### VHLA Programmatic Initiatives

Joshua Mann, MPH  
Director of Engagement and Outreach  
VHL Alliance  
Josh.mann@vhl.org

### MyVHL: Patient Natural History Study

vhl.org/MyVHL

- Patient registry where VHL patients can contribute to research by completing surveys about:
  - Medical history
  - Lifestyle
  - Medications
  - Other factors that impact the disease and quality of life.

- Helps patients better understand their condition with statistical insights.

- Helps researchers:
  - Know where to focus their efforts
  - Identify and uncover factors that may increase risk, inhibit or slow tumor growth, or lead to an effective cure

### Phone Hotline

- Toll-free hotline  
- Manned by volunteers with years of experience dealing with VHL  
- Available from 8am to 10pm ET, 7 days a week  
- Volunteers rotate coverage to help you stay connected  
- Opportunity to identify any needs that aren’t being met and promote VHLA resources

### Discussion Calls

- Moderated discussion phone calls  
- Defined rotating topics, followed by a general discussion about thriving, not just surviving, with VHL  
- Support and education from VHLer peers

- Moderated by professional life coach **Leona deVinne**  
  - Patient/Caregiver Call - vhl.org/ptcgcall  
  - Parents of VHLers Call - vhl.org/parentscall

- Moderated by Josh Mann  
  - Low/No Vision Call - vhl.org/lownovisioncall
Peer Mentoring Program

- Patients and caregivers who are in need of support, reassurance and information are paired with other VHLers who have gone through similar circumstances.
- Can help guide patients and caregivers through overwhelming and frightening situations.
- Positive way to manage expectations and identify needed resources.

Young Adult Initiative

- VHL Young Adults Committee
  - Leadership opportunity for future VHLA board members and influencers
  - Tasked with planning and organizing events for young adult VHLers:
    - Annual Young Adult Retreat
    - Family Weekend Young Adult Event
    - Other regional and virtual events
- Annual Young Adult Retreat (vhl.org/yr)
  - Primary goal: to create a support structure and life-long bonds between young adults living with VHL.

Birthday Club

- Opportunity for VHLA to celebrate birthday milestones with VHLers
- VHL community exists not only to console and advise each other during tough times, but also to encourage and acknowledge each other during happy times as well.
- Makes sure that the VHLer knows about and is getting any resources that they might need.
- Reminder for VHLers to participate in MyVHL.

Well Wishes Program

- VHLers can enter information about upcoming surgeries for themselves or loved ones
- Everybody entered is contacted before and after their surgery
  - Ensure that any questions are answered and that all needs are being met
- Assist managing patient and family expectations
- Reminder for VHLers to participate in MyVHL.
VHLApp

vhl.org/VHLApp

- Premier and most up-to-date mobile resource for people with VHL, their families and medical professionals
- One-stop-shop for VHL Active Surveillance Guidelines, news and events, mobile scheduling and appointment recording tools.
- Must-have for every VHL patient, caregiver and medical professional.
- Keeps VHLers in the loop on news and events and encourage participation in MyVHL.
- Only available for iOS

VHLentines

vhl.org/VHLentine

- Fun way for patients and families to personally thank the healthcare professionals that take care of them.
- Allows healthcare professionals chance to see the positive impact they have on their patients.
- Encourages healthcare professionals to keep up the good work and continue to work hard towards better treatments and finding a cure.

Questions?

VHL Alliance
1208 VFW Parkway, Suite 303, Boston, MA 02132
617.277.5667 x 4 / vhl.org / info@vhl.org

VHL Alliance is dedicated to research, education, and support to improve awareness, diagnosis, treatment, and quality of life for those affected by VHL.
The VHL Alliance is a 501(c)(3) non-profit organization - Tax ID: 04-3180414