

Written by Parents, Drawn by the Kids, VHL Family Alliance Announces the First Guide for Kids Dealing with Hereditary Cancer Syndromes: The VHL Handbook Kids' Edition

BOSTON, Mass., June 1 (SEND2PRESS NEWSWIRE) – The VHL Family Alliance (VHLFA) announced today that the very first “VHL Handbook Kids' Edition” (ISBN: 978-1-929539-02-4) is now available at Amazon.com. The book was written and reviewed by a team of parents and professionals and illustrated with charming drawings and photographs from children with VHL, their siblings and friends. “This colorful handbook brings to life an easy to understand lesson on managing health for kids, with a message that is upbeat and hopeful,” says genetic counselor, Gayun Chan at Mass General hospital in Boston, MA. The handbook has already received rave reviews locally from doctors at Mass General Hospital in Boston, MA and on a national level from doctors and genetic counselors.



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The Kids' Edition team wrote the handbook to be a guide and a reference book for parents and children of all ages living with von Hippel-Lindau syndrome

(VHL). VHL is a hereditary cancer syndrome that increases one's risk of having tumors of the eye, brain, spinal cord, kidneys, pancreas, and adrenal glands. The book is specifically designed for parents to read with their children to begin answering their questions about VHL. It is meant to be used as a starting point for discussions about how VHL has affected the family. The handbook gives children a basic understanding of VHL and information on how to live with it and manage their own health.

The book can also be a resource for families dealing with other hereditary cancer syndromes. It explains genetics in simple terms and is a tool to teach children about this topic. The book is available for \$12.99 from Amazon.com or from the VHLFA at www.vhl.org. Members of the VHLFA are eligible to receive a copy of the book at a fifty percent discount from the association.

Also released this week is a video trailer about the book put together by VHLFA parent and child team, Renee and Noah Sissons, available for viewing on YouTube now at youtube.com/vhlfa. To find out more about VHL Handbook Kids' Edition, call 1-800-767-4VHL. Visit vhl.org/vhlsales/kidsbook.php for an inside look at the book and its illustrations.

About Von Hippel-Lindau Disease

VHL is a genetic risk factor for a number of tumors that is 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. It 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. It has been endorsed by the BBB and ICA as one of the Best Charities in America.

A VNR (video news release) for this story can be found here:
<http://www.Send2Press.com/newswire/2009-06-0601-003.shtml>

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