OVERVIEW OF SICKLE CELL DISEASE ASSOCIATION OF AMERICA'S (SCDAA) COVID-19 EFFORTS & RESOURCES

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SCD and COVID-19

- Individuals living with SCD suffer from both acute and chronic complications that require close contact with the medical system
- Conflicts with COVID-19 "stay at home" strategy
- Poses diagnostic, treatment and logistical challenges in meeting the SCD healthcare needs during the COVID-19 pandemic

Chronic Complications

- Nephropathy
- o Iron Overload
- o Avascular necrosis
- o Retinopathy
- Pulmonary hypertension
- o Cardiomyopathy
- Chronic pain
- o Asthma

Acute Complications

- Acute sickle cell pain
- o Fever / Infection
- o Stroke
- Priapism
- Splenic sequestration crisis
- Cholecystitis
- Acute chest syndrome***

Acute Chest Syndrome

- Term used for a constellation of findings that includes:
 - Chest pain
 - Cough
 - Fever
 - Hypoxia
 - New lung infiltrates
- High risk for respiratory distress, intubation and mortality

ACS



COVID-19



SCD High Risk for Severe COVID-19

 Overlap of lung disease from COVID-19 with ACS may result in increased complications and amplification of healthcare utilization among individuals with SCD

- Patients, caregivers and providers need guidance
 - Safety / prevention measures
 - Preparedness
 - Clinical vigilance

United States

- ~100,000 individuals
- Limited access to care, especially adults
- Heavy reliance on acute care facilities



Figure 3. Estimated number of individuals with SCD, based on state-specific African-American and Hispanic birth-cohort disease prevalence and 2008 U.S. Census population, corrected for early mortality SCD, sickle cell disease

> https://www.cdc.gov/ncbddd/sicklecell/data.html, accessed 9/11/17 Lanzkron S et al. Am J Hematol. 2010 Oct; 85(10): 797–799.

SCD vs COVID-19

Accessed 3/30/2020

European Migration Increases SCD Prevalence

http://www.iran-daily.com/News/14496.html

http://www.bbc.com/news/world-africa-32311358

Many of these European countries are in the midst of COVID-19 pandemic

Blood Shortages

SCDAA's Actions

Education and Awareness

Monetary support for local communities

Blood Donation Call to Action

Education and Awareness

MARAC

- 33 members, international committee
- Developed guidelines (Patient / Provider)
 - Lay the basis of important advocacy, awareness, education, support
 - Living documents; regular updates
 - Wide dissemination globally
 - Web, Social Media, WhatsApp, Global Networks, Professional Societies, Pharmacies, Pharmaceutical companies, Blood banks

SCDAA MARAC Patient /Caregiver Advisory

- Recommendations on how to self-manage during pandemic
- Version(s) that can be utilized outside U.S.
- Translation: Arabic, French, Spanish

Health Alert for Patients and Caregivers تنبيه صحي لمرضى فقر الدم المنجلي والعاملين في الرعاية الصحية للتأهب لفيروس (COVID-19)

في 17 مارين 2000, ومع POID-19 من مللومة عنول الجميع, تقدم اللجنة الاستثارية العلى والموت الطبقة (MARAO) الدئمة لجمينة مردن عن السر المنطي الأبركية (MARAO) مطيحات تقتيقة عرال العرس مما يقام من القاني ويقترح الله مسافة نشاف - ومثالف - من الإمسافة بالمردن شكل المناطر السريون سنتجيز في الأبام والأسابي والأثمين القاضة، كذلك ممرفتا حول كتيفية كموال عمكمنا تتياتية الإستخاص الذين يمتون مع مردن عن المرالسر القاضة، كماك ممرفتا حول كيفية تأثير وOUD على عاملة التي توقع ويها MARAO على المال مستشر مع الملحة المالية مع محمل عن المراسي ومن المهم أن تقنى على الملحة عنتظم في الملحية الملحين الملحين المرالية الملحة على عمل معرف مع مردن المهم أن تقنى على الملح مع الملحية الملحية الملحين المراحية الملحة الملحية المسرحين من مردن عن هذا للمحمل المرايين على الملحيان الملحية الملحين الملحية الأرامية الليريين ومحمل عامل معرف على مع ملحين عاملاتي مقتلية الملحين الملحين من معرف الملحين الملحين على من مردن عن الملحين من مردن على ملحينا على الملحين مع على الملح الملحين الملحين الملحين الملحين الملحين الملحين من مردن عن المالي مع الملحين من المرين على الملحين الملحين الم

SCDAA MARAC Companion Provider Advisory

- Insures advice to patients

 / caregivers mirrors
 adaptations to clinical
 practice
- Grounded in evidence

Guidance

This document will be updated weekly as data and evidence emerge.

