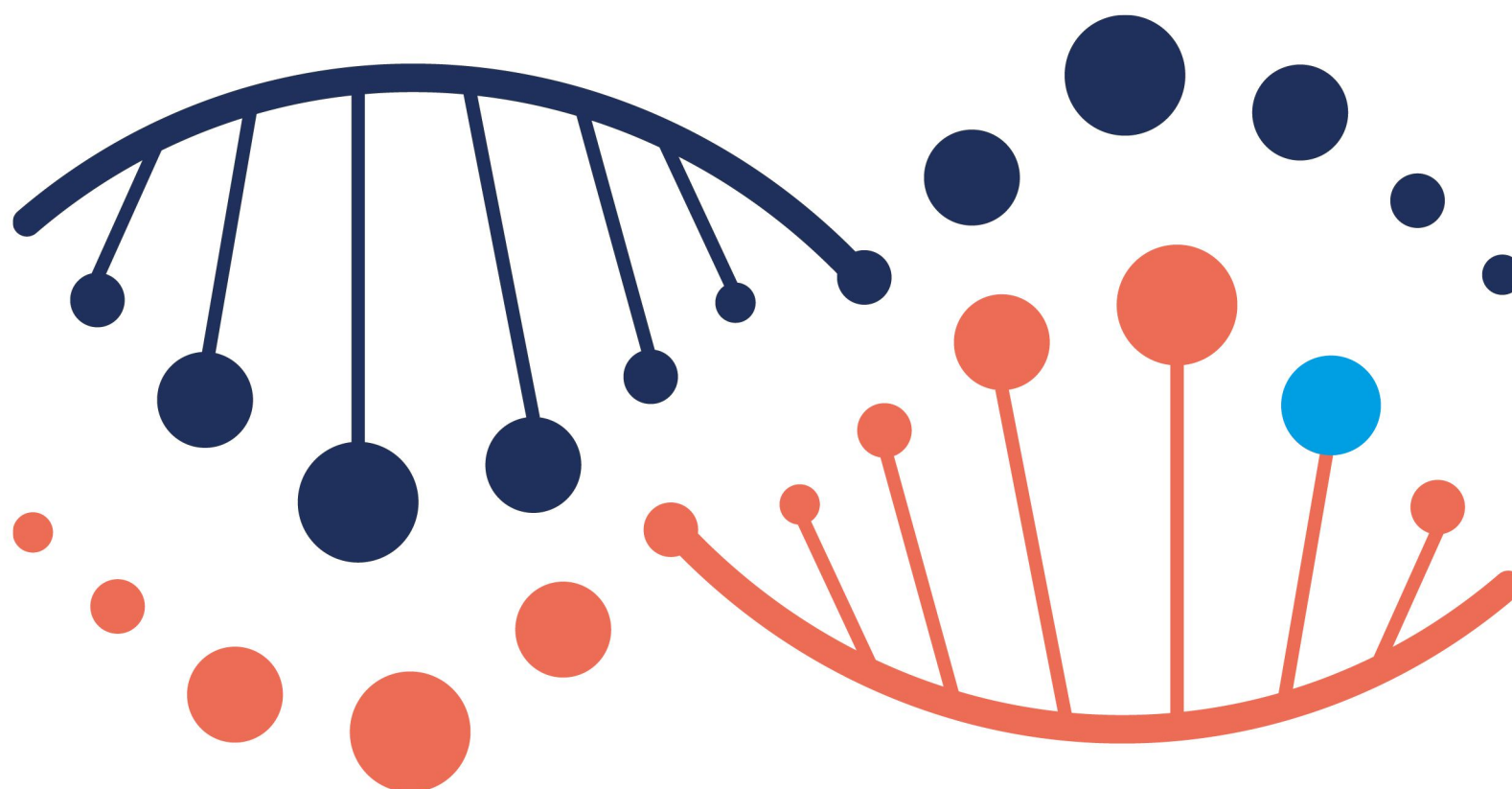




All people are designed to have two working copies of the **VHL** gene, one inherited from the mother and one inherited from the father. People who have **VHL** are born with one working copy and one altered copy.



