

VHL Family Alliance Kicks off May Awareness Month, Announcing 8 Events Coast to Coast

BOSTON, Mass., May 1 (SEND2PRESS NEWSWIRE) – A neoburlesque sci-fi play in Providence, a Crabfest in Maryland, a music festival on Boston Common – all to support the VHL Family Alliance (VHLFA) in its fight to get attention for its rare disease population. Thirteen year old Alex Anderson from New Jersey formed the idea of a worldwide fundraiser to benefit the VHLFA. The VHLFA announced today the beginning of a month long celebration highlighted by International VHL Day, May 9th to spread awareness for von Hippel-Lindau disease (VHL).



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Alex was diagnosed with VHL at the age of four and has been through numerous surgeries. He has dedicated much of his time to helping spread awareness of VHL. With eight scheduled events, the VHLFA, a small organization, run by 5 staff and 150 volunteers proves today that the “little guy” can spread awareness in a big way. The VHLFA serves people dealing with vascular tumors of the eye, brain, spinal cord, kidney, pancreas, and adrenal glands. These and other tumors occur in a condition called von Hippel-Lindau disease (VHL). There is a clear link between VHL and cancer. The VHLFA funds research to find the right drugs to treat VHL and help find a cure for cancer.

Alex says, "I have often felt that kids feel powerless in today's society. Giving them an opportunity to participate in helping to cure cancer also gives them a feeling of significance." This year Alex and his family will be hosting several booths throughout Margate, New Jersey, with information about VHL and will be partnering with the popular eatery, "Steve & Cookies by the Bay" on May 9th to encourage all their customers to dine and donate to VHLFA. According to Alex who has already raised more than \$10,000 for VHL, "When I'm fundraising, I always feel more significant in the world, like I really matter."

Among its events, will be a benefit performance of the first play ever written about VHL, "The Thing That ate My Brain...Almost" at the Perishable Theater in Providence, RI. Playwright, Amy Lynn Budd, a VHLFA member, also plays the leading role in this neo-burlesque sci-fi play based off her experiences with VHL. The VHLFA will be posting news about its upcoming events on its website The page contains contact information for each event, along with links to purchase its new releases VHL Day t-shirts. The VHLFA is actively encouraging its members and the general public to attend an event nearest them during month of May.

Three states have already declared May 9th to be VHL Day. The VHL Family Alliance is also using the internet to "tweet" and cause a buzz about International VHL Day. In addition, to creating event pages via its Facebook group, "VHL: Spreading the Awareness of von Hippel-Lindau disease." VHLFA has also established a YouTube channel, which displays inspirational videos from its young members with VHL (www.youtube.com/vhlfa).

For more information on awareness activities or to confirm your attendance to one of these events, please visit vhl.org/announce/09aware.

About Von Hippel-Lindau Disease

VHL is a genetic risk factor for a number of tumors, caused by a tiny misspelling in one copy of one gene, the VHL gene. People who carry this flaw are at increased risk for tumors of the retina, brain, spinal cord, kidneys, pancreas, and adrenal glands.

About VHL Family Alliance

VHLFA is a non-profit organization that provides information for families and physicians about this disorder and local and online self-help support groups for families affected with VHL. It is dedicated to improving diagnosis, treatment, and quality of life for individuals and families affected by von Hippel-Lindau disease. Endorsed by the BBB and ICA as one of the Best Charities in America. Visit the pressroom, at <http://www.vhl.org/press>.

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