



RARE DISEASE DAY®

Our story when life
threw a rare disease
our way....

Raise awareness for VHL
#CuringCancerthroughVHL

What is VHL

Von Hippel Lindau (VHL) is a genetic condition involving the abnormal growth of blood vessels in up to 10 parts of the body.

It is caused by the flaw in one gene which regulates cell growth causing patients to battle a series of tumors throughout their life.



Brain and spine hemangioblastoma

Retina hemangioblastoma

Endolymphatic Sac Tumor

Benign Lung Lesion

Pancreatic Cysts/Tumor/Cancer

Pheochromocytoma

Liver Lesion

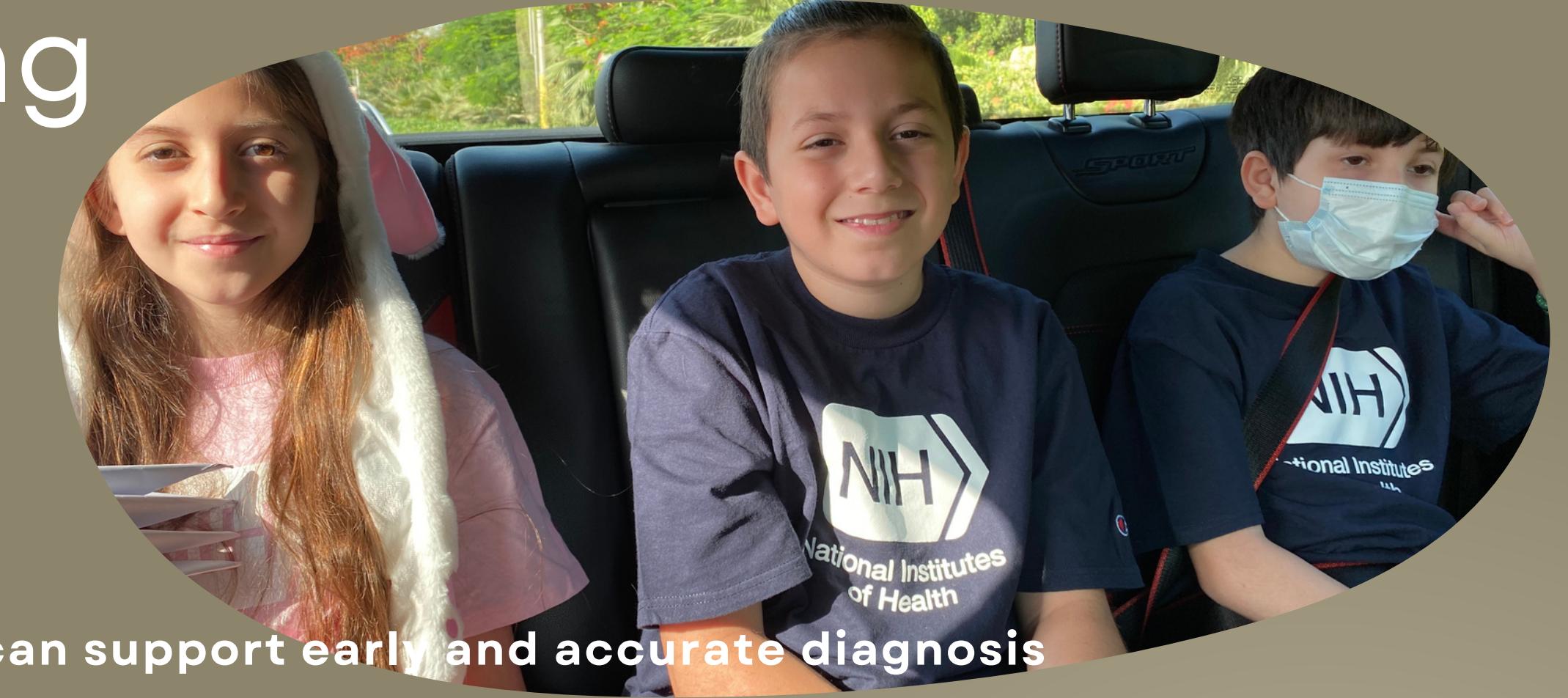
Kidney Cancer

Cystadenomas

Why is spreading awareness important?



