



Medical and Research Advisory Committee Sickle Cell Disease Association of America, Inc.

MARAC Advisory Statement on Post-secondary and Boarding School Education in the Age of COVID-19

SHOW THIS TO YOUR SCHOOL ADMINSTRATOR TO HELP THEM HELP YOU.

July 31, 2020 – Opportunities for education after high school include traditional 4-year universities or colleges, 2-year community colleges, trade schools and technical institutes. This information also compliments the Kindergarten through grade 12 considerations for individuals living with sickle cell disease who are going away to boarding schools. Going away to school provides additional benefits of practicing independent living; meeting new friends; developing new interests; and developing knowledge and skills for a successful career. Sickle cell disease can present additional challenges but most individuals living with the disease are now achieving success in reaching their goals.

It is important to start early and plan carefully to be successful. This starts in high school with identifying interests and potential careers; taking appropriate high school courses; exploring careers; visiting potential campuses; learning expectations of the school; and developing a financial plan. Factors to consider will be presented in two parts. The first suggestions are general recommendations for transition to education after high school and the second are specific things to consider with COVID-19. There are additional excellent resources for transition including Got Transition, FloridaHATS, and PACER's National Parent Center on Transition and Employment.¹⁻³

General Recommendations

- Do your Homework
 - Start early to identify your interests, strengths, and educational goals
 - Choose a school taking access to care into consideration
 - Determine how to support your education
 - Visit schools and submit applications
- Know your disease
 - What type of sickle cell do you have?
 - Learn about your disease from trusted sources including your care team, books, and the internet.
 - How do your choices affect your disease? What keeps you healthy and makes you sick?
- Learn your medications
 - What medications are your taking, how, and when?
 - What are each of your medications for?
 - How do you get them filled and refilled?
 - What are their side-effects?
- Learn your allergies, if you have any

- Develop a care plan with your sickle cell team
 - Who is going to take care of you at home and while you are at school?
 - Sickle cell care, emergency care, and regular health care
 - Visit student healthcare center before school starts
 - Have short care plans for:
 - Your regular health care
 - Emergency care for pain and other complications
 - Transition for pediatric to adult care
 - Make the plans available to you, your family, and healthcare providers
 - One or two-page written summaries
 - On your cell phone
 - Consider a medical alert bracelet or necklace

- While you are attending school, develop healthy habits
 - Stay hydrated
 - Eat well
 - Get plenty of rest
 - Avoid excesses
 - If you choose to have sex, practice safely

- Develop a plan with the school's Disabilities Services Office (DSO)
 - Determine if you need accommodations
 - Let your teachers and professors know if you will need special accommodations in advance

- Be prepared for problems
 - Determine where you will go for pain episodes and other urgent problems
 - Have a confidant who knows your health issues and can help you if you have problems
 - Roommate
 - Friend
 - Network of friends

Special Considerations during the COVID-19 Pandemic

Individuals with sickle cell disease are generally doing fairly well when infected with COVID-19, however, they often present with pain episodes, need hospitalization, and may be at somewhat greater risk of death.⁴ Individuals living with sickle cell disease are considered high risk by the Center for Disease Control and Prevention (CDC) and American Society of Hematology (ASH). In addition, sickle cell disease tends to present more problems for young adults.^{5,7} These considerations make the preparation listed above for education after high school even more important.

The post-secondary educational experience is greatly enhanced by attending classes in person and may be mandatory for laboratories and acquiring hands-on skills. Individuals living with sickle cell disease should consider remote education when possible if the school is in an area with active COVID-19 infections. There are many other considerations such as whether other individuals in your family are in a high-risk group. This information is changing rapidly and must be individualized based on your goals and the rates of COVID-19 in the school's community. If you are considering attending classes in person or living on campus you need to take extra precautions to protect yourself from infection. CDC recommendations should be followed.⁵ The SCDA MARAC recommendations for K through 12 schooling should be considered.⁶ A partial list of other things to consider and do in areas where COVID-19 infections are active include:

- Try to maximize online courses
- Practice all behaviors to prevent infection⁸

- Physical distancing
 - Always wear a mask when physical distancing cannot be maintained
 - Frequent handwashing using CDC recommended techniques
 - Avoid touching face and eyes
 - Avoid crowds
- Contact the Disabilities Services Office (DSO) at the school and determine what special accommodations can be made for you for attending classes, taking tests, getting between classes, and living options.
 - Learn about access to student health services
 - Determine if special living conditions will provide a single room; easy access to food, fluid, and lavatory; temperature control; monitoring residents' health; and physical distancing.
 - Plan ahead! There is more, excellent information and links to other sources available on the PACER's National Parent Center on Transition and Employment website.³
 - Develop a plan to access healthcare while in school (who, where, how, and when).
 - Student health services
 - Primary care
 - Emergency care
 - Sickle cell care
 - The COVID pandemic has changed health care so many providers are providing ongoing care using telemedicine. Determine if your "home" sickle cell team can provide ongoing care while you are away at school.
 - Develop and practice skills for independent living before leaving for school.

