

VHLA: Plans for 2014

At the VHL Alliance, we are always working to find ways to better serve our constituency. Challenges being faced by VHL patients and their caregivers or often identified through VHLA's Facebook (www.facebook.com/groups/VHLawareness) and Inspire discussion groups (www.inspire.com/groups/vhl-alliance).



One concern frequently expressed through these venues is the emotional rollercoaster of living with VHL. Ups and downs with anyone, directly or indirectly, impacted by a long-term medical condition such as VHL, are inevitable. Anxiety may be triggered by events such as the diagnosis, preparing for annual scans, decisions on when to operate, and thoughts about future health.

Complicating the emotional rollercoaster is the feeling of isolation and loneliness. Is there anyone who can actually understand? How do others with VHL cope? What can I learn from them?

VHLA's online support communities help meet some of the needs of many people impacted by VHL. These are international discussions on living with VHL. One can learn from the experience of others while providing and receiving support and sharing tips for dealing with the emotional rollercoaster.

The question is: "What more can VHLA do to help people during those challenging times." Are there more programmatic efforts or website content that VHLA can offer?

As we begin 2014, we have decided that finding answers to dealing with the emotional rollercoaster will be a major piece of VHL Alliance's work for the upcoming year. What services need to be created? What training for staff and Chapter Leaders and Hotline volunteers should be implemented? Are there self-help tools that can help our constituency deal with the emotional rollercoaster of VHL? Should discussions about the emotional rollercoaster be included in a patient's annual screening? And how can we help family members with their feelings of anxiety?

As always, the best way for us to learn is by hearing from you, our constituency. Please call (800-737-8845 x4) or email us (director@vhl.org) with your ideas and thoughts. We are always here to listen!

Worry does not empty tomorrow of its sorrow,
it empties today of its strengths."

— Anonymous

Appealing Insurance Denial for Screening Tests

The following article was written for you to share with any of your physicians who have ordered screening tests to help manage your VHL disease and monitor any lesions. The technical wording and "insurance-ese" will assist you and any of your doctors who run into a denial for a screening test and need to appeal this decision. Please notify wellness@vhl.org if you are having issues with insurance coverage for screening tests as we want to document this.

An all too common challenge faced by VHL patients is a denial by their health insurance company for a recommended screening test. The reason for this denial is given as "lack of medical necessity." An informed VHL patient working with their doctor can educate the insurance company and demonstrate that it is in the best interest of both the patient and the insurance company to cover recommended screening tests. Screening will find any problems in the early stage which is the most successful and least expensive time for treatments. Improved surveillance guidelines have increased the life expectancy of individuals with VHL by over 16 years since 1990 [Wilding *et al*, 2012].

Insurance companies, HMOs, Medicaid/Medi-Cal, and Medicare have guidelines in place for determining "medical necessity." Each insurer may develop their own guidelines, follow the policies of their umbrella association (ex: Blue Cross Blue Shield), or contract with a company that creates "utilization management" guidelines. The claims reviewers deciding upon medical necessity for specific claims are often advance practice nurses working with a physician medical director. They are not experts in rare genetic diseases and may deny something that they do not understand. They can be persuaded, though, by well-accepted national guidelines and reviews such as: USPTF (US Preventative Services Task Force) recommendations, NCCN (National Comprehensive Cancer Network) recommendations,

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