Increased awareness of rare disease can support early and accurate diagnosis



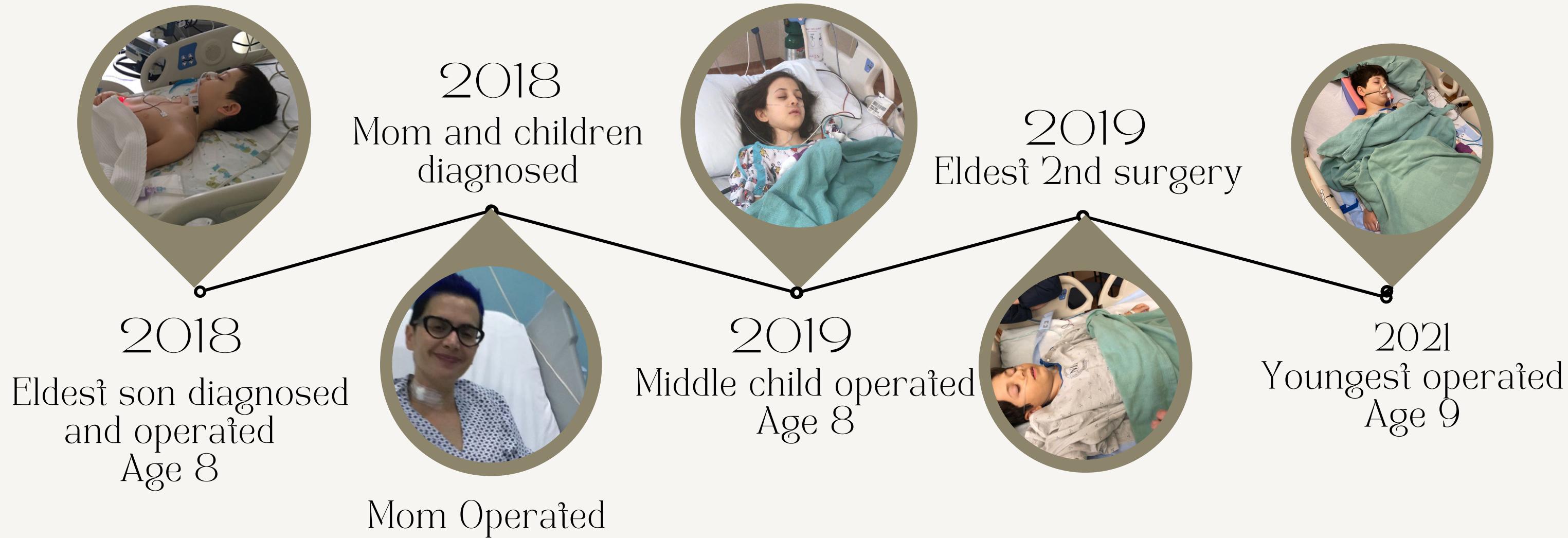
- There are between 5,000–8,000 known rare diseases
- An early and accurate diagnosis can improve the patient's quality of life as patients receive the required treatment and care for their disease
- Rare Diseases are frequently chronic with many starting in childhood
- Minimising diagnostic delays by improving genetic and rare disease recognition and appropriate specialist referrals can improve outcomes

CURING CANCER THROUGH VHL

Organizations and research hospitals such as VHL Alliance and NIH are dedicated to research, education, and support improve awarness, diagnosis, treatment and quality of life for those affected by VHL.

Kidney cancer sits on the VHL gene, advancements in research can end kidney cancer or find a cure.

How VHL - a rare cancer syndrome turned our lives upside down





Our life with VHL

includes

Frequent doctor visits

Yearly body scans

Loads of anxiety

Blood tests

Eye tests

Again loads of anxiety

The Unknown...

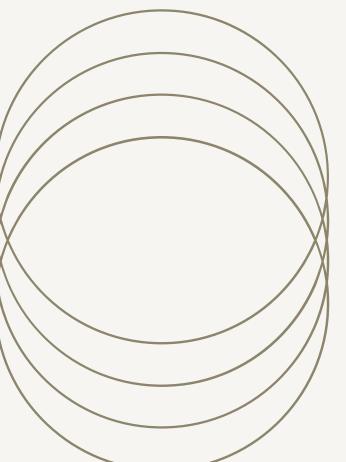


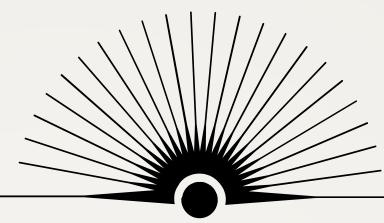
What is the NIH?

The National Institutes of Health (NIH), a part of the U.S. Department of Health and Human Services, is the nation's medical research agency – making important discoveries that improve health and save lives.

What's The Children Inn at NIH?

The Children's Inn at the National Institutes of Health (NIH) is a nonprofit that provides residential services and a wide range of programs to children, teens, and young adults with rare and serious diseases whose best hope for a diagnosis or treatment is an NIH clinical research study.





How can one help



Health fund for what the future might bring.



Raise awareness about VHL and donate to the VHL alliance.



Donate towards The Children Inn.

Thank You