



A.S.A.P.

Advancing Sickle Cell
Advocacy Project Inc.



EST. 2015

BROWARD ▪ MIAMI-DADE

www.asapbeinformed.org



WHO ARE WE

The Advancing Sickle Cell Advocacy Project, Inc. (ASAP) is a nonprofit 501 c 3 community-based organization established in 2015. We provide support services for people living with Sickle Cell Disease (SCD) in South Florida. A.S.A.P. is comprised of Sickle Cell Disease (SCD) warriors, caregivers, those affected by Sickle Cell trait & people dedicated to making a difference in the Sickle Cell community.

OUR MISSION

A.S.A.P.'s mission is to change the narrative concerning Sickle Cell Disease by bringing awareness, educating the community, advocating on behalf of sickle cell warriors, and bridging the gap between the medical community and sickle cell clients. We are serving as a voice to the voiceless on a silent disease that needs to be heard.

OUR VISION

A.S.A.P. stands as a pioneering advocate for enhancing hospital protocols, fostering awareness, creating diverse support systems, and offering educational and networking services. Our unwavering commitment is aimed at enhancing the quality of life for individuals living with sickle cell disease (SCD) in South Florida.

WHAT WE DO

Since 2015 A.S.A.P. has developed a wide range of support services designed to improve the quality of life for people living with SCD, including:

- Bi-monthly Virtual Support Groups for Teens & Adults
- Advocacy Town Halls
- Annual Picnic and Resource Fair for Sickle Cell Families
- Faith Brunch for Sickle Cell
- Seminars Workshops with Community Partners
- Wellness Checks on Sick & Hospitalized warriors
- Focus Groups
- Community of Parents Empowered (COPE) Program
- Virtual Chronic Pain Self-Management Program



STRATEGIC PARTNERSHIPS



A.S.A.P. established viable partnerships with many organizations, healthcare systems & schools. We have partnered with the City of Miami Gardens & Councilman Robert Stephens III to bring education, awareness and information on sickle cell. On July 30, 2022, we received a proclamation declaring this day Advancing Sickle Cell Advocacy Day in the City of Miami Gardens.

State Representative Felicia Robinson, House District 104, Broward College's RN to BSN Nursing program, Broward County Radiance Chapter of Top Ladies of Distinction, Miami Chapter of Top Ladies of Distinctions, Sisters In Sync, Metropolitan Dade County Chapter of National Council of Negro Women, Florida International University & Nova Southeastern University and many more.

We have successfully built a continuing partnership with FIU & Nova Southeastern University for educational workshops with their nursing and medical programs and sickle cell warriors since 2017. These panel discussion workshops are vital because they assist current and future healthcare providers with firsthand knowledge of understanding how Sickle Cell impacts the person to initiate change in medical staff attitudes toward the management of Sickle Cell Disease.

These programs are used to address implicit biases that impact health outcomes and cause the health disparities seen in people with SCD with acute pain in outpatient and inpatient healthcare settings. Therefore, educators in healthcare and academia should include implicit bias training in their curriculum and continuing education programs relating to SCD.



STRATEGIC PARTNERSHIP

In December 2019, ASAP issued a call to action to Memorial Healthcare System (MHS) to address concerns of the sickle cell community. MHS answered the call by creating an SCD task force to identify and address the gaps in care.

The University of Miami Pediatric Sickle Cell Program
Florida Community Engages SCD (Florida CES) Sickle Cell Disease
Newborn Screening Follow-Up Program

These partnerships and collaborations demonstrate ASAP's work's effectiveness and positive impact within the community.



MEETING THE NEED

SUPPORT GROUPS

"As in other chronic diseases, people who have sickle cell disease may feel sad, frustrated and stressed at times."

SCD takes a toll on the psycho-emotional state of a patient as well as the family/caregiver. It is important to address this just as much as medical needs.

Support groups provide a sense of community, unconditional acceptance, and information about living with Sickle Cell Disease. These support groups are morale boosters, in contrast to the isolation, rejection, and lack of knowledge about SCD, which are most frequently experienced outside the group.

ASAP Peer Support Groups are for adults and teens. We provide an opportunity for our participants to share their personal experiences and feelings. Some individuals share coping strategies and firsthand information about their disease and/or treatments.

Before the pandemic, we held monthly in-person support group meetings in Dade and Broward County. We now meet on the third Saturday of each month unless otherwise indicated.



ASAP does not endorse any facility or drug. We inform our participants to consult their healthcare provider before making any changes to their medical care. Participants include: sickle cell warriors, caregivers, college students, nurses, physicians, hospital staff, and Team ASAP advocates.

THE C.O.P.E. PROGRAM



The Community of Parents Empowered (C.O.P.E.) program is designed to empower parents of sickle cell warriors and enhance the quality of life for their children. We engage families in creative outlets that promote self-awareness, self-care and community building to strengthen the family support systems.

We facilitate proper stress, pain management techniques, and coping skills that focus on personal advocacy and self-expression with services that families normally only receive as an inpatient but can now participate in in the community or at home. These services include:

Music Therapy sessions improve physical well-being, promote healthy attitudes, and enrich mind, body, and spirit. They provide emotional support for individuals and their families and foster an outlet for expressing feelings.



Art Therapy sessions can improve cognitive and sensorimotor functions, foster self-esteem and self-awareness, cultivate emotional resilience, promote insight, enhance social skills, reduce and resolve conflicts and distress, and advance societal and ecological change.

Mindfulness sessions will focus on developing self-awareness through formal and informal meditation practices. Mindfulness helps relieve stress, reduce chronic pain, and improve sleep.



Parent Talks sessions with a licensed therapist encourage parents to share experiences and learn coping techniques. In a non-formal group setting, talk with other parents who are going through similar events, which can help parents feel less alone.

