

SICKLE CELL DISEASE COALITION (SCDC)



Build Your Own SCD School Binder

Sickle cell disease (SCD) is an inherited, chronic blood disorder that can lead to complex complications for individuals born with the disease. SCD complications often arise in infancy and range in type and severity from person to person; some common complications associated with the disease include chronic pain, blood clots, high blood pressure, breathing and sleeping issues, kidney problems, and vision impairment. SCD impacts more than 100,000 individuals in the United States and more than 100,000,000 people worldwide. With early diagnosis and access to comprehensive biopsychosocial care and support services, individuals living with SCD can maintain their health and thrive with a high-quality of life.

School personnel, caregivers, and other community members can play a critical role in improving health and academic outcomes of students living with SCD.

The ***Build Your Own SCD School Binder*** offers school personnel, students, caregivers, and other stakeholders a repository of evidence-based resources and recommended interventions to support the academic and biopsychosocial wellness of students living with SCD.

Resources included reflect a diversity of topics, perspectives, and needs. This toolkit is designed to provide a wealth information that may become relevant at different points of a student’s educational journey – from daycare to higher education and employment. For ease of access, resources are organized by relevancy to different stakeholders, including:

Teachers • School Nurses • School Administrators • Coaches • Caregivers • Students



Use this repository to build your own personalized “SCD School Binder” by:

- 1.) reviewing the resources listed in each section (see Table of Contents, pg.3),**
- 2.) downloading and/or printing relevant items, and**
- 3.) compiling these materials into a binder for reference throughout the school year.**

To learn more about SCD and access additional resources, visit: www.scdcoalition.org.

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A. Building Blocks to Support Students with SCD

i. General Guidance on SCD & School Support

- [Education: Sickle Cell Disease & Supportive Care](#) (Source: Sickle Options)
- [Management of Sickle Cell Disease in the Educational Setting](#) (Source: Kennedy Krieger Institute)
- [Maryland State School Health Services Guideline: Management of Sickle Cell Disease in Schools](#) (Source: Maryland Sickle Cell Disease Association (MSCDA), Maryland State Department of Education, Maryland Department of Health)
- [Sickle Cell Handbook for Schools](#) (Source: Children’s Hospital of Philadelphia (CHOP))
- [Sickle Cell Information Center: Teachers and Students](#) (Source: Emory School of Medicine)
- [Sickle Cell and School: A Guide to School Policy and Best Practices](#) (Source: The Parent-to-Parent Initiative and Sickle Cell Community Consortium)
- [Sickle Cell and Thalassemia: A Guide to School Policy](#) (Source: Simon Dyson, PhD)
- [Sickle Cell Trait Toolkit](#) (Source: CDC, ASH, SCDA)
- [Steps to Better Health for People with Sickle Cell Disease Toolkit](#) (Source: Centers for Disease Control and Prevention (CDC), American Society of Hematology (ASH), and Sickle Cell Disease Association of America (SCDAA))
- [Tips for Supporting Students with Sickle Cell Disease Booklet](#) (Source: CDC)
- [Understanding the Child with Sickle Cell Disease: A Handbook for School Personnel](#) (Source: Virginia Sickle Cell Awareness Program, Virginia Department of Health)
- [Understanding Sickle Cell Disease](#) (Source: National Heart, Lung, and Blood Institute (NHLBI))
- [“8 Tips to Support Students with Sickle Cell Disease”](#) (Source: Black Health Matters)

ii. Protected Rights & Accommodations for Students Living with SCD

- [Accommodation and Compliance: Sickle Cell Anemia](#) (Source: Job Accommodation Network (JAN))
- [Caregiver Information on 504 Plans and IEPs](#) (Source: CHOP)
- [Parent Advocacy Materials](#) (Source: CHOP)
- [Reasonable Accommodations for College Students with Sickle Cell Disease](#) (Source: New England Pediatric Sickle Cell Consortium)
- [Transitioning to Adult Care – Legal and Health Guidance for Patients](#) (Source: Boston Children’s Hospital)
- [What Happens When I Turn 18?](#) (Source: Boston Children’s Hospital)
- [504 Plan for Education because of SCD](#) (Source: St. Jude Children’s Research Hospital)

