



September 20, 2019

Institute for Clinical and Economic Review
Two Liberty Square
Boston, MA 02109

RE: Stakeholder List for Sickle Cell Disease

Dear Dr. Pearson,

Sick Cells is pleased to submit comments about the Institute for Clinical and Economic Review (ICER) Sickle Cell Disease: Stakeholder List.

The sickle cell disease (SCD) community has a vast reach of community-based organizations. Each region of the United States faces its own, unique challenges. With this in mind, each CBO works within its local governments and healthcare systems to increase access to and quality of care for SCD patients and families. Partner organizations of the SCDA should be evaluated as stand-alone CBOs.

The current list of stakeholders is incomplete and missing key CBOs and professional societies that contribute to the landscape of SCD. Sick Cells encourages ICER to work with all SCD CBOs and professional societies across the United States to better understand and accurately capture disease states. Sick Cells included a list of active CBOs including those already listed in the current Stakeholders List.

Sickle Cell Disease Community-Based Organizations

Alabama

- North Alabama Sickle Cell Foundation – Huntsville
- SCDA-West Alabama Chapter – Northport
- Central Alabama Sickle Cell Foundation – Birmingham
- SCDA- Mobile Chapter, Inc.
- Sickle Cell Foundation of The River Region- Montgomery
- Southeast Alabama Sickle Cell Association, Inc.- Tuskegee

California

- Cayenne Wellness
- Axis Advocacy
- Sickle Cell 101
- Sickle Cell Disease Foundation of California
- Sickle Cell Warriors, Inc.

Colorado

- Colorado Sickle Cell Association, Inc. – Denver

Connecticut

- Citizens for Quality Sickle Cell Care, Inc.-New Britain/Hartford



- SCDAAs Southern Connecticut, Inc.- Bridgeport/New Haven

Delaware

- Tova Community Health

Florida

- SCDAAs of Escambia & Santa Rosa Counties – Pensacola
- SCDAAs Dade County Chapter, Inc. – Miami
- SCDAAs St. Petersburg Chapter
- Sickle Cell Association of Hillsborough County
- Sickle Cell Disease Association of Florida, Inc.-Tampa, FL
- Sickle Cell Disease Association of Tri-County, Inc. – Orlando
- Sickle Cell Foundation, Inc.- Tallahassee
- Foundation for Sickle Cell Disease Research

Georgia

- Sickle Cell Foundation of Georgia, Inc.- Atlanta
- The Sickle Cell Community Consortium

Illinois

- Sickle Cell Disease Association of Illinois – Chicago

Indiana

- Martin Center, Inc. – Indianapolis

Kansas

- Uriel Owen Sickle Cell Disease Association of the Midwest

Louisiana

- Northeast Louisiana Sickle Cell Anemia Foundation – Monroe
- Southwest Louisiana Sickle Cell Anemia, Inc- Lake Charles

Maryland

- Maryland Sickle Cell Disease Association, Inc. (MSCDA)
- Sickle Cell Disease Association of America, Inc.

Massachusetts

- Greater Boston Sickle Cell Disease Association, Inc.

Michigan

- SCDAAs Michigan – Detroit

Missouri

- Sickle Cell Association of St. Louis

Nevada

- Nevada Childhood Cancer Foundation- Las Vegas

New Jersey

- The Sickle Cell Association of New Jersey, Inc. – Newark

New Mexico

- The Sickle Cell Council of New Mexico – Albuquerque
- Kids Conquering Sickle Cell Disease and the Young Adult Sickle Cell Alliance

New York



- Falling Angels Sickle Cell Foundation
- Queens Sickle Cell Advocacy Network – Queens Village
- Sickle Cell Thalassemia Patients Network (SCTPN)

North Carolina

- Bridges Pointe Sickle Cell Foundation – Durham
- Community Health Interventions and Sickle Cell Agency, Inc. – Fayetteville
- Piedmont Health Services and Sickle Cell Agency – Greensboro

Ohio

- SCDA-Ohio Sickle Cell & Health Association – Columbus
- American Sickle Cell Anemia Association

Oklahoma

- Supporters of Families with Sickle Cell

Oregon

- Sickle Cell Anemia Foundation of Oregon – Portland

Pennsylvania

- Children’s Sickle Cell Foundation, Inc.- Pittsburgh
- SCDA-Philadelphia/Delaware Valley Chapter
- The South Central PA Sickle Cell Council – Harrisburg

South Carolina

- James R. Clark Memorial Sickle Cell Foundation – Columbia

Tennessee

- Sickle Cell Foundation of Tennessee – Memphis

Texas

- Sickle Cell Association of Houston
- Sickle Cell Association of Texas Marc Thomas Foundation

Virginia

- Sickle Association Inc.- Norfolk

Sickle Cell Disease Professional Societies

- International Association of Sickle Cell Disease Nurses and Physician Assistants
- National Minority Quality Forum
- American Society of Pediatric Hematology/Oncology