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
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| **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 MilamRegroup 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 VolchenboumPanel 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 OutcomesSpeaker: 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 HermistonPanelists: Olive Eckstein, Ilia Buhtoiarov |
| **4:00 pm** | Patient-Reported Outcomes – Primer on PROs/How do we start? (20 min)Speaker: I-Chan HuangGroup Discussion (25 min) |
| **4:45 pm** | Wrap-up and summary (15 min)* Eli Diamond
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| **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
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| **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 JubranPanelists: 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 AllenPanelists: Jerry Lee, Birte Wistinghausen, Gaurav Goyal, Kathy Wisniewski |
| **1:30 pm** | Workshop Wrap-Up (30 min)* Carl Allen
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| **2:00 pm** | Dismissed |
| **2:30pm** | \*Closed Meeting\*Patient Advisory Board Orientation |

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