too painful. There are also some opinions that this stretching actually provokes the D. (scar) tissue to contract more rapidly while the disease is active.

The German doctors emphasized the important distinction between this and a splint that simply MAINTAINS the hand position at night. This is a long time when the hand naturally rests in a closed position and affected fingers tend to contract towards this position during sleep. If you wear the 'maintenance' splints diligently, it stops this night time contraction and I find that in the morning my fingers seem straighter.

It is also much more comfortable to wear these splints overnight than the ones that put more pressure on the joint all the time. This splint was made as an exact fit to my finger, right after surgery. In the morning, I find I can straighten the finger a bit, inside the splint, suggesting that the finger has 'loosened up' overnight. Just recently I found an Internet post about this, actually written by Dr. Meinel at <http://www.dupuytrensymposium.com/Abstracts/Meinel1.pdf> that explains it well. Videos from the Miami conference show Dr. Meinel on <http://www.youtube.com/user/DupuytrenFoundation#p/u/0/kq4hr06tOtY> and <http://www.youtube.com/user/DupuytrenFoundation#p/u/0/882JB9cXDME> .

On Friday, Dr. Staub treated my right hand (little finger), by himself this time. For this hand he recommended a special hand splint much like one of the ones that I had made for myself. This one is very easy to put on and off and you can even adjust the angles by bending the metal supports in the back. This fancy leather one costs about 60 Euros (mine cost a few dollars for an old glove and a stiff board). I was also using velcro straps with mine to try to stretch the fingers.





I was impressed by the care and precision of the work of the German doctors and also by their manner and the very pleasant way they treated me.

## **RADIOTHERAPY**

The following Monday, I began my radiotherapy with Dr. H. at the hospital in Bad Homburg. He treated both hands as well as my left foot which had a growing nodule of Ledderhose.

For each hand (and foot) they prepare a special shield to determine exactly which part of the hand or foot will get the radiation. You also get to wear special glasses and shields around your waist and neck.



Then the unit is placed over the hand (or foot) and you get your 3Gys (Grays) in exactly 19 seconds. It's very quick once they have made the shields which are re-used (this is pretty quick also). This dosage has apparently been standardized across Germany and I think in the UK also.

There are 5 sessions so you get 15Gys, and then you repeat this a couple of months later for a total of 30Gys per site. This is quite a low dose compared to standard cancer treatments. I have had almost no side effects and they suggest a special creme that minimizes any tendency for dry skin or a mild sunburn effect.



In August, I went back to Frankfurt for my second week of radiotherapy, this time in Frankfurt-Höchst, another suburb of Frankfurt.

I had a most enjoyable cycle from the Eckenheim area in Frankfurt to the hospital, about 45 minutes along the Nidda river.



Or the public transportation is really great so I sometimes took the U-Bahn.

(I called it the U-boat as it uses the same naming system as the old submarines - I took the U-5)



To the S-Bahn, change at Konstablerwache or Hauptwache (I loved the rail systems).



I was usually in and out of the hospital in about 20 minutes or less including a short wait to be seen. Most of the medical staff I saw speak what THEY call 'Pidgeon English' which is quite good enough to have basic conversations .. and better than my high school German.

While I was still looking for a surgeon, I also contacted Wolfgang Wach (who runs this website in two languages!). He was very helpful (he also had lots of stories), and was very friendly and approachable. This web site is a tremendous resource for all of us who have this disease and I would like to express my appreciation for all the work that Wolfgang, and everyone else who contributes, has put into the site. Each one of us probably has a small piece of knowledge that can be useful for others and this is a great place to share it.

Here are my personal two cents of advice that I would like to have given to myself a year or so ago:

**1. Do not delay too long in seeking radio therapy if you want to avoid surgery.** I only finally zeroed in on the RT after my fingers started actually contracting and by then I had to have N/A first (twice in the end). Germany is quite a bit less expensive for RT than the UK and a great place to visit. If you are thinking about this, allow your hands to take you on a great adventure!

2. If you miss this 'radiation window' and have the N/A, then **DO take the splinting process VERY SERIOUSLY if you have to do it.** Wear them EVERY NIGHT for 6 mths (or as directed). Perhaps I might have avoided my 2nd round of N/A if I had done this.

Good luck to everyone!

Jonn Ord

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"The Great Spirit gave us each a song."

Native American Proverb