**Appendix B: SCDTDP Data Summit Participants**

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| 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@tovacommunityhealth.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 Network | Allison King | Pediatric Hematologist | King\_A@kids.wustl.edu  |
| 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@cchmc.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@cdph.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 Coordinating Center | John Strouse | Pediatric hematologist | 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 |