iii. Sample SCD Care Plans & Accommodation Letters

○ **Sample SCD Care Plans:**

- [Athletic Department Action Plan for the Student with SCD](#) (Source: CHOP)
- [Before and Aftercare Action Plan for Students with SCD](#) (Source: CHOP)
- [Early Childhood Education Provider Action Plan for the Student with Sickle Cell Disease](#) (Source: CHOP)
- [School Health Services Action Plan for Students with SCD](#) (Source: CHOP)
- [Sickle Cell Anemia School Nurse Care Plan](#) (Source: Sarah Portle, Med., BSN, RN, NCSN)
- [Sickle Cell Anemia Teacher Action Plan](#) (Source: Sarah Portle, Med., BSN, RN, NCSN)
- [Sickle Cell Handbook for Schools](#) (Source: CHOP)
- [Sickle Cell and School: A Guide to School Policy and Best Practices – COVID Edition](#) (Source: The Parent-to-Parent Initiative and Sickle Cell Community Consortium)
- [Sickle Cell and Thalassemia: A Guide to School Policy](#) (Source: Simon Dyson, PhD)
- [Summer Camp Action Plan for Students with SCD](#) (Source: CHOP)
- [Teacher/Substitute Teacher Action Plan for Students with SCD](#) (Source: CHOP)

○ **Sample SCD Accommodation Letters:**

- [Reasonable Accommodations for College Students with Sickle Cell Disease](#) (Source: New England Pediatric Sickle Cell Consortium)
- [Sample SCD letter - general](#) (Source: Dr. Sunnye Mayes)
- [Sample SCD letter - day care](#) (Source: Dr. Sunnye Mayes)
- [Sample SCD letter - college](#) (shared by Dr. Sunnye Mayes)
- [Sample SCD Letter to Employers from Caregiver](#) (Source: SCDA MARAC)
- [Sample SCD Letter to Employers from Individuals Living with SCD](#) (Source: SCDA MARAC)
- [Sickle Cell Anemia Care Plan Letter](#) (Source: Sarah Portle, Med., BSN, RN, NCSN)

B. SCD School Guidance & Resources Organized by Topic

i. After School Care, Camp, & Sports

- [“Athletes: Don’t Get Sidelined by Sickle Cell Trait! Help Them Play It Safe with These Helpful Tips!” Fact Sheet](#) (Source: CDC, ASH, SCDAAs)
- [Athletic Department Action Plan for Student with SCD](#) (Source: CHOP)
- [Before and Aftercare Action Plan for Student with SCD](#) (Source: CHOP)
- [“Coaches: Don’t let your athletes get sidelined by sickle cell trait! Help them play it safe with these helpful tips!” Fact Sheet](#) (Source: CDC, ASH, SCDAAs)
- [Diet and Exercise: Living Well with Sickle Cell](#) (Source: Blackdoctor.org)
- [Exercise and Athletics with Sickle Cell Disease](#) (Source: SickleCell.com)
- [Managing Acute Pain if You Have Sickle Cell Disease](#) (Source: CDC, ASH, SCDAAs)
- [Managing Chronic Pain if You Have Sickle Cell Disease](#) (Source: CDC, ASH, SCDAAs)
- [Sample SCD letter - day care](#) (Source Dr. Sunnye Mayes)
- [Sickle Cell Trait Toolkit](#) (Source: CDC, ASH, SCDAAs)
- [Steps to Better Health Toolkit for People with Sickle Cell Disease](#) (Source: CDC, ASH, SCDAAs)
- [Summer Camp Action Plan for Student with SCD](#) (Source: CHOP)
- [“Team Doctors \(Trainers\): Don’t Let Your Athletes Get Sidelined by Sickle Cell Trait!” Fact Sheet](#) (Source: CDC, ASH, SCDAAs)
- [Tips for Supporting Students with Sickle Cell Disease Booklet](#) (Source: CDC)

ii. Early Child Care & Preschool

- [Early Childhood Education Provider Action Plan for Student with SCD](#) (Source: CHOP)
- [Elementary School Age Children and Sickle Cell Disease](#) (Source: Children’s Hospital of Pittsburgh)
- [Get Screened to Know Your Sickle Cell Status Fact Sheet](#) (Source: CDC, ASH, SCDAAs)
- [Infants and Toddlers and Sickle Cell Disease](#) (Source: Children’s Hospital of Pittsburgh)
- [Parents’ Handbook for SCD: Birth to Six Years of Age](#) (Source: California Department of Health Services)
- [Preschoolers and Sickle Cell Disease](#) (Source: Children’s Hospital of Pittsburgh)
- [“Psychoeducational Screening in Pediatric Sickle Cell Disease: An Evaluation of Academic and Health Concerns in the School Environment”](#) (Source: Mayes, Wolfe-Christensen, Mullins, and Cain)

