Easy Steps to share your VHL story:

What is VHL?
The VHL gene is in all of us, helping to suppress the growth of tumors. Those with von Hippel-Lindau (VHL) have a flaw in this gene, and are prone to develop tumors throughout their bodies, in up to 10 different organs. With no known pharmacological treatment, active surveillance and surgery (as needed) are the only options for VHL patients as they battle a series of tumors throughout their life. Researchers are racing to identify and control the pathways that allow tumor growth in VHL and other cancers. Their progress provides hope for all of us by Curing Cancer through VHL.

Who is the VHL Alliance?
Founded in 1993, the VHL Alliance (VHLA) is the world’s leading organization supporting von Hippel-Lindau Syndrome. VHLA is a 501(c)3 nonprofit dedicated to improving the lives and optimizing the treatment of those affected by VHL while aggressively pursuing cure.

Your Story.
What is your connection to VHL?
Do you have VHL? If so, when were you diagnosed?
Do other family members that have it? Manifestations and surgeries.
Focus and attitude as a result of living with VHL… do you consider yourself to Thrive with VHL and be a VHL Warrior? If so, why?

Why Support VHLA?
How has the VHL Alliance been there to support and educate you along the way and why you feel it is important to spread awareness and support the VHL Alliance? VHLA is a leading funder of VHL research, committing over $2.3 million to support studies seeking a cure. Since the VHL gene controls the major pipeline that feeds every tumor, its cure brings us closer to curing many other forms of cancer. Ongoing research has resulted in approval for multiple cancer drugs in use today.
VHL patients can help researchers unravel the mysteries of this and other types of cancer by participating in the MyVHL: Patient Natural History Study. For more information, visit vhl.org/MyVHL.

How to support VHLA?
vhl.org/donate
Facebook fundraisers
Local fundraising events – see if anyone wants to help you organize something
Amazon Smile or iGive.com to give while you shop

Please email Heidi at the VHL Alliance with any questions!