March 24, 2020- Sickle cell disease (SCD) affects 100,000 individuals in the United States and millions globally. Individuals living with SCD suffer from both acute and chronic complications that require close contact with the medical system. These include acute sickle cell pain, fever, and the acute chest syndrome. (ACS) which is the term used for a constellation of findings that includes chest pain, cough, fever, hypoxia and new lung infiltrates. There is a significant concern that the overlap of lung disease from COVID-19 with ACS may result in increased complications and amplification of healthcare utilization among individuals with SCD. Moreover, individuals with SCD, in general, experience high utilization of acute care services including emergency departments and hospitals and often present with fever, signs and symptoms of pneumonia or evolving ACS, as well as acute sickle cell pain requiring parenteral therapy. Thus, there may be specific diagnostic, treatment and logistical challenges in meeting the healthcare needs of this population during the COVID-19 pandemic.

Here, we provide suggested guidelines for the acute and chronic disease management of patients with SCD given the multidimensional and evolving changes and challenges in our healthcare operational landscape.

Routine Clinical Care

- If possible, convert all routine inperson appointments to virtual or telephonic appointments. Do not simply cancel appointments as patients need guidance and planning now more than ever.
- Educate patients and parents over the telephone about COVID-19 signs and symptoms and the importance of physical distancing to limit chances of exposure and infection. Encourage enhanced emotional connection through virtual or cellular-based modalities.
- Counsel patients and parents to continue to seek medical help for fever and other signs of infection. Counsel them to call first - their hospital, doctor, or nurse - for advice on where to go safely for evaluation.

Infographics: Emotional well-being

Monetary Support for Local Communities

- SCDAA launched the COVID-19 Emergency Fund Campaign
 - Funding for mini grants to MOs → basic needs to SCD patients in their local communities

March 27, 2020

Call us at (800) 421-8453

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Sickle Cell Disease Association of America Aims to Raise \$100,000 in 10 Days to Address Coronavirus

Donate Now: www.sicklecelldisease.org

Call to Action

Contact Congress About the Urgent Need for Safe, Organized, and Ongoing Blood Donations During COVID-19

During the ongoing response to COVID-19, there is a major concern that there will be a blood shortage due to blood drives being cancelled. Many hematologists across the country are being asked to decrease transfusions in chronically transfused patients, which is already a huge concern.

We need help to get the word out that people can still make an appointment to donate blood. Please click "Take Action" below to contact your elected officials to ask for their help in getting out the message about the urgent need for safe, organized and ongoing blood donations during this time of crisis.

Also:

- E-blasts to community encouraging blood donation
- Direct facilitation of communication between MOs and ARC Regional Offices to collaborate in respective regions to increase blood drive participation

March 25, 2020

Bonnie McElveen-Hunter, Chairman of the Board, American Red Cross Gail J. McGovern, President and Chief Executive Officer, American Red Cross

Dr. Beth Shaz, MD, President, AABB Debra BenAvram, Chief Executive Officer, AABB

Mike Parejko, President, America's Blood Centers Kate Fry, MBA, CAE, Chief Executive Officer, America's Blood Centers

Greetings,

On behalf of the American Society of Hematology (ASH) and the Sickle Cell Disease Association of America, Inc. (SCDAA), we would like to thank you for being here to support our hospitals and our patients. ASH and SCDAA recognize and commend you for all of the important steps your groups have taken to address the significant challenges to maintaining the national blood supply and collection as result of the COVID-19 pandemic. Hematologists and the SCD community hope to partner with you to conserve the blood supply and recruit donors. We are especially concerned about an adequate blood supply for individuals with sickle cell disease (SCD) for whom transfusions are life-saving and prevent complications, including devastating complications such as stroke.

Since patients with SCD are at a very high risk of alloimmunization, providing prophylactic C, E, and K matched red cells must remain the standard of care, and this requires minority blood donors. We urge you to implement programs to enhance minority donor recruitment during the COVID-19 pandemic. ASH and SCDAA are pleased to be part of the Sickle Cell Disease Coalition's Minority Blood Donation Workgroup, which your groups created and manage, and we encourage you to leverage the dedicated members of this group to help with that recruitment effort. ASH and SCDAA are committed to partnering with you as well.

Additionally, a committee of physician experts from ASH and SCDAA have developed the following guidance to providers who care for individuals with SCD to help conserve red cell units and encourage donation and recruitment. We plan to share this broadly with the SCD provider and advocacy

Questions

www.sicklecelldisease.org

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