iii. Higher Education / Employment

- [Accommodation and Compliance: Sickle Cell Anemia](#) (Source: Job Accommodation Network (JAN))
- [Accommodation and Compliance Series: Employees with Sickle Cell Anemia](#) (Source: JAN)
- [“College Students Living with a Chronic Condition”](#) (Source: Center for Online Education)
- [College Students with Chronic Health Conditions](#) (Source: Edu Med)
- [Co-Pay Relief Fund](#) (Source: Patient Advocate Foundation)
- [High School Staff and Guidance Counselor Reference for College- and Career-Bound Student with SCD](#) (Source: CHOP)
- [“I Have Sickle Cell Disease. What Should I Know About Going Away to College?”](#) (Source: Nemour’s Children’s)
- [Managing Acute Pain if You Have Sickle Cell Disease](#) (Source: CDC, ASH, SCDAAC)
- [Managing Chronic Pain if You Have Sickle Cell Disease](#) (Source: CDC, ASH, SCDAAC)
- [“Managing Chronic Illness in College”](#) (Source: Collegiate Parent)
- [Reasonable Accommodations for College Students with Sickle Cell Disease](#) (Source: New England Pediatric Sickle Cell Consortium)
- [Sample SCD letter - college](#) (shared by Dr. Sunnye Mayes)
- [Sample SCD Letter to Employers from Caregiver](#) (Source: SCDAAC MARAC)
- [Sample SCD Letter to Employers from Individuals Living with SCD](#) (Source: SCDAAC MARAC)
- [Steps to Better Health Toolkit for People with Sickle Cell Disease Fact Sheet](#) (Source: CDC, ASH, SCDAAC)
- [Teens with Sickle Cell Disease](#) (Source: Children’s Hospital of Pittsburgh)
- [Tip Sheet for the College- and Career-Bound Student](#) (Source: CHOP)
- [Transitioning to Adult Care – Legal and Health Guidance for Patients](#) (Source: Boston Children’s Hospital)
- [What Happens When I Turn 18?](#) (Source: Boston Children’s Hospital)
- [What You Should Know About Sickle Cell Trait Fact Sheet](#) (Source: CDC, ASH, SCDAAC)
- [“9 Tips to Living well with SCD in College”](#) (Source: CDC)
- [“28 Hacks that Can Make Going to College with a Chronic Illness Easier”](#) (Source: The Mighty)

iv. Mental Health & Wellness

- [A Guide to Living with SCD: Define Yourself, Define Your Life](#) (Source: Sickle Cell 101)
- [Be the Match Patient Support Center: Counseling Services](#) (Source: Be The Match)
- [Cayenne Wellness Center California SCD Mental Health & Wellness Program](#) (Source: Cayenne Wellness)
- [Children with Chronic Illness: Dealing with Emotional Problems and Depression](#) (Source: American Academy of Pediatrics (AAP))
- [Faces of SCD Storytelling Program](#) (Source: Sick Cells)
- [Fostering Emotional Well Being](#) (Source: CHOP)
- [Mental Health America: Online Mental Health Screening](#)
- [Mental Health Resources for Patients and Families](#) (Source: AAP)
- [Psychosocial: Sickle Cell Disease & Supportive Care](#) (Source: Sickle Options)
- [Resources for Siblings of Children with Chronic Illnesses or Disabilities](#) (Source: AAP)
- [Tips and Strategies for Managing Anxiety When Returning to School](#) (Source: CHOP)
- [Understanding SCD in the Classroom: Fostering Emotional Wellbeing](#) (Source: CHOP)

v. Nutrition

- [Daily Water Consumption Recommendations](#) (Source: CHOP)
- [Diet and Exercise: Living Well with Sickle Cell](#) (Source: Blackdoctor.org)
- [Diet and Nutrition in SCD PowerPoint](#) (Source: Sickle Cell Info Center, Dr. Allan Platt)
- [Exercise and Athletics with Sickle Cell Disease](#) (Source: SickleCell.com)
- [Nutrition for the Child with Sickle Cell Anemia](#) (Source: Academy of Nutrition and Dietetics)
- [Nutrition Guide for Sickle Cell Disease](#) (Source: Physicians Committee for Responsible Medicine)
- [“School Nurses Guide to Sickle Cell Disease” Training Presentation](#) (Source: Indiana Hemophilia & Thrombosis Center (IHTC))
- [Steps to Better Health Toolkit for People with Sickle Cell Disease Fact Sheet](#) (Source: CDC, ASH, SCDA)

