



Annual Family Meeting

October 14, 2017
 Moffitt Cancer Center
 12902 USF Magnolia Drive
 Tampa, FL

Agenda

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| 7:45 AM | Registration & Coffee | |
| 8:15 AM | Introduction and Welcome | <i>Philippe Spiess, MD:</i> Moffitt Cancer Center CCC Sponsor, Associate Professor of Oncology and Urology, University of South Florida <i>Ilene Sussman:</i> Executive Director, VHL Alliance |
| 8:30 AM | Initial and annual evaluation of patients with VHL | <i>John Tourtelot, MD:</i> Department of Endocrinology, Moffitt Cancer Center |
| 9:00 AM | The Emotional Roller Coaster of VHL: <i>Separate Breakout Sessions for Patients and Caretakers</i> Patients: Psychosocial challenges faced by patients with VHL and techniques to manage them Caregivers: Psychosocial challenges faced by caregivers of patients with VHL and techniques to manage them | <i>Damon Reed, MD:</i> Adolescent and Young Adult Program, Medical Director of the Sarcoma Department, Moffitt Cancer Center; Assistant Professor of Pediatrics, University of South Florida <i>Leona deVinne, CPCC, ACC:</i> Accendo Consulting; VHL Alliance |
| 10:30 AM | Why is a regular ophthalmological exam critical in VHL | <i>Brian Maddow, MD:</i> Department of Ophthalmology, University of South Florida |
| 11:00 AM | Endocrinological advances in the management of VHL | <i>John Tourtelot, MD:</i> Department of Endocrinology, Moffitt Cancer Center |
| 11:30 AM | Role of renal ablative therapy and minimally invasive surgery in the management of VHL | <i>Wade Sexton, MD, PhD:</i> Department of Urology, Moffitt Cancer Center |
| 12:00 PM | Lunch | |

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| 1:00 PM | Liver and pancreatic manifestations of VHL | <i>Mokenge Malafa, MD</i> : Department Chair and Program Leader, Gastrointestinal Oncology, and head of the Section of Pancreatic Oncology, Moffitt Cancer Center |
| 1:30 PM | Neurological manifestations of VHL | <i>Arnold Etame, MD, PhD</i> : Neurological Surgeon and Scientist, Moffitt Cancer Center, Assistant Professor of Oncology, University of South Florida, College of Medicine |
| 2:00 PM | Advances in genetic screening for VHL | <i>Xia Wang, MD, PhD</i> : Department of Genetics, Moffitt Cancer Center |
| 2:30 PM | Applications of personalized medicine in the care of patients with VHL and other hereditary renal malignancies | <i>Howard McLeod, PharmD</i> : Department of Personalized Medicine, Moffitt Cancer Center |
| 3:00 PM | Break | |
| 3:15 PM | State of VHLA: 2016 | <i>Manuel Greco</i> : Chair, VHLA Board of Directors |
| 3:30 PM | Important lessons learned from our patients and their families: Case Presentations | MODERATOR <i>Philippe Spiess, MD</i> : Moffitt Cancer Center CCC Sponsor, Associate Professor of Oncology and Urology, University of South Florida |
| 4:00 PM | Caring for young patients with VHL: Insuring needs and demands are met | <i>Damon Reed, MD</i> : Director, Adolescent and Young Adult Program, Medical Director of the Sarcoma Department, Moffitt Cancer Center; Assistant Professor of Pediatrics, University of South Florida |
| 4:30 PM | The Past, Present, and Future of VHL: A Clinical and Research Perspective | <i>Eric Jonasch, MD</i> : Professor, Department of Genitourinary Medical Oncology, Division of Cancer Medicine, The University of Texas MD Anderson Cancer Center |
| 5:00 PM | Concluding Remarks | <i>Philippe Spiess, MD</i> : Moffitt Cancer Center CCC Sponsor, Associate Professor of Oncology and Urology, University of South Florida <i>Ilene Sussman</i> : Executive Director, VHL Alliance |
| 5:15 PM | Adjourn | |

Updated 6/30/2017