May is **VHL Awareness Month**. Please share to help us raise awareness.

vhl-uk-ireland.org/vhl-awareness-month

#vhlawareness

May is **VHL** Awareness Month

The cure for cancer is in our genes...



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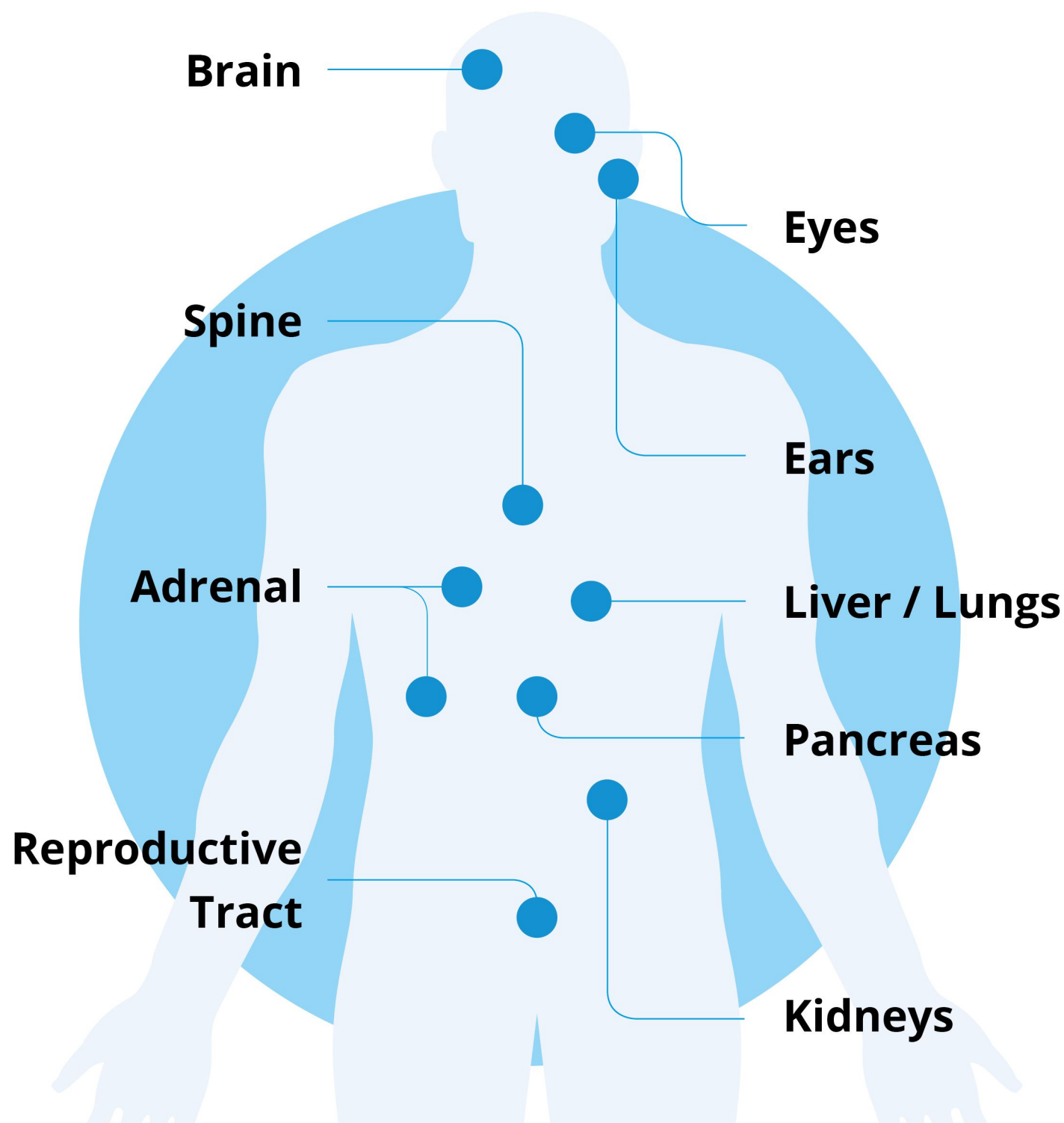
#vhlawareness

What is VHL?

von Hippel Lindau



VHL is a lifelong genetic condition characterised by blood vessel tumours in up to ten areas of the body. These tumours can be benign or cancerous. The *VHL* gene controls the major feeding pipeline of every tumour.