vi. Sexual Health & Dating

- ["Family Planning Options for Couples with Sickle Cell Trait or Sickle Cell Disease \(SCD\)" Fact Sheet](#) (Source: Sickle Cell Reproductive Health Education Directive (SCRED))
- [Get Screened to Know Your Sickle Cell Status Fact Sheet](#) (Source: CDC, ASH, SCDAAC)
- [Men's Health and Sickle Cell Disease](#) (Source: Sickle Cell 101)
- [Sexual Health and Sickle Cell Disease](#) (Source: Children's National Hospital)
- [Sickle Cell Disease and Menstruation](#) (Source: SickleCell.com)
- [Sickle Cell Disease: Population Impacts](#) (Source: SickleCell.com)
- [SCRED Educational Library](#) (Source: SCRED)
- [SCRED Resources on Maternal Health, Fertility Preservation, & Priapism](#) (Source: SCRED)
- [Sickle Cell Trait Toolkit](#) (Source: CDC, ASH, SCDAAC)
- [Speaking with Your Partner about SCD](#) (Source: SickleCell.com)
- [Telling a Potential Partner That I Have Sickle Cell Disease](#) (Source: Sickle Cell Disease News)
- [Tips for Dating with Sickle Cell](#) (Source: SickleCell.com)
- [The Challenges of Invisible Illnesses and Intimacy](#) (Source: SickleCell.com)
- [What You Should Know About Sickle Cell Trait Fact Sheet](#) (Source: CDC, ASH, SCDAAC)
- [Women with Sickle Cell Disease](#) (Source: SickleCell.com)

vii. Unique Academic Needs

- [Caregiver Information on 504 Plans and IEPs](#) (Source: CHOP)
- [Classroom Guidelines: Supporting a Student Who Has Had a Stroke](#) (Source: CHOP)
- [College Students with Chronic Health Conditions](#) (Source: Edu Med)
- [Education: Sickle Cell Disease & Supportive Care](#) (Source: Sickle Options)
- [Parents' Handbook for SCD: Six to Eighteen Years of Age](#) (Source: California Department of Health Services)
- ["Psychoeducational Screening in Pediatric Sickle Cell Disease: An Evaluation of Academic and Health Concerns in the School Environment"](#) (Source: Mayes, Wolfe-Christensen, Mullins, and Cain)
- [Reasonable Accommodations for College Students with Sickle Cell Disease](#) (Source: New England Pediatric Sickle Cell Consortium)
- [Resources for Supporting Learners with Disabilities](#) (Source: Digital Promise)
- [Tips for Supporting Students with Sickle Cell Disease Booklet](#) (Source: CDC)
- [504 Plan for Education because of SCD](#) (Source: St. Jude Children's Research Hospital)

