



Sharon

LIVING WITH HEREDITARY HEMORRHAGIC TELANGIECTASIA (HHT)

I wonder how we ever missed the signs. They were there in front of our faces, and they were missed by lack of knowledge and lack of awareness. And not just by us.

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Living with HHT is very isolating. Not a lot of people can deal with bleeding, especially the way we bleed.

It’s the constant breathlessness, exhaustion, sleep deprivation, joint pains, constant trips to A&E to name but a few and a daily battle to clean up what resembles a crime scene that’s left behind.

Raising awareness is paramount to saving lives. For me, living in Co Antrim, it is getting easier with the help of Haematology team at my local Haemophilia Centre at Belfast City Hospital and also the team Rosehall Medical Practice, Glengormley in N. Ireland. But there is still such a long way to go before we mention HHT and it’s not met with “I’ve never heard of that before?”

My dad and brother both passed away without getting a diagnosis so it is bittersweet at times...

Would it have made any difference? I guess that’s a question I’ll never know the answer to.

I look back at photos of my dad and I can see the telangiectases so prominent on his face, with my dad saying, “it’s just that blood thing your Grandad had and we have too”. I think of the several strokes he had. I remember well the many times he was hospitalised with “a nosebleed” and eventually losing him to Lymphoma.

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In the meantime, if I can help make the path easier for anyone with symptoms coming behind me then that can’t be a bad thing. It’s always better to get checked

out and most importantly - don't miss the signs. If you feel you have any of the following symptoms, I advise you to speak with your GP and ask for a referral to haematology consultant

Ireland patient support organisation via their website - hhtireland.org
The support we have all been shown is absolutely incredible.....

- Recurrent unexplained nosebleeds
- Telangiectases (red spots) mainly on hands, face, lips & tongue
- Arteriovenous Malformations (AVMs)
- A family history of these symptoms

If you live in N. Ireland you can contact HHT UK via their website - hhtuk.org
Donate blood by calling 08085 534 666. Alternatively visit their website www.nibts.org or text BLOOD to 60081

In Northern Ireland upwards of 850 units of blood are used by 500 patients every week. 94% of the eligible population still do not donate. Donated blood is usually transfused within 3-4 days of donation and needs to attract 115 new donors every week. The blood is used numerous ways, cancer patients, rare blood disorders, mothers giving birth, surgeries, traumas.....one giving 3 living

In the Republic of Ireland - you can contact the HHT