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VHL is a lifelong genetic condition characterised by tumours and cysts in the body. These tumours can be benign or cancerous.

200k

200k people worldwide with **VHL**

3

VHL has appeared on at least popular TV shows including Grey's Anatomy & House

36k

One in 36k people in the world have **VHL**

**32
years**

The average age of diagnosis for **VHL** is 32 years of age

50%

The chance a person with **VHL** has of passing it on to each of his or her children

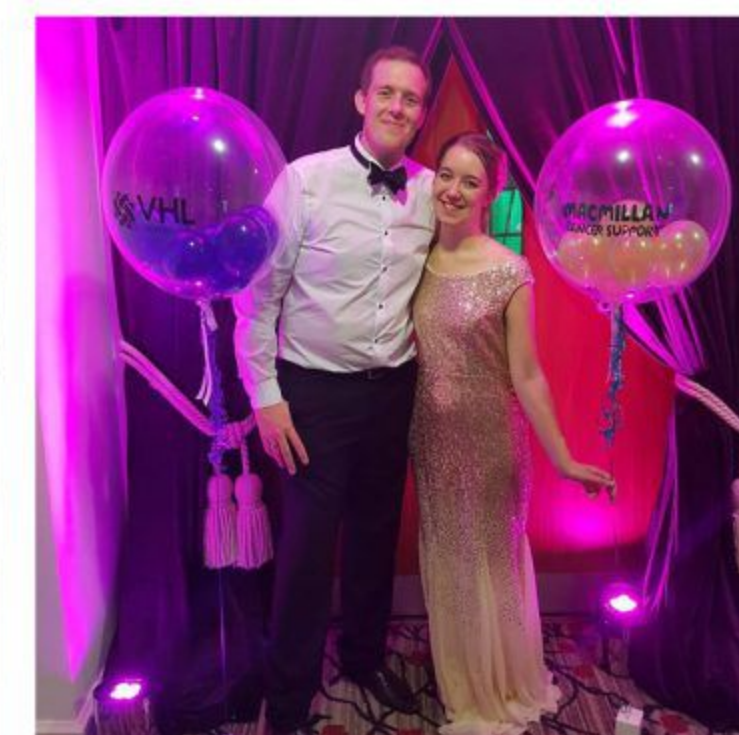
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How will you fundraise for VHL UK/Ireland?



Support **VHL UK/Ireland** by creating your own event or join one that is already planned.
Host a bake sale, team up for a run or run/walk, or come up with something unique!

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Did you know?



The gene that is involved in *VHL* is also involved in other more common cancers, such as kidney cancer and breast cancer.



If researchers are able to overcome the gene mutation for *VHL*, they may be able to do the same for other cancers.



Through fundraising, we are able to provide vital support to research clinics

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Screening for new tumours and cysts is vitally important for **VHL** patients. Here are just a few screening methods:

Eye examination

Retinal tumours
(retinal capillary
hemangioblastoma)



Blood / urine test

Adrenal gland tumours
(Pheochromocytoma)



MRI imaging

Brain, spine,
kidney & pancreas
tumours/cysts



Abdominal ultrasound

Kidney & pancreas
tumours/cysts



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Patient stories



View all of our patient and family stories at: www.vhl-uk-ireland.org/your-story



Janko,
VHL patient

"I accidentally discovered that I had a half-sibling I had never known about. After twenty years of medical challenges. I went to this foreign clinic where my sibling lives and got tested for VHL. The tests came back positive... I love to live, and although difficult, life with VHL can be beautiful, too"

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Patient stories



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"It was my first realisation of what VHL was really like. My partners' scans had been stable up until now. All that I could think about was, 'how am I going to explain this to our little boy?'"



*Natasha,
partner and parent to VHL patients*

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VHL Warrior



n: A *VHL* warrior is a person who faces a series of tumours throughout their life



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