Defining Clinical Research Priorities and Strengthening Diversity and Patient-Stakeholder Engagement in Histiocytic Disorders

# Feb 1

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| **8:30 am** | Breakfast (30 min) |
| **9:00 am** | Welcome and Opening Remarks (30 min)   * Carlos Rodriguez-Galindo |
| **9:30 am** | State of Science for Histiocytic Disorders (60 min)  Speakers: Eli Diamond, Carl Allen, and Carlos Rodriguez-Galindo |
| **10:30 am** | **Break (15 min)** |
| **10:45 am** | Design and execution of clinical trials for rare cancers and blood disorders (45 min)  Speaker: Carrie Diamond (15 min)  Group Discussion (30 min) |
| **11:30 am** | Therapeutic trials in histiocytic neoplasms and HLH (2 breakout rooms – histiocytic neoplasms and HLH)  Discussion: Prioritization of therapeutic trials (45 min)  Breakout moderators: Ronald Go – histiocytic neoplasms (Meeting Room 2), Mike Jordan – HLH (Meeting Room 3)  Patient/stakeholder participants: Grace Whiting, Chris Waddell, Andrea Rocha, Deanna Fournier, Robin and Mark Ross, Nate Milam  Regroup and summary (15 min) |
| **12:30 pm** | Lunch (60 min) |
| **1:30 pm** | Data Harmonization and Longitudinal Studies -Where are we now? (15 min)  Speaker: Sam Volchenboum  Panel Discussion: Opportunities for Collaboration and Harmonization of Observational Studies (45 min)  Moderator: Carlos Rodriguez-Galindo  Panelists: Gaurav Goyal, Milen Minkov, Rima Jubran |
| **2:30 pm** | Histiocytosis: Neurologic Considerations and Outcomes  Speaker: Eli Diamond (5 min), Mike Jordan (5 min),  Discussion (20 min) |
| **3:00 pm** | Break (15 min) |
| **3:15 pm** | Harmonizing Endpoints - Biomarkers and Response Assessment in Histiocytic Disorders (45 min)  Moderator: Michelle Hermiston  Panelists: Olive Eckstein, Ilia Buhtoiarov |
| **4:00 pm** | Patient-Reported Outcomes – Primer on PROs/How do we start? (20 min)  Speaker: I-Chan Huang  Group Discussion (25 min) |
| **4:45 pm** | Wrap-up and summary (15 min)   * Eli Diamond |
| **5:00 pm** | Depart St. Jude Campus |
| **5:30-7:30pm** | Reception at Old Dominick Distillery |

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| Feb 2 | |
| **8:30 am** | Breakfast (30 min) |
| **9:00 am** | Welcome and Summary of Workshop Day #1 (15 min)   * Carlos Rodriguez-Galindo |
| **9:15 am** | **Expanding Engagement with Patients and Stakeholders in Research (60 min)**  **Speaker: Deanna Fournier (15 min)**  **Patient-Centered Research Opportunities**  **Speaker: Carly Paterson (15 min)**  **Panel Discussion (30 min)**  **Moderator: Grace Whiting**  **Panelists: Eli Diamond, Kim Nichols, Michelle Meadows, Andrea Rocha** |
| **10:15 am** | Break (15 min) |
| **10:30 am** | Intro to Diversity and Disparities Research – What questions do we need to ask? (45 min)  Speaker: Joshua Budhu (15 min)  Panel Discussion (30 minutes)  Moderator: Rima Jubran  Panelists: Joshua Budhu, Michelle Hermiston, Erin Peckham-Gregory |
| **11:15 am** | Breakout Sessions: (30 min)   * Developing plans for incorporating patients into clinical trial design (Board Room)   + Facilitator: I-Chan Huang & Eli Diamond * Solving the time to diagnosis problem (Meeting Room 2)   + Facilitator: Jen Picarsic & Deanna Fournier * Increasing diversity in clinical trials (Meeting Room 3)   + Facilitator: Josh Budhu & Kim Nichols   Key Takeaways (15 min) |
| **12:00 pm** | Lunch (60 min) |
| **1:00 pm** | Panel Discussion: Career Enhancement and Junior Investigators – Challenges and unmet needs (30 min)  Moderator: Carl Allen  Panelists: Jerry Lee, Birte Wistinghausen, Gaurav Goyal, Kathy Wisniewski |
| **1:30 pm** | Workshop Wrap-Up (30 min)   * Carl Allen |
| **2:00 pm** | Dismissed |
| **2:30pm** | \*Closed Meeting\*  Patient Advisory Board Orientation |

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