

**NATIONAL CANCER INSTITUTE
CHILDHOOD CANCER DATA INITIATIVE SYMPOSIUM**

July 29 – 31, 2019

Marriott Marquis, Washington, D.C.

DRAFT AGENDA & SESSION GOALS

MONDAY, JULY 29TH

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| 4:30 p.m. – 5 p.m. | Registration & Gathering |
| 5 p.m. – 5:25 p.m. | Welcome & Opening Remarks
Doug Lowy, M.D.
National Cancer Institute, NIH |
| 5:25 p.m. – 5:50 p.m. | Dialogue: FDA Principal Deputy Commissioner
Amy Abernethy M.D., Ph.D.
Food and Drug Administration |
| 5:50 p.m. – 7:10 p.m. | Envisioning a National Childhood Cancer Data Initiative
(Panel Discussion)
Peter Adamson, M.D. (Children’s Hospital of Philadelphia)
Elaine Mardis, Ph.D. (Nationwide Children’s Hospital)
Charles Roberts, M.D., Ph.D. (St. Jude Children’s Research Hospital)
Donald William Parsons, M.D. Ph.D. (Texas Children’s Hospital)
Jaclyn Taroni, Ph.D. (Childhood Cancer Data Lab) |
| 7:10 p.m. – 7:30 p.m. | Patient-Centered Data Management for Discovery
(10 minutes each)

<i>Ethics Around Data Science & Sharing</i>
Vasiliki Rahimzadeh
McGill University

<i>Meeting Patient Needs through Data</i>
Amanda Haddock
DragonMaster Foundation |
| 7:30 p.m. – 8 p.m. | Poster Set-Up & Mingling |
| 8 p.m. – 9:30 p.m. | Poster & Networking Reception (Poster presentations split into two 45-minute sessions) |
| 9:30 p.m. | Adjourn |
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TUESDAY, JULY 30TH

8 a.m. – 8:30 a.m.

Registration & Gathering

8:30 a.m. – 10 a.m.

Setting the Stage for a Childhood Cancer Data Initiative

(Panel Discussions; 45 minutes each)

Goal of this session:

- This session will outline each of the focus areas of the NCI Childhood Cancer Data Initiative to provide a more comprehensive overview for broad discussion.

1. Prioritizing scientific and clinical research data needs for therapeutic progress

NCI Moderators – Malcolm Smith, M.D., Ph.D. & Brigitte Wideman, M.D.

Panelists – Susan Cohn, M.D. (University of Chicago)

Katherine Janeway, M.D. (Dana-Farber Cancer Institute)

John Maris, M.D. (Children’s Hospital of Philadelphia)

Soheil Meshinchi, M.D., Ph.D. (Fred Hutchinson Cancer Research Center)

Charles Mullighan, MBBS, M.D. (St. Jude Children’s Research Hospital)

Leslie Robison, Ph.D. (St. Jude Children’s Research Hospital)

2. Creating meaningful datasets for clinical care and associated research progress

NCI Moderators – Stephen Chanock, M.D. & Jaime Guidry Auvil, Ph.D.

Panelists – Todd Alonzo, Ph.D. (University of Southern California)

Sharon Plon, M.D., Ph.D. (Baylor College of Medicine)

Logan Spector, Ph.D. (University of Minnesota)

Adam Resnick, Ph.D. (Children’s Hospital of Philadelphia)

Sam Volchenboum, M.D., Ph.D. (University of Chicago)

10 a.m. – 10:15 a.m.

Break

10:15 a.m. – 11:45 a.m.

Setting the Stage for a Childhood Cancer Data Initiative – *continued*

(Panel Discussions, 45 minutes each)

3. Infrastructure to enable federation among pediatric data repositories

NCI Moderators – Tony Kerlavage, Ph.D. & Lynne Penberthy, M.D.

Panelists – Gregory Armstrong, M.D., MSCE (St. Jude Children’s Research Hospital)

Allison Heath, Ph.D. (Children’s Hospital of Philadelphia)

Anne Kirchoff, Ph.D., MPH (University of Utah)

Jeff Trent, Ph.D. (Translational Genomics Research Institute)

Olena Vaske, Ph.D. (University of California, Santa Cruz)

4. Development of tools and methods to extract knowledge from data

NCI Moderators – Jennifer Couch, Ph.D. & Juli Klemm, Ph.D.

Panelists – Eric Durbin, DrPH (University of Kentucky)

Joel Milam, Ph.D. (University of Southern California)

Tamara Miller, M.D. (Emory University)

Jinghui Zhang, Ph.D. (St. Jude Children’s Research Hospital)

11:45 p.m. – 12: 30 p.m.

Governance & Authorities: Establishing a Pediatric Data Ecosystem

NCI Moderators – Jaime Guidry Auvil, Ph.D. & Vivian Ota Wang, Ph.D.

Panelists – Maryrose Franko, Ph.D. (Health Research Alliance)

Peter Goodhand (Global Alliance for Genomics & Health)

Amanda Haddock (DragonMaster Foundation)

Salvatore La Rosa, Ph.D. (Children’s Tumor Foundation)

Lena Winestone, M.D. (University of California, San Francisco)

12:30 p.m. – 2 p.m.

Networking Lunch & Poster Viewing (Lunch on your own)

2 p.m. – 5:30 p.m.

Focus Breakout Track Sessions

Goal of this session:

- Attendees will be broken out into focus groups along primary tracks:
 1. **Prioritizing scientific and clinical research data needs for therapeutic progress**
 2. **Creating meaningful datasets for clinical care and associated research**
 3. **Infrastructure to enable federation among disparate pediatric data repositories**
 4. **Development of tools and resources to extract knowledge from data**

5:30 p.m.

Adjourn for the day (Dinner on your own)

WEDNESDAY, JULY 31ST

8 a.m. – 8:30 a.m.

Networking & Gathering

8:30 a.m. – 10:30 a.m.

Reports Out from Focus Breakout Sessions (30 minutes each)

Goal of this session:

- A representative from each area of focus will report out to the symposium on each breakout session from the previous day.
 1. **Prioritizing scientific and clinical research data needs for therapeutic progress**
 2. **Creating meaningful datasets for clinical care and associated research**
 3. **Infrastructure to enable federation among disparate pediatric data repositories**
 4. **Development of tools and resources to extract knowledge from data**

10:30 a.m. – 10:45 a.m.

Break

- 10:45 a.m. – 11:15 a.m. **Questions and Answers about CCDI**
- 11:15 a.m. – 11:55 a.m. **Key Perspectives on CCDI: NCI Leadership**
Doug Lowy, M.D.
Dinah Singer, Ph.D.
James Doroshow, M.D., FACP
- 11:55 a.m. – 12 p.m. **Final Thoughts and Charge for Future**
Doug Lowy, M.D.
National Cancer Institute, NIH
- 12 p.m. Adjourn