For More Information, contact info@sicklecelldisease.org

References:

1. Got Transition. <https://www.gottransition.org/>
2. FloridaHATS. <https://www.floridahats.org/secondary-post-secondary-education/>
3. PACER's National Parent Center on Transition and Employment. <https://www.pacer.org/transition/learning-center/postsecondary/>
4. SECURE-SCD. <https://covidsicklecell.org/>
5. People Who Need to Take Extra Precautions. Center for Disease Control and Prevention (CDC) <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/index.html>
6. <https://www.sicklecelldisease.org/2020/07/27/scdaa-marac-position-on-2020-school-reopening/>
7. COVID-19 and Sickle Cell Disease: Frequently Asked Questions. American Society of Hematology (ASH). <https://www.hematology.org/covid-19/covid-19-and-sickle-cell-disease>
8. CDC How to Protect Yourself & Others. <https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/prevention.html>

SCDAA Medical and Research Advisory Committee Members

Miguel R Abboud, MD

Professor of Pediatrics and Pediatric Hematology-
Oncology
Chairman
Department of Pediatrics and Adolescent
Medicine
American University of Beirut, Lebanon

Biree Andemariam, MD

Chair, Medical and Research Advisory Committee,
Sickle Cell Disease Association of America
Chief Medical Officer, Sickle Cell Disease
Association of America
Director, New England Sickle Cell Institute
Associate Professor of Medicine
University of Connecticut Health
Farmington, Connecticut

Shawn Bediako, PhD

Professor
Department of Psychology
University of Maryland Baltimore County
Baltimore, Maryland

Andrew Campbell, MD

Center for Cancer and Blood Disorders
Children's National Health System
Associate Professor of Pediatrics
George Washington University School of Medicine
and Health Sciences
Washington, DC

Raffaella Colombatti, MD, PhD

Physician Azienda Ospedaliera-Università di
Padova
Department of Womens' and Child Health
Clinic of Pediatric Hematology Oncology
Via Giustiniani 3
35129 Padova Italy

Lori Crosby, PsyD

Co-Director, Innovations in Community Research,
Division of Behavioral Medicine & Clinical
Psychology
Co-Director, CCTST, Community Engagement Core
Psychologist, Research, Behavioral Medicine &
Clinical Psychologist
Cincinnati Children's
Professor, UC Department of Pediatrics
Cincinnati, Ohio

Deepika Darbari, MD

Center for Cancer and Blood Disorders
Children's National Health System
Professor of Pediatrics
George Washington University School of Medicine
and Health Sciences
Washington, DC

Payal Desai, MD

Associate Professor
Director of Sickle Cell Research
The Ohio State University
JamesCare at Ohio State East Hospital
Columbus, Ohio

James Eckman, MD

Professor Emeritus, Hematology & Medical
Oncology
Emory University School of Medicine
Department of Hematology and Medical Oncology
Atlanta, Georgia

Mark Gladwin, MD

Professor and Chair
Department of Medicine
Founder, Pittsburgh Heart, Lung, and Blood
Vascular Medicine Institute
University of Pittsburgh
Pittsburgh, Pennsylvania

Jo Howard, MB Bchir, MRCP, FRCPath

Head of Red Cell/Sickle Cell Service
Guy's and St Thomas'
NHS Foundation Trust
London, United Kingdom

Lewis Hsu, MD, PhD

Co-Chair, Medical and Research Advisory
Committee, Sickle Cell Disease Association of
America
Vice Chief Medical Officer, Sickle Cell Disease
Association of America
Director of Pediatric Sickle Cell
Professor of Pediatric Hematology-Oncology
University of Illinois at Chicago
Chicago, Illinois

Baba Inusa

Professor of Paediatric Haematology
Evelina London Children's Hospital
Guy's and St Thomas NHS Foundation Trust
Women and Children's Academic Health
King's College London
United Kingdom