C. SCD School Guidance & Resources by Stakeholder

i. School Nurses

- [Caring for Common Complications of Sickle Cell Disease Fact Sheet](#) (Source: CDC, ASH, SCDA)
- [Management of Sickle Cell Disease in the Educational Setting](#) (Source: Kennedy Krieger Institute)
- [Managing Acute Pain if You Have Sickle Cell Disease](#) (Source: CDC, ASH, SCDA)
- [Managing Chronic Pain if You Have Sickle Cell Disease](#) (Source: CDC, ASH, SCDA)
- [Maryland State School Health Services Guideline: Management of Sickle Cell Disease in Schools](#) (Source: MSCDA, Maryland State Department of Education, Maryland Department of Health)
- [Men's Health and Sickle Cell Disease](#) (Source: Sickle Cell 101)
- ["Psychoeducational Screening in Pediatric Sickle Cell Disease: An Evaluation of Academic and Health Concerns in the School Environment"](#) (Source: Mayes, Wolfe-Christensen, Mullins, and Cain)
- [School Health Services Action Plan for Student with SCD](#) (Source: CHOP)
- ["School Nurses Guide to Sickle Cell Disease" Training Presentation](#) (Source: Indiana Hemophilia & Thrombosis Center (IHTC))
- [Sickle Cell Anemia Care Plan Letter](#) (Source: Sarah Portle, Med., BSN, RN, NCSN)
- [Sickle Cell Anemia School Nurse Care Plan](#) (Source: Sarah Portle, Med., BSN, RN, NCSN)
- [Sickle Cell Disease and Menstruation](#) (Source: SickleCell.com)
- [Sickle Cell Trait Toolkit](#) (Source: CDC, ASH, SCDA)
- [Steps to Better Health for People with Sickle Cell Disease Toolkit](#) (Source: CDC, ASH, SCDA)
- [Steps to Better Lung Health for People with Sickle Cell Disease Fact Sheet](#) (Source: CDC, ASH, SCDA)
- [Steps to Better Kidney Health for People with Sickle Cell Disease Fact Sheet](#) (Source: CDC, ASH, SCDA)
- [Supporting a Student Who Has Had a Stroke](#) (Source: CHOP)
- [Sickle Cell Handbook for Schools](#) (Source: CHOP)
- [Tips for Supporting Students with Sickle Cell Disease Booklet](#) (Source: CDC)
- [What Can Trigger a Sickle Cell Crisis?](#) (Source: Healthline)
- [Women with Sickle Cell Disease](#) (Source: SickleCell.com)
- ["8 Tips to Support Students with Sickle Cell Disease"](#) (Source: Black Health Matters)

iv. Teachers / Substitutes

- [Classroom Guidelines: Supporting a Student Who Has Had a Stroke](#) (Source: CHOP)
- [“Explore the Mystery of Blood” Curriculum & Teaching Guide: Grades 9-12](#) (Source: ASH & Scholastic)
- [Management of Sickle Cell Disease in the Educational Setting](#) (Source: Kennedy Krieger Institute)
- [Maryland State School Health Services Guideline: Management of Sickle Cell Disease in Schools](#) (Source: MSCDA, Maryland State Department of Education, Maryland Department of Health)
- [SCD Reading Lists](#) (Source: SCDC)
- [School Health Services Action Plan for Students with SCD](#) (Source: CHOP)
- [Sickle Cell Anemia Teacher Action Plan](#) (Source: Sarah Portle, Med., BSN, RN, NCSN)
- [Sickle Cell Information Center: Teachers and Students](#) (Source: Emory School of Medicine)
- [Sickle Cell and School: A Guide to School Policy and Best Practices – COVID Edition](#) (Source: The Parent-to-Parent Initiative and Sickle Cell Community Consortium)
- [Sickle Cell and Thalassemia: A Guide to School Policy](#) (Source: Simon Dyson, PhD)
- [Sickle Cell Handbook for Schools](#) (Source: CHOP)
- [Sickle Cell Information for Teachers, Students, and Employers](#) (Source: Sickle Cell Info Network)
- [Steps to Better Health Toolkit for People with Sickle Cell Disease](#) (Source: CDC, ASH, SCDA)
- [Tips for Supporting Students with Sickle Cell Disease Booklet](#) (Source: CDC)
- [Teacher/ Substitute Teacher Action Plan for Student with SCD](#) (Source: CHOP)
- [Understanding the Child with Sickle Cell Disease: A Handbook for School Personnel](#) (Source: Virginia Sickle Cell Awareness Program, Virginia Department of Health)
- [Understanding SCD in the Classroom: Fostering Emotional Wellbeing](#) (Source: CHOP)
- [Vein to Vein: The Science of Blood Donation: A High School Biology Education Program](#) (Source: ADRP, An International Division of America’s Blood Centers)
- [What Can Trigger a Sickle Cell Crisis?](#) (Source: Healthline)
- [“8 Tips to Support Students with Sickle Cell Disease”](#) (Source: Black Health Matters)
- [504 Plan for Education because of SCD](#) (Source: St. Jude Children’s Research Hospital)

