

Powerful Patient 18

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International VHL Day! and the Kids' Handbook

[Mary Zennett was detained, so we have re-booked with her for May 14.]

This week Joyce talks with Mary Lou Linn about the many events happening in May to raise awareness of VHL. We announce the new VHL HANDBOOK KIDS' EDITION to help parents speak with children about VHL and managing their health.

1) About Our Guest

Mary Lou Linn is the Member Services Coordinator for the VHL Family Alliance.

2) About VHL Awareness Month

May is VHL Awareness Month. Many states are in the process of releasing declarations raising awareness of VHL in their states. In addition, a number of events will be going on around the country to raise money for the VHL Family Alliance. The Powerful Patient is a project of the VHL Family Alliance.

The full list of events can be found at <http://vhl.org/announce/09aware>, or chronologically at <http://vhl.org/meetings>

3) About the Kids' Edition

Over the past two years, a committee of parents and professionals has collaborated to produce the VHL HANDBOOK KIDS' EDITION, which will be published June first, 2009. This delightful book, illustrated by children with VHL, is upbeat and hopeful, helping children understand VHL and how to manage their health.

Order copies now for delivery beginning June 1, 2009. See <http://vhl.org/vhlsales/kidsbook.php>

