## VIRTUAL Annual Family Meeting

**October 24, 2020**

**VIRTUAL**

### Agenda

**NOTE: All times are Eastern times**

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<th>Time</th>
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| 10:00 AM   | Introduction and Welcome                                                 | Samantha Greenberg, MS, CGG: Huntsman Cancer Institute, VHL CCC  CCCC Point of Contact  \
|            |                                                                         | Ilene Sussman: Executive Director, VHL Alliance                                     |
| 10:15 AM   | VHL 101                                                                 | Kristen Pauley, MS, CGC: Huntsman Cancer Institute                                |
| 10:45 AM   | Living with VHL: Coping with the Diagnosis and Medical Management       | Yelena Wu PhD: Assistant Professor, Department of Dermatology  \
|            |                                                                         | Huntsman Cancer Institute Investigator                                              |
| 11:15 AM   | The Emotional Roller Coaster of VHL: Separate Breakout Sessions for Patients and Caretakers | Leona deVinne, CPCC, ACC: Accendo Consulting; VHL Alliance  \
|            | **Patients:** Psychosocial challenges faced by patients with VHL and techniques to manage them | Rod Miller, MBA, CPHR MHCS: Trained & Certified Life Coach  \
|            | **Caregivers:** Psychosocial challenges faced by caregivers of patients with VHL and techniques to manage them |                                                                                   |
| 12:15 AM   | Urological Findings in VHL                                              | Alejandro Sanchez, MD: Assistant Professor in the Division of Urology,  \
|            |                                                                         | University of Utah School of Medicine; Huntsman Cancer Institute Investigator   |
### VHL and Brain Tumors: Bench to Bedside
**Randy Jensen, MD, PhD**: Brain Tumor Research Team at Huntsman Cancer Institute

### Lunch Break

### VHL and Endocrine Tumor Susceptibility
**Heloisa Soares, MD**: NET Program, Huntsman Cancer Institute

### Retinal Findings in VHL
**Eric Hansen, MD**: Fellow of Vitreoretinal Diseases and Surgery, Moran Eye Center, University of Utah Health

### Radiology Imaging
**Glen Morrell, MD, PhD**: Department of Radiology, Huntsman Cancer Institute

### Screening Guidelines
**Othon Iliopoulos, MD, PhD**: Associate Professor, Medicine, Harvard Medical School; Associate Professor of Medicine, Center for Cancer Research, Massachusetts General Hospital

### Break

### Screening Adherence in Adolescents and Emerging Adults
**Samantha Greenberg, MS, CGG**: Huntsman Cancer Institute, VHL CCCC Point of Contact

### State of VHLA: 2020
**Camron King**: Chair, VHLA Board of Directors

### Research Update
**Mei Koh, PhD**: Assistant Professor of Pharmacology and Toxicology, University of Utah School of Medicine, invited

### Clinical Trial Update
**Benjamin Maughan, MD, PharmD**: Assistant Professor in the Division of Medical Oncology, Huntsman Cancer Institute

### Concluding Remarks
**Ilene Sussman**: Executive Director, VHL Alliance

### Adjourn