v. School Administrators / Guidance Counselors

- [Accommodation and Compliance: Sickle Cell Anemia](#) (Source: Job Accommodation Network (JAN))
- [Children with Chronic Illness: Dealing with Emotional Problems and Depression](#) (Source: American Academy of Pediatrics (AAP))
- [Faces of SCD Storytelling Program](#) (Source: Sick Cells)
- [Fostering Emotional Well Being](#) (Source: CHOP)
- [High School Staff and Guidance Counselor Reference for College- and Career-Bound Student with SCD](#) (Source: CHOP)
- [Management of Sickle Cell Disease in the Educational Setting](#) (Source: Kennedy Krieger Institute)
- [Maryland State School Health Services Guideline: Management of Sickle Cell Disease in Schools](#) (Source: MSCDA, Maryland State Department of Education, Maryland Department of Health)
- [Mental Health Resources for Patients and Families](#) (Source: AAP)
- [“Psychoeducational Screening in Pediatric Sickle Cell Disease: An Evaluation of Academic and Health Concerns in the School Environment”](#) (Source: Mayes, Wolfe-Christensen, Mullins, and Cain)
- [Psychosocial: Sickle Cell Disease & Supportive Care](#) (Source: Sickle Options)
- [Sickle Cell Information Center: Teachers and Students](#) (Source: Emory School of Medicine)
- [Sickle Cell and School: A Guide to School Policy and Best Practices – COVID Edition](#) (Source: The Parent-to-Parent Initiative and Sickle Cell Community Consortium)
- [Sickle Cell and Thalassemia: A Guide to School Policy](#) (Source: Simon Dyson, PhD)
- [Sickle Cell Handbook for Schools](#) (Source: Children’s Hospital of Philadelphia (CHOP))
- [Sickle Cell Information for Teachers, Students, and Employers](#) (Source: Sickle Cell Info Network)
- [Tips for Supporting Students with Sickle Cell Disease Booklet](#) (Source: CDC)
- [Tip Sheet for the College- and Career-Bound Student](#) (Source: CHOP)
- [Understanding the Child with Sickle Cell Disease: A Handbook for School Personnel](#) (Source: Virginia Sickle Cell Awareness Program, Virginia Department of Health)
- [Tips & Strategies for Managing Anxiety When Returning to School](#) (Source: CHOP)
- [Understanding SCD in the Classroom: Fostering Emotional Wellbeing](#) (Source: CHOP)
- [“8 Tips to Support Students with Sickle Cell Disease”](#) (Source: Black Health Matters)
- [504 Plan for Education because of SCD](#) (Source: St. Jude Children’s Research Hospital)

vi. Physical Education Teachers / Coaches

- [Athletic Department Action Plan for Student with SCD](#) (Source: CHOP)
- [“Athletes: Don’t Get Sidelined by Sickle Cell Trait! Help Them Play It Safe with These Helpful Tips!”](#) (Source: CDC, ASH, SCDAAs)
- [Before and Aftercare Action Plan for Student with SCD](#) (Source: CHOP)
- [“Coaches: Don’t Let Your Athletes Get Sidelined by Sickle Cell Trait!”](#) (Source: CDC, ASH, SCDAAs)
- [Daily Water Consumption Recommendations](#) (Source: CHOP)
- [Diet and Exercise: Living Well with Sickle Cell](#) (Source: Blackdoctor.org)
- [Diet and Nutrition in SCD PowerPoint](#) (Source: Sickle Cell Info Center, Dr. Allan Platt)
- [Exercise and Athletics with Sickle Cell Disease](#) (Source: SickleCell.com)
- [Get Screened to Know Your Sickle Cell Status Fact Sheet](#) (Source: CDC, ASH, SCDAAs)
- [Nutrition for the Child with Sickle Cell Anemia](#) (Source: Academy of Nutrition and Dietetics)
- [Nutrition Guide for Sickle Cell Disease](#) (Source: Physicians Committee for Responsible Medicine)
- [School Health Services Action Plan for Students with SCD](#) (Source: CHOP)
- [Sickle Cell Trait Toolkit](#) (Source: CDC, ASH, SCDAAs)
- [Steps to Better Health Toolkit for People with Sickle Cell Disease](#) (Source: CDC, ASH, SCDAAs)
- [Summer Camp Action Plan for Student with SCD](#) (Source: CHOP)
- [Supporting a Student Who Has Had a Stroke](#) (Source: CHOP)
- [“Team Doctors \(Trainers\): Don’t Let Your Athletes Get Sidelined by Sickle Cell Trait!”](#) (Source: CDC, ASH, SCDAAs)
- [Tips for Supporting Students with Sickle Cell Disease Booklet](#) (Source: CDC)
- [Understanding the Child with Sickle Cell Disease: A Handbook for School Personnel](#) (Source: Virginia Sickle Cell Awareness Program, Virginia Department of Health)
- [What Can Trigger a Sickle Cell Crisis?](#) (Source: Healthline)
- [What You Should Know About Sickle Cell Trait Fact Sheet](#) (Source: CDC, ASH, SCDAAs)
- [“8 Tips to Support Students with Sickle Cell Disease”](#) (Source: Black Health Matters)

