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### **May is VHL Awareness Month**

May 2008 is VHL Awareness Month and the VHL Family Alliance is working hard to increase awareness of von Hippel-Lindau and associated medical issues. As an annual event, Awareness Month is an opportunity to focus education efforts, reach out to the media and decision makers, communicate with the medical community and provide an arena for bringing VHL into greater recognition in our communities, the country and the world.

The VHL Family Alliance is increasing Awareness Month efforts this year to include outreach and education to members of Congress, provide more information and contact with the media around the country focus attention on people living, working and thriving with VHL. Education is one of our strongest tools and the Awareness Month campaign is a great chance for each and every person connected with VHL to talk about life, challenges and living with the disease. Every person that hears about VHL is another person to carry the news, increasing awareness exponentially!

### **You Can Get Involved!**

Every person touched by VHL, either personally or as a friend, family member or supporter can get involved! Each person impacted by VHL has a story to tell, be it to your doctors, neighbors, clubs, local media, etc. – your personal story has a major impact and helps educate those in our communities and thus increases awareness! Chat with folks around you, write a letter to your local newspaper, call your local radio or television station – offer to tell your story!

Fundraising is another great way to increase awareness and help fund vital research and outreach campaigns! Every dollar raised is a step in the right direction towards increasing the quality of life for people impacted by VHL, and ultimately, to finding a CURE!

Call your elected officials! Everyday, members of state government, members of Congress, even local elected officials are tackling issues associated with health care, providing access or involving important services – having your story in their minds help keep VHL in the forefront with these folks as they are making crucial decisions.

### **Local Events/Meetings/etc.**

Take the chance to plan or advertise local support groups, meetings, workshops or provide contact for local resources.

### **Resources**

Many states and local areas have a large number of resources, be they through local hospitals, organizations or the community that might be of interest to VHLFA members in your chapters. Here's another opportunity to reach out to your members with these resources!

