

Appendix B: SCDTDP Data Summit Participants

| SDCTDP Data Summit Participants | | | |
|--|--------------------|---|--|
| Organization | Contact Person | Role | E-mail |
| Boston Medical Center | William Adams, MD | Pediatrician, informatics researcher | Bill.Adams@bmc.org |
| Northeast Coordinating Center | Michele Ako | Research intern, pediatric hematology | |
| Northeast Coordinating Center | Nina Anderson | Primary care provider | nina@tovacomunityhealth.org |
| SCDAA | Mary Brown | President & CEO of the Sickle Cell Disease Foundation of California | maryb@scdfc.org |
| NICHQ | Emily Clermont | Senior Project Manager | |
| Northeast Coordinating Center | Alice Cohen | Hematologist | acohen@barnabashealth.org |
| Heartland Sickle Cell Disease Network | Ben Cooper | Data Manager | ben.cooper@wustl.edu |
| AHRQ | Denise Dougherty | Federal Partner | Denise.Dougherty@ahrq.hhs.gov |
| Emory University School of Medicine | Jim Eckman | Hematologist | jeckman@emory.edu |
| NICHQ | Patricia Finnerty | Improvement Advisor | pfinnerty@nichq.org |
| FDA | Jonathan Goldsmith | Federal Partner | Jonathan.Goldsmith@fda.hhs.gov |
| CDC | Althea Grant | Epidemiologist | ang4@CDC.GOV |
| The Johns Hopkins School of Medicine | Carlton Haywood | Epidemiologist, clinical researcher, patient with SCD | chaywoodjr@jhu.edu |
| NICHQ | Charlie Homer | Pediatrician, former CEO of NICHQ | |
| CDC | Mary Hulihan | Health Sciences Researcher | ibx5@cdc.gov |
| Pacific Sickle Cell Regional Collaborative | Alan Ikeda | Pediatric Hematologist | aikeda@cure4thekids.org |
| HRSA | Donnell Ivy | Project Officer | eivy@hrsa.gov |
| Boston Medical Center | Trish Kavanagh | Pediatrician | Patricia.Kavanagh@bmc.org |
| Heartland Sickle Cell Disease | Allison King | Pediatric Hematologist | King_A@kids.wustl.edu |

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| Network | | | |
| NHLBI | Norma Lerner | Federal Partner | norma.lerner@nih.gov |
| HRSA | Michael Lu | Associate Administrator, MCHB, HRSA | Michael.Lu@hrsa.hhs.gov |
| Sickle Cell Treatment and Outcomes Research in the Midwest (STORM) | Tammy Nordheim | Project Manager | Tamara.Nordheim@cc-hmc.org |
| Pacific Sickle Cell Regional Collaborative | Diane Nugent | Pediatric Hematologist | dianenugent7@gmail.com |
| NICHQ/ Children's Hospital at Montefiore | Suzette Oyeku | Pediatrician, NCC Medical Director | soyeku@nichq.org |
| Pacific Sickle Cell Regional Collaborative | Susan Paulukonis | Epidemiologist | Susan.paulukonis@cd-ph.ca.gov |
| HRSA | Madelyn Reyes | Federal Partner | mreyes1@hrsa.gov |
| NIH | Yaffa Rubinstein | Federal Partner | Yaffa.Rubinstein@nih.gov |
| Sickle Cell Treatment and Outcomes Research in the Midwest (STORM) | Kay Saving | Pediatric Hematologist | kls@uicomp.uic.edu |
| HRSA | Joan Scott | Genetic Service Branch Chief, Division of Services for Children with Special Health Needs, Health Resources and Services Administration | JScott2@hrsa.gov |
| NICHQ | Avery Seefeld | Project Manager | |
| Sickle Cell Treatment and Outcomes Research in the Midwest (STORM) | Lisa Shook | Health services researcher | Lisa.Shook@cchmc.org |
| The Children's Hospital of Philadelphia | Kim Smith-Whitley | Pediatric hematologist | whitleyk@email.chop.edu |
| Northeast Coordinating Center | Rosalyn Stewart | Pediatrician | rstewart@jhmi.edu |
| HRSA | Bonnie Strickland | retired | retired |
| Northeast | John Strouse | Pediatric hematologist | |

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| Coordinating Center | | | jstrous1@jhmi.edu |
| HRSA | Christina Turgel | Federal Partner | CTurgel@hrsa.gov |
| NICHQ | Kate Vaughan | Associate Director | |
| FDA | Nicole Verdun | Federal Partner | nicole.verdun@fda.hhs.gov |
| NHLBI | Ellen Werner | Program Director at National Heart, Lung, and Blood Institute/NIH | wernere@nhlbi.nih.gov |
| Northeast Coordinating Center | Lauren Whiteman | Program Coordinator; Analyst | Lwhitem1@jhmi.edu |