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

SHOW THIS TO YOUR SCHOOL ADMINISTRATOR 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
  o 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
  o Have short care plans for:
    ▪ Your regular health care
    ▪ Emergency care for pain and other complications
    ▪ Transition for pediatric to adult care
  o 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
  o Stay hydrated
  o Eat well
  o Get plenty of rest
  o Avoid excesses
  o If you choose to have sex, practice safely

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

• Be prepared for problems
  o Determine where you will go for pain episodes and other urgent problems
  o 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. 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. 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. The SCDAA MARAC recommendations for K through 12 schooling should be considered. 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 infection
○ 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:
4. SECURE-SCD. https://covidsicklecell.org/
**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

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

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
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-Shorney, 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