Advocacy 101 sessions will empower SCD warriors and their caregivers with the information they need to navigate healthcare, education, and career-related challenges. This workshop will include education on the importance of understanding their correct sickle genotype and the factors that trigger major disease complications (i.e. stroke). Empowering the SCD patient/caregiver to communicate their pain effectively needs healthcare providers.

Medication Management sessions will provide access to information and resources that help guide SCD patients and caregivers on how to use effective techniques for pain management at home and prepare for hospital visits. Working with each participating SCD family to create a plan to organize and prioritize medication/appointment scheduling, the importance of refilling prescriptions, and providing access to additional resources.

Teen Talks sessions with a licensed therapist encourage teens to share experiences and learn coping techniques. In a non-formal group setting, talk with other teens who are going through similar events, and gain educational and emotional support.

School Preparedness session addresses issues faced by SCD warriors and their families when dealing with ongoing medical considerations, educational needs, and the social aspects of navigating the educational process. It includes an introduction to 504 and IEP Plans, a discussion of possible school intervention strategies, a selection of daycares, and how to communicate effectively with the school.

Healing with Food nutrition sessions encourage developing healthy eating strategies and an individual action plan for optimal success. Learn how to develop healthy eating habits and how certain foods can impact SCD triggers.

The successful outcomes from the first year of the C.O.P.E. program was documented and presented as an abstract and accepted for inclusion in the Foundation for Sickle Cell Disease Research's conference. In 2022 we were awarded the Access to Care Empowerment (ACE) grant from Global Blood Therapeutics for our innovative C.O.P.E. program.



A.S.A.P.'s Virtual Chronic Pain Self-Management Program (CPSMP)

According to the National Institutes of Health (NIH) about 50% of people with Sickle Cell experience chronic pain and this has a negative impact on their quality of life.

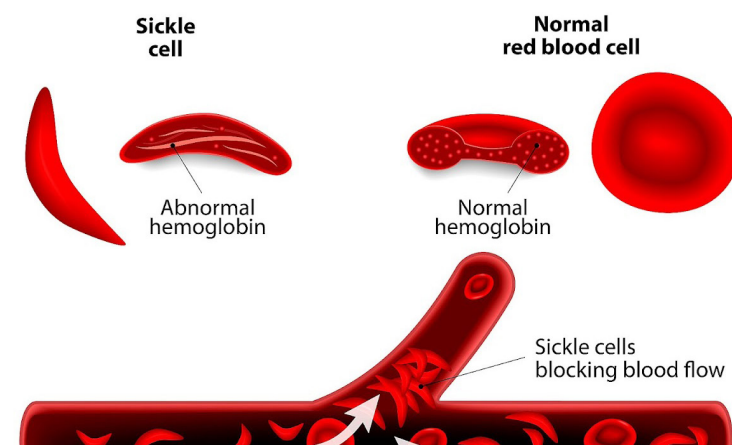
In Spring 2023, ASAP launched the Virtual Chronic Pain Self-Management Program (CPSMP) created by Stanford University, made possible through grant funding from United Way Miami. This is the first time a program of its kind has been offered to sickle cell warriors led by trained warriors and caregivers, showing a commitment to advancing and improving care for those with SCD.

This fun, interactive, FREE 6 - week program targeting sickle cell warriors aged 16 and older is designed to increase the quality of life, manage pain, sleep, fatigue, mood, energy, and more!!

The program consists of 6 coaching sessions that take place over 6 consecutive weeks and last for 2.5 hours each session.

Bonuses and incentives include:

- Access to an online coaching app
- A copy of the Living a Healthy Life with Chronic Pain book
- The Moving Easy Program CD and/or MP3
- Relaxation for Mind and Body MP3
- A gift card



WHAT IS SICKLE CELL

SCD is a group of inherited red blood cell disorders that affect hemoglobin, the protein that carries oxygen through the body. The condition affects more than 100,000 people in the United States and 20 million people worldwide.

People with SCD inherit two faulty hemoglobin genes, one from each parent. A person has a sickle cell trait when the faulty hemoglobin gene is inherited from only one parent, and a normal hemoglobin gene—hemoglobin A—is inherited from the other.

Red blood cells are normally disc-shaped and flexible enough to move easily through the blood vessels. If you have sickle cell disease, your red blood cells are crescent- or "sickle"-shaped. These cells do not bend or move easily and can block blood flow to the rest of your body.

The blocked blood flow through the body can lead to serious problems, including stroke, eye problems, infections, and episodes of pain called pain crises.

SCD is a lifelong illness. A bone marrow transplant is currently the only cure, but there are effective treatments that can reduce symptoms and prolong life. On December 8, 2023, The FDA approved groundbreaking Gene Therapy for SCD.

In 1983, the federal government officially recognized September as National Sickle Cell Awareness Month. Sickle Cell Disease is often thought of as a disease affecting blacks only. In reality, people from Central and South America, people of Indian, Middle Eastern, Hispanic, and Mediterranean heritage are also commonly affected.

A.S.A.P. MAKING AN IMPACT

Impact Story #1: The UM Hematologist referred M.M., a Hispanic mother of a 10-year-old sickle cell warrior, to ASAP. The same day, she called in and expressed the difficult experience she was having with the hospital handling her warrior's treatment and her eagerness to learn how she could better advocate for her son. She struggled with feeling supported as a caregiver to a child with sickle cell and felt isolated. She joined the C.O.P.E. program hoping to meet other families with sickle cell and has been an engaged participant in the monthly sessions. Her warrior was able to meet and connect with other kids just like him for the first time. With the safe space to express herself without judgment and in the community with other parents, she has been open and vulnerable to her feelings and struggles. She has expressed gratitude for being able to find comfