

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

July 29 – 31, 2019

Marriott Marquis, Washington, D.C.

AGENDA & SESSION GOALS

MONDAY, JULY 29

- 4:30 p.m. – 5 p.m. **Registration & Gathering**
- 5 p.m. – 5:25 p.m. **Welcome & Opening Remarks**
Douglas 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)
Ethics Around Data Science & Sharing
Vasiliki Rahimzadeh, Ph.D. (McGill University)
Meeting Patient Needs through Data
Amanda Haddock (DragonMaster Foundation)
- 7:30 p.m. – 8 p.m. **Poster Set-Up & Mingling**
- 8 p.m. – 9:30 p.m. **Poster Session & Networking Reception**
Hosted by the Foundation for the National Institutes of Health
(Poster presentations split into two 45-minute sessions)
- 9:30 p.m. Adjourn
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TUESDAY, JULY 30

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 Childhood Cancer Data Initiative to provide a 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 Widemann, 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, Dr.PH (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.

Lunch

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

WEDNESDAY, JULY 31

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. – 11:55 a.m. **Key Perspectives and Discussion: NCI Leadership**

Douglas 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**

Douglas Lowy, M.D.

National Cancer Institute, NIH

12 p.m. Adjourn