



For Kids & Teens

If you, your friend, or a family member is diagnosed with VHL, it can be scary and confusing. For kids and teens, this can be particularly stressful.

If you just received a diagnosis, please remember: although VHL disease is rare, you are certainly not alone. The good news is that by being diagnosed early, you can learn how to manage the disease most effectively.

If a family member was just diagnosed, you may be at risk for having VHL, too. Ask your doctor or your parents to determine if you, too, should have a genetic test for VHL.

In either situation, please remember: taking on new responsibilities while also dealing with having a chronic condition, like VHL, can lead to increased stress. It is important to manage your stress levels and talk to your parents if you feel you cannot handle any additional responsibilities.

Teenage years are a time of great changes and challenges, and having a disease like VHL can heighten your level of stress. There are a number of resources to help you learn to cope with stress and develop strategies to lessen its effect on you.

Check out these resources to learn about how to cope if you or someone you know has VHL disease.

Talking to Your Friends about VHL

The decision to share your diagnosis with different people in your life is personal. It is up to you to decide who you want to tell and when you want to tell them. You may even wish to keep it completely private. That's ok.

People who talk to their friends about VHL often find it helpful to have people who understand and can support them on this journey. By sharing their story and answering questions about VHL, friends better understand why they may have certain limitations, why



they may have so many doctors' appointments, etc. The more your peers understand VHL, the more likely they will be sensitive towards your specific situation.

Remember that you are in control over what and how you share information with others. Some people prefer to be straightforward while others prefer to incorporate humor. Some enjoy sharing all their emotions and clinical details, others only wish to share when they need a surgery. Regardless of your approach, here are some tips to help you explain VHL and start the conversation with friends:

Keep it simple. Use your own words and keep it basic, at least in the beginning. You do not have to explain everything at once; people can ask if they want more specific details. Your parents or relatives can help. It might be helpful to talk to your parents or another family member if you are feeling anxious about telling people about VHL. You can practice the conversation with them to get comfortable with what you plan to say. You can also ask them for advice, since one of them has probably had conversations about VHL with their own friends.

Don't worry! You might be stressed out about telling people. Try to keep things in perspective:

- Your friends and classmates may have already guessed that something is going on with you or a family member. By opening up with your friends, they will be able to better help you.
- Let your friends help you. It might be hard for your friends to know what to do or say after learning about VHL. They will probably want to help you, but might not know how. Letting them know when and how to help will be a relief to both you and them. This could include sharing notes / recordings from class, helping you catch up on the work you miss when you are at doctors' appointments, or just being a listening ear when you are ready to talk about the many ways (including physically and emotionally) that VHL impacts your life.

For Parents: Raising a Teen who has VHL

While people gain certain legal rights as an "adult" at age 16, 18, and 21, growing up does not happen on a single birthday. It is a process that happens over time. Learning to take



responsibility for healthcare decisions is an important piece of the transition process, especially for teens with VHL.

It is important that teens practice advocating for themselves at an early age so that they will feel comfortable taking control of their medical needs as they move from the health care they received as a child to the health care they will need as an adult.

Adults and teens do not always agree or get along. There will always be clashes between parents and children, ranging from disagreements about style to fights over curfew. The struggle for independence can be especially complicated for teens with VHL. On one hand, it can be frustrating for teens to feel like they are treated like a little kid such as being told what surveillance appointments they need to make – especially when they are asymptomatic or simply feel ready to take care of themselves. On the other hand, teens can sometimes feel overwhelmed with the responsibility of managing their health care and might just want someone else to take care of everything. It can be exhausting to keep track of surveillance appointments and anticipate future needs all while planning for the future and trying to make healthy choices every day.

Parents and teens should work for a balance of responsibility that shifts as the child gets older and becomes more responsible for managing their own health care needs.

Sometimes it helps to sit down together and make a plan for transition outlining when the teen will become responsible for each specific task. It is important for parents to prepare for the transition by educating children about VHL and involving them in health decisions and discussions. Practicing independence helps teens understand their medical needs and learn important skills for selfadvocacy and healthy living. Research shows that teens want their parents to engage in open and honest discussions about genetic conditions ([Rowland and Metcalfe, 2012](#)). Having a conversation about VHL means children can ask questions and have their parents answer them informatively and accurately.

Openness also provides opportunities for children to use their parents as role models for their own coping with VHL. While disclosure of a genetic condition has been shown to improve family cohesion and strengthen familial bonding, it can be hard for parents to talk



about something like VHL with their children. They might feel guilty, afraid, or just not know how to start a conversation about it. The VHLA has a [Kids' Edition of the VHL Handbook](#) which includes some tips for parents to talk with their children about VHL. We also encourage parents to speak with their health care provider or a social worker for additional support.