

Väntrum

Koagulationsmottagning Barn & Vuxna

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Anmäl er eller barnet
i kassan eller i själv-
registreringsapparaten
på plan 3.

Sitt sedan ned och vänta
tills ni blir uppropade.

Välkomna!

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**Patienter till mottagning och
dagvård endokrina tumörer och
sarkom fortsätt till A10:01**

Välkomna!



Elias outside the HTC in Sweden
Photo: Mindi Palm

Amanda (Mindi) Palm is a former
Australian community member and
blogger, now living in Sweden

LIVING LIKE A SWEDE

Mindi Palm

We've had three years of haemophilia management at our Haemophilia Treatment Centre at Westmead Children's Hospital, NSW, working closely with our haemophilia nurse Robyn who has become a wonderful friend and support to our family.

Sadly, we said our final goodbyes in July 2018 before we embarked on a new journey and chapter to live in Stockholm, Sweden and learn to 'do as the Swedes do' with groovy ABBA music playing in the background.

Our son Elias was diagnosed with severe haemophilia A as an eight-month-old baby in 2015 and had received factor 'on demand' intermittently when we were living in Australia.

Upon our first visit to The Karolinska University Hospital here in Solna, Stockholm we learnt a few

things. Firstly, there is a panel of haemophilia doctors and nurses who regularly meet and make decisions for their patients based on group consensus. Children with haemophilia receive a dedicated carer at pre-school, funded wholly by the local government, hence why the taxes are so high!

Incidentally, we learnt that the longest word in all of medical history is: **Barnkoagulationsmottagningen**. Did you get that? It's the Swedish word for 'children's coagulation centre.' Now that's a mouthful!

Our family has started the process of learning how to give Elias factor intravenously, so not only is our Little Bleeder learning to get comfortable with needles, but he's also learning how to speak and act like a Swede!

Until the next update, hej då!

Q&A

MOVING TO SWEDEN

Mindi took the time to answer a few of HFA's questions about the move to Sweden.

HFA: What did you do with the Sydney and Stockholm Haemophilia Treatment Centres (HTCs) to prepare for the move?

Mindi: I consulted with our HTC Nurse, Robyn Shoemark, and haemophilia doctor, Dr Juliana Teo, at the Children's Hospital at Westmead who had a final consultation, blood test and wrote up a letter for us to give to our haematologist here in Sweden. Elias, our son, and Lucy, our daughter, both had bloods taken for final factor level testing and then (somehow) Robyn managed to find the clinic we attend now, 'Barnkoagulationsmottagningen' in Solna, Stockholm.

In the first few weeks we arrived, Elias had several incidents where he was bleeding through the nose, in the mouth and he had a swollen and bruised foot. So I commissioned my husband Tommy to go in for the first consult as it was considered an emergency and I was really in no state to handle it all - in Swedish! He gave them the letter from the HTC at Westmead and from there we started having regular consults. All children in Sweden – citizens, residents, and immigrants - are covered by the government for free access to healthcare, dentistry and medicine, so that was not an issue.

HFA: How did you manage the plane flights and international travel?

Mindi: Though not recommended, we opted to not have insurance as we had only one stop-over in Bangkok and straight onto Stockholm. So we just decided, it's a straight flight there and hopefully we wouldn't run into problems. Each time we travel overseas Robyn writes us a letter and we take that with us along with a supply of medication, which gets checked at every security gate. It's no problem taking it with us and, as we have the letter, there are no problems with international customs.

HFA: What is different for you and Elias in relation to haemophilia and care in Sweden?

Mindi: A marked difference is that our local government or 'kommun' issues a specific carer/aid person in Elias' pre-school to help watch him for any incidents. This is certainly new to us! 🇸🇪



Elias and Robyn at the HTC in Australia
Photo: Mindi Palm