

The N.C. Sickle Cell Initiative

State and Local Resources

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The Historical Context

- 102 Years ago the Sickle Cell was identified
- 60 Years ago, A Duke Researcher discovered Hemoglobin-Durham
- Nixon established the Sickle Cell Treatment Act
- Community Groups advocated for sickle cell services
- House Bill 32 passes in North Carolina

Elements of the Rich History

- Political Action
- Clinical Care
- Research
- Community-Based Organizations
- Innovation
- Contributions to the Advancement of Sickle Cell Disease Management

The Organizational Context

- The Federal Effort
- The N.C. Sickle Cell Syndrome Program
- The Governors' Council on Sickle Cell
- Statewide Contracts

Medical Centers

- Carolinas Medical Center
- Wake Forest University
- UNC- Chapel Hill
- Duke University
- East Carolina

Community Based Centers

Charlotte

Greensboro

Fayetteville

Jacksonville

Member Organizations

Sickle Cell Disease Association of America (SCDAA)

Bridges Pointe Foundation of Durham

RESOURCES PROVIDED

Coverage in 100 Counties

Statewide Collaboration

Newborn Screening

Early Intervention

Genetic Counseling

Medical Reimbursement

Advocacy and Education

Provider Contracts

Health Maintenance

Medical Care

Community Intervention

Resources , Cont.

- Clinical Research
- Patient and Community Education
- Clinical Social Work
- Social Support
- Information and Referrals

Local Resources

LOCAL RESOURCES

Duke Comprehensive Sickle Cell Center
Pediatrics

George Phillips Adult Sickle Cell
Center

Durham Support Group

Bridges Pointe Foundation

Bridges Pointe Apartments

Innovation

- Legislative Mandate
- 25 Years of Funding by NHLBI
- Psychosocial Research
- Day Hospital

Emerging Resource Needs

- Adult Services
- Behavioral Health Services
- Funding
- Advocacy at the Federal Level
- Research Funding
- Social Support and Education Funding

Conclusion

A well developed network.....

But still work to be done