

Australian experience with Prof Seegenschmiedt in Hamburg

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At age 45, I found myself in January 2011 with rapidly progressing bilateral ML, consisting of a large nodule on the left foot and a medium-sized nodule on the right. First discovered in 2007 when they were both pea-sized, the nodules only started actively progressing in mid-2010. By the end of the year they became symptomatic, and I started to actively search for treatment options. Since then a second nodule formed on my right foot, so I'm glad I acted quickly.

Pathway to Prof S.

General practitioners closed the conversation with, "there is no current treatment, only surgery which is not recommended". My podiatrist discouraged me from seeking further advice from a surgeon, "as they are just interested in operating", and she warned me to avoid this at all costs.



So I started comparing all the treatment options and found that the best outcomes were from RT. Radiation oncologists in Australia haven't got much experience in treating the condition, so I looked further afield and found Prof S. in Hamburg. At this point I sought out everything he and others had published on the topic and familiarised myself with patient experiences on the Dupuytren's Society website before starting an email dialogue with Prof S.

Six weeks later I was on a flight over Sydney (pictured, above) and on my way to Hamburg!

Airport – hotel - clinic

Hamburg (Fuhlsbuettel) airport is actually walking distance to at least three decent, budget-priced hotels, including the Mercure Hamburg Airport, Mein and Airport Marriot. However, walking is NOT recommended if you are exhausted from a long-haul flight and have sore feet (or hands) and luggage! Some hotels have airport shuttles, and taxis are readily available.

You can also walk the (estimated) 2.5 km walk to the clinic from your hotel, or save your feet by catching a bus to the clinic that runs along the Langenhorner Chaussee.

The treatment

The first day requires you to attend two fixed appointments, the consultation and the first treatment. After the first day, you can present at the clinic at whatever time suits you for the rest of your treatments. Staff members understand sufficient English for you to get by without any German at all and one or two have a good command of English if you find you need some more detailed communication. Prof S. speaks excellent English, so you won't have any difficulties communicating with him at all.

The first consultation

At my first visit, I was greeted by Prof S., and led into his office for my consultation. He took images of my feet on a photocopier he keeps on the floor and then did a physical examination of my feet to review the size and scope of the condition. The large nodules (6cm x 3.5cm on the left and 3cm x 2.5cm plus 5cm x 3.5cm on the right – pictured, right) were obvious, but to my surprise, the Prof identified cords on both feet as well. The circles drawn with a felt pen indicate the position of the nodules; the lines indicate cords. The square around the affected area indicates the treatment area. I was surprised at the wide margin drawn around the affected area, which also received RT (and would have been affected by surgery, should I have taken that path). Prof S. then checked my hands and fortunately confirmed no sign of Dups “yet” (phew!) although he did circle some possible areas of concern for me to monitor every 6 months (pictured, below).



The first treatment

After you present at reception for your first treatment, you’re told to sit in a waiting room until called on a speaker by reception staff, then to proceed down two flights of stairs to the treatment room where you are led into a little ‘waiting cabin’, before being called again to enter the treatment room for your RT. The whole process usually only took me about 10 – 20 minutes, although the first treatment took a bit longer for the initial set-up and supervisory visit by Prof S.



How my feet handled the treatment and travel

The treatment is painless and I had no visible side-effects during the first cycle, but my feet did get tender and the nodules a bit hard and sore by Day 4. At first I wasn’t sure if this is because I over-did the walking, but then my MRI turned up “some inflammation consistent with arthritis” (which I don’t have) “or too much walking” (which I did do - about 10 kms per day). Instead, I would suggest that if you are keen to make a holiday of it, try to do most of your sightseeing a week BEFORE your treatment and rest and be kind to your feet while having treatment ☺!

It’s a long-haul trip from Australia, and in the end, it wasn’t the flight that caused stress on my feet as I had feared, but all the walking and long queues at the large international airports. In hindsight, accepting wheelchair assistance (which my identity as a fit, self-sufficient person

didn't permit!) would get you through without undue stress on your feet and no-one will think twice as you breeze by them to jump the queue, even if you are only 45 and healthy looking! I will be sure to accept help after my second treatment cycle if it's anything like the first time. It's a big investment to travel to Germany, and it's worthwhile doing whatever you can to support your recovery. Note: You'd best book this service with your airline in advance.