viii. Caregivers / Parents

- [Caregiver Back-to-School Checklist](#) (Source: CHOP)
- [Caregiver Information on 504 Plans and IEPs](#) (Source: CHOP)
- [Co-Pay Relief Fund](#) (Source: Patient Advocate Foundation)
- [Education: Sickle Cell Disease & Supportive Care](#) (Source: Sickle Options)
- [Elementary School Age Children and Sickle Cell Disease](#) (Source: Children's Hospital of Pittsburgh)
- [Fostering Emotional Well Being](#) (Source: CHOP)
- [Maryland State School Health Services Guideline: Management of Sickle Cell Disease in Schools](#) (Source: MSCDA, Maryland State Department of Education, Maryland Department of Health)
- [Managing Acute Pain if You Have Sickle Cell Disease](#) (Source: CDC, ASH, SCDA)
- [Managing Chronic Pain if You Have Sickle Cell Disease](#) (Source: CDC, ASH, SCDA)
- [Mental Health Resources for Patients and Families](#) (Source: AAP)
- [Parent Advocacy Materials](#) (Source: CHOP)
- [Parents' Handbook for SCD: Birth to Six Years of Age](#) (Source: California Department of Health Services)
- [Parents' Handbook for SCD: Six to Eighteen Years of Age](#) (Source: California Department of Health Services)
- [Resources for Siblings of Children with Chronic Illnesses or Disabilities](#) (Source: AAP)
- [Rule the School webpage](#) (Source: CVS Specialty Health)
- [Sample SCD letter - general](#) (Source: Dr. Sunnye Mayes)
- [Sample SCD letter - day care](#) (Source Dr. Sunnye Mayes)
- [Sample SCD letter - college](#) (shared by Dr. Sunnye Mayes)
- [Sample SCD Letter to Employers from Caregiver](#) (Source: SCDA MARAC)
- [SCD Reading Lists](#) (Source: SCDC)
- [Sickle Cell Anemia Care Plan Letter](#) (Source: Sarah Portle, Med., BSN, RN, NCSN)
- [Sickle Cell Caregiver Help Desk](#) (Source: Sick Cells)
- [Sickle Cell Handbook for Schools](#) (Source: CHOP)
- [Sickle Cell Information Center: Teachers and Students](#) (Source: Emory School of Medicine)
- [Sickle Cell Information for Teachers, Students, and Employers](#) (Source: Sickle Cell Info Network)
- [Sickle Cell and School: A Guide to School Policy and Best Practices](#) (Source: The Parent-to-Parent Initiative and Sickle Cell Community Consortium)
- [Sickle Cell Trait Toolkit](#) (Source: CDC, ASH, SCDA)
- [Steps to Better Health Toolkit for People with Sickle Cell Disease](#) (Source: CDC, ASH, SCDA)

- [The Journey Map of a SCD Caregiver](#) (Source: Sick Cells)
- [Tip Sheet for the College- and Career-Bound Student](#) (Source: CHOP)
- [Tips and Strategies for Managing Anxiety When Returning to School](#) (Source: CHOP)
- [Tips for Supporting Students with Sickle Cell Disease Booklet](#) (Source: CDC)

