

LCH STEERING COMMITTEE REPORT - JULY 2019

July 12, 2019

Members: Carl Allen and Karin Buetel (Acting Co-Chairs); Patrick Campbell, Michael Girschikofsky, Michelle Hermiston, Rima Jubran, Stephan Ladish, Milen Minkov, Vasanta Nanduri, Barrett Rollins, Kimo Stine, Johannes Visser, Matthew Collin, Cor van den Bos.

Activities:

1. LCH Blueprint. The major activity of the LCH SC this year has been to review the unmet needs of LCH patients and discuss research priorities that will lead to improved outcomes. Our goal is to create a “Blueprint” document for the HS Leadership that may serve as a platform for discussions and strategic planning for LCH activities within the HS. Some of these activities may also be expanded into review articles or other work products to benefit the broader community. Topic areas include

- a. Defining diagnostic criteria/response criteria
- b. Identifying and treating late effects of LCH and therapeutic exposure
- c. Understanding etiology of LCH in adults and optimizing therapeutic strategies
- d. Developing and implementing targeted treatments
- e. Establishing basic and translational research priorities

2. HS 2019. We are planning for the HS 2019 meeting in Memphis. During the “pre-meeting” there will be a closed Steering Committee meeting to follow-up on action items and plan for 2020 activities. We are also organizing an open session to publicly discuss the “Blueprint”. We also welcome agenda items from the HS community.

3. Leadership Announcement. Congratulations to Michelle Hermiston who will formally take over as Chair of the LCH Steering Committee at the next HS Meeting. We appreciate her commitment and look forward to growth of the LCH SC under her leadership.

4. Membership Communication. Please send Carl (ceallen@txch.org) and Karin (Karin/Beutel@mri.tum.de) and comments or questions. Suggestions are appreciated for content for the LCH pre-meeting in Memphis.