Elizabeth Klings, MD

Associate Professor of Medicine, Boston
University School of Medicine
Program Director, Center of Excellence in Sickle
Cell Disease
Director, Pulmonary Hypertension Inpatient and
Education Program
Medical Director, Pulmonary Rehabilitation
Program, Boston Medical Center
Boston, Massachusetts

Lakshmanan Krishnamurti, MD

Professor of Pediatrics, Director of BMT
Joseph Kuechenmeister Aflac Field Force Chair
Aflac Cancer and Blood Disorders Center
Children's Healthcare of Atlanta/Emory University
Atlanta, Georgia

Sophie Lanzkron, MD, MHS

Director, Sickle Cell Center for Adults
The Johns Hopkins Hospital
1800 Orleans St
Baltimore, Maryland

Julie Makani, FRCP, PhD

Associate Professor
Department of Haematology and Blood
Transfusion
Muhimbili University of Health and Allied Sciences
Dar es Salaam, Tanzania

Caterina P. Minniti, MD

Director, Sickle Cell Center
Montefiore Health System
Professor of Medicine and Pediatrics
Albert Einstein College of Medicine
Bronx, New York

Genice T. Nelson, DNP, APRN, ANP-BC

Program Director
New England Sickle Cell Institute & Connecticut
Bleeding Disorders Programs
UConn Health
Farmington, Connecticut
Board Member, Sickle Cell Disease Association of
America

**Isaac Odame, MB ChB, MRCP(UK), FRCPath,
FRCPCH, FRCPC**

Professor, Department of Paediatrics
University of Toronto
The Hospital for Sick Children
Division of Haematology/Oncology
Toronto, Ontario

Kwaku Ohene-Frempong, MD

Director Emeritus, Comprehensive Sickle Cell Center
Emeritus Professor of Pediatrics, University of Pennsylvania
President, Sickle Cell Foundation of Ghana
Emeritus Board Member, Sickle Cell Disease Association of America

Gwendolyn Poles, D.O.

Honorary Medical Staff Member
Former Medical Director, Kline Health Center
Faculty, Internal Medicine Program
UPMC Pinnacle
Harrisburg, Pennsylvania
Board Member, Sickle Cell Disease Association of America

John Roberts, MD

Yale Adult Sickle Cell Program
Smilow Cancer Hospital at Yale New Haven
New Haven, Connecticut

Wally Smith, MD

Professor
Scientific Director, VCU Center on Health Disparities
Director, VCU Adult Sickle Cell Program
Department of Internal Medicine
Division of General Internal Medicine
Richmond, Virginia

Crawford J Strunk MD

Pediatric Hematology/Oncology
Pediatric Hematology/Oncology Program at Toledo Children's Hospital
Toledo, Ohio

Immacolata Tartaglione, MD PhD

Department of Woman, Child and General and Specialist Surgery
Università degli Studi della Campania "Luigi Vanvitelli"
Naples, Italy

Marsha Treadwell, PhD

Director, Sickle Cell Care Coordination Initiative
Regional Director, Pacific Sickle Cell Regional Collaborative
Professor of Psychiatry and Pediatrics
University of California San Francisco Benioff Children's Hospital Oakland
Oakland, California

Winfred C. Wang, MD

Emeritus, St. Jude Faculty
Member, Department of Hematology
St. Jude Children's Research Hospital
Memphis, Tennessee

Russell E. Ware, MD, PhD

Director, Division of Hematology
Institute Co-Director, Cancer and Blood Diseases Institute
Director, Global Health Center
Marjory J. Johnson Chair of Hematology
Translational Research
Cincinnati Children's
Professor, UC Department of Pediatrics
Cincinnati, Ohio

Julie Kanter Washko, MD

Associate Professor
Division of Hematology Oncology
University of Alabama at Birmingham
Birmingham, Alabama

Kim Smith-Whitley, MD

Professor of Pediatrics
Director Comprehensive Sickle Cell Center
Division of Hematology
The Children's Hospital of Philadelphia
Philadelphia, Pennsylvania
Board Member, Sickle Cell Disease Association of
America

Wanda Whitten-Shurney, MD

CEO & Medical Director
Sickle Cell Disease Association, Michigan Chapter
Inc.
Board Member, Sickle Cell Disease Association of
America
Detroit, Michigan

Ahmar U. Zaidi, MD

Assistant Professor of Pediatrics
Comprehensive Sickle Cell Center, Children's
Hospital of Michigan, Wayne State
University/Central Michigan University School of
Medicine
Detroit, Michigan