ix. Students Living with SCD

- [Accommodation and Compliance: Sickie Cell Anemia](#) (Source: Job Accommodation Network (JAN))
- [A Guide to Living with SCD: Define Yourself, Define Your Life](#) (Source: Sickie Cell 101)
- [“Athletes: Don’t Get Sidelined by Sickie Cell Trait! Help Them Play It Safe with These Helpful Tips!”](#) (Source: CDC, ASH, SCDA A)
- [Be the Match Patient Support Center: Counseling Services](#) (Source: Be The Match)
- [Cayenne Wellness Center California SCD Mental Health & Wellness Program](#) (Source: Cayenne Wellness)
- [College Students with Chronic Health Conditions](#) (Source: Edu Med)
- [Daily Water Consumption Recommendations](#) (Source: CHOP)
- [Diet and Nutrition in SCD PowerPoint](#) (Source: Sickie Cell Info Center, Dr. Allan Platt)
- [Education: Sickie Cell Disease & Supportive Care](#) (Source: Sickie Options)
- [Faces of SCD Storytelling Program](#) (Source: Sick Cells)
- [Fostering Emotional Well Being](#) (Source: CHOP)
- [Maryland State School Health Services Guideline: Management of Sickie Cell Disease in Schools](#) (Source: MSCDA, Maryland State Department of Education, Maryland Department of Health)
- [Managing Acute Pain if You Have Sickie Cell Disease](#) (Source: CDC, ASH, SCDA A)
- [Managing Chronic Pain if You Have Sickie Cell Disease](#) (Source: CDC, ASH, SCDA A)
- [Men’s Health and Sickie Cell Disease](#) (Source: Sickie Cell 101)
- [Mental Health Resources for Patients and Families](#) (Source: AAP)
- [Nutrition for the Child with Sickie Cell Anemia](#) (Source: Academy of Nutrition and Dietetics)
- [Nutrition Guide for Sickie Cell Disease](#) (Source: Physicians Committee for Responsible Medicine)
- [Sample SCD Letter to Employers from Individuals Living with SCD](#) (Source: SCDA A MARAC)
- [SCD Reading Lists](#) (Source: SCDC)
- [Sickie Cell Disease and Menstruation](#) (Source: SickieCell.com)
- [Sickie Cell Information for Teachers, Students, and Employers](#) (Source: Sickie Cell Info Network)
- [Sickie Cell Information Center: Teachers and Students](#) (Source: Emory School of Medicine)

- [Sickle Cell and School: A Guide to School Policy and Best Practices](#) (Source: The Parent-to-Parent Initiative and Sickle Cell Community Consortium)
- [Sickle Cell Trait Toolkit](#) (Source: CDC, ASH, SCDA)
- [Steps to Better Health Toolkit for People with Sickle Cell Disease](#) (Source: CDC, ASH, SCDA)
- [Teens with Sickle Cell Disease](#) (Source: Children’s Hospital of Pittsburgh)
- [Tip Sheet for the College- and Career-Bound Student](#) (Source: CHOP)
- [Tips and Strategies for Managing Anxiety When Returning to School](#) (Source: CHOP)
- [Transitioning to Adult Care – Legal and Health Guidance for Patients](#) (Source: Boston Children’s Hospital)
- [What Happens When I Turn 18?](#) (Source: Boston Children’s Hospital)
- [“9 Tips to Living well with SCD in College”](#) (Source: CDC)
- [“28 Hacks that Can Make Going to College with a Chronic Illness Easier”](#) (Source: The Mighty)

D. SCD School Guidance & Resources Created for / by Non-U.S. Stakeholders

i. United Kingdom (UK) & Europe

- [Sickle Cell and Thalassemia: A Guide to School Policy](#) (Source: Simon Dyson, PhD)

ii. Nigeria

- [A Parent Handbook for Sickle Cell Disease in Nigeria Part 1 \(0-6 years\)](#) (Source: Biobele Brown, FWACP, Adeyinka G. Falusi PhD, FAS, Paula Kienberger Jaudes, MD)
- [A Parent Handbook for Sickle Cell Disease in Nigeria Part 2 \(6-18 years\)](#) (Source: Biobele Brown, FWACP, Adeyinka G. Falusi PhD, FAS, Paula Kienberger Jaudes, MD)
- [Nigerian Version - Sickle Cell Disorders: A Guide to School Policy \(English\)](#) (Source: Simon Dyson, PhD & Sickle Cell Open: Online Topics and Education Resources (SCOOTER) project)
- [Nigerian Version - Sickle Cell Disorders: A Guide to School Policy \(Hausa\)](#) (Source: Simon Dyson, PhD & SCOOTER project)
- [Nigerian Version - Sickle Cell Disorders: A Guide to School Policy \(Igbo\)](#) (Source: Simon Dyson, PhD & SCOOTER project)
- [Nigerian Version - Sickle Cell Disorders: A Guide to School Policy \(Yoruba\)](#) (Source: Simon Dyson, PhD & SCOOTER project)

ii. Sierra Leon

- [A Sierra Leonian Approach to Sickle Cell & School Inclusion: A Guide to School Policy \(English\)](#) (Source: Simon Dyson, PhD & SCOOTER project)

iii. Brazil / Portugal

- [Sickle Cell Disease School Health & Safety Policy \(Portuguese\)](#) (Source: Simon Dyson, PhD & SCOOTER project)