Immediately following Treatment Cycle 1:

The nodules and plantar tendon have tightened causing a bit more pain than usual. My feet burn and turn red when my body temperature increases (e.g. after a meal or when active) and this is eased by putting feet up. There is tenderness in the ball of my feet when I put pressure on them and I'm walking carefully to avoid nodule pain and an uncomfortable (over-?) stretching sensation in my tendon. I am not overly concerned as I am sure this is a normal reaction to RT, and perhaps too much walking (?) and that given a little recovery time, this will improve and hopefully so will the ML! The worst is at night, but it's bearable and ibuprofen provides relief.

German culture

German's are friendly and courteous and most speak English (this and a Lonely Planet Phrase Book got me through with ease). Germans have a quaint convention of greeting each other when entering a small space such as the clinic waiting room or hotel dining room. Don't be alarmed if *everyone* eyeballs you at once and sings out a welcoming 'Morgen!' or 'Gutentag!' and later, 'Tschuess!' It was a bit confronting at first for this Aussie, but I grew to enjoy this as it made me feel part of the community.

Things to do in Hamburg

The Hamburg card, available at stations and the airport for about 25 Euros, includes all trains



and bus transport for five days and discounts for tourist attractions. After my treatments, I walked to Fuhlsbuettel Nord station and caught a train straight into Hamburg (20 mins) to start my daily adventure!

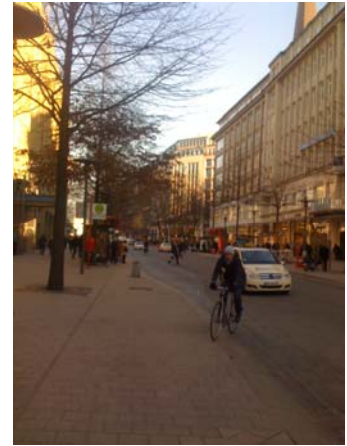
Local highlights for me included the Mo Grill and sitting at the harbour in the winter sunshine at **Jungfernstieg**; the **Hamburg Museum** –all about Hamburg and everything translated into English; the **Botanic Gardens** (Planten und

Blumen - pictured above); **Harbour tour** – a must! Tours take you through meandering canals between newly converted warehouse apartments and high-rise developments with including some state-of-the-art architecture; **Cycling** - the landscape is flat and there's a bike shop near the hotels on Langenhorner Chaussee; **Art and culture** - the main churches, art exhibitions, music and performances to suit all tastes... a visit to the Opera House is highly recommended as it is one of the leading Opera companies in Germany. Finally the **Inter-City Express (ICE)** – the rest of Germany is only a short trip away on the ICE. Enjoy!

Planning

Timeline (from Australia)

For one treatment cycle, you need to be in Hamburg between Mon – Fri for five daily treatments. Travel from Australia takes at least 24 hours, so add two days. On the way there you make up a bit of time because Germany is about 10 hours behind. I flew in on a Saturday night flight and arrived in Germany on Sunday afternoon, so I had the night to recover in preparation for my appointment in the morning. The way back is more demanding because you lose the 10 hours you gained on the way there. This means that if you leave Hamburg on a Sat, you don't arrive home until Mon morning! I was okay when I arrived in Germany, but needed 3 days to START to recover from jet-lag on the return trip. You also need to expect that you might be a bit sore when you return, so it's advisable to build in a little margin to recover before returning to work.



Money exchange

I used a Travelex card to carry my Euros. It acts as a pre-paid currency card (like the old Traveler's cheques), doubles as a Visa Debit and ATM Card, and it gives you a better rate of exchange than if you use your credit card (the exchange rate your bank decides to pass on to you). Travelex online rates of exchange usually beat their agencies' rates. Best not to buy currency at airports or large banks – they give you the lowest rates of exchange. The clinic accepts Travelex Visa-debit cards (pictured, left).



Tax return scheme (TRS – Australia)

Purchase any item you need for your trip and you can claim back your GST from a TRS desk (in Australia) after you get through customs. The hook is you have to carry the goods on you (I wore mine and carried them in my new travel bag!).

I hope my experience helps inform you and I wish you all the best for your treatment and recovery.

To be continued...

Cyclist (Di), March 2011