VHL Alliance
Clinical Care Center
Process Improvement

VHL International Research Symposium
October 6, 2018

What is a Clinical Care Center?

A Clinical Care Center (CCC) is a VHL Alliance recognized healthcare organization that has committed to providing holistic, coordinated care for VHL patients.

VHL Alliance Clinical Care Goals

- To improve diagnosis and treatment of VHL
- To provide coordination of care across medical specialties
- To provide resource centers to patients and physicians who are new to VHL
- To provide a ready channel for communicating advances to these centers of expertise
- To provide a model that can be replicated elsewhere
- Increase awareness of MyVHL and the importance of patient and caregiver emotional well-being

Clinical Care Center Reach

- 21 Clinical Care Centers
- 12 Comprehensive CCCs
- 19 International Locations
Comprehensive Clinical Care Centers – Clinical Care Centers that have been active for two years and have **showed exemplary service** may become Comprehensive Clinical Care Centers (CCCCs). Institutions designated as a CCCC also have additional multi-specialty care team members.

Clinical Care Center Patient Liaisons are patients that serve as a resource of other VHL patients and their families for a given clinical care center.

Patient Feedback

- “Doctors who know about VHL, the recommended procedures and protocol.”
- “Leader of CCCC is very committed and wants to have a meeting of his core support team to clarify expectations.”
- “I have seen no info on the Patient Natural History Study.”
- “Coordinating doctors’ visits is almost entirely on me.”
- “Only some of the members of the C/CCC realize they are part of a larger group.”

Introduction to the CCC Process Improvement Committee
Committee Mission & Vision

Mission: To improve the experience at designated clinical care centers (C/CCC) for both patients and physicians through support, collaboration, and enhanced communication.

Vision: Patients, physicians and care teams, and the VHL Alliance collaborating to achieve coordinated, quality care and improved quality of life for VHL patients.

Committee Objectives

- Increase accountability of designated clinical care centers
- Use of surveillance guidelines
- Assess patient & caregiver well-being
- Enhance the VHL patient experience with clinical care centers
- Provide support and resources for clinical care centers to improve patient care, quality of life, and patient experience

Current Committee Initiatives

- Patient Welcome Packet
  - Welcome Letter
  - MyVHL Brochure
  - Overview of Clinical Team
  - Introduction to VHL Alliance
  - Introduction to CCC Patient Liaisons
  - ER Card

- C/CCC Meetings
  - Center Kick-off Celebration - will be held when a clinical care center is newly designated or re-designated.
  - VHLA Check-in Meetings - VHLA staff/committee member(s) will arrange periodic meetings to check in with the CCC care team to give/receive updates and feedback.
  - Internal CCC Meetings – The VHLA encourages regular, internal full care team meetings to discuss patients, protocols, etc.
  - Grand Rounds – Designated C/CCCs host one Grand Rounds focused on some aspect of VHL at their institution each year.
What’s next?

- Implement Patient Welcome Packets across all VHLA clinical care centers
- Continue collecting patient feedback
- Create a formal process for giving and receiving feedback from clinical care centers
- Ongoing committee meetings to develop new ideas

What can you do to help improve VHL care?

- Follow the active surveillance guidelines
- Connect patients to the VHLA Alliance
- Educate patients on MyVHL
- Check on patient and caregiver well-being
- Participate in the Wellness Coaching Program
- Help us build the patient liaison program!
- Let the VHLA know how we can help!

Thank you!

Thoughts, feedback, ideas, or interest in joining the committee – contact me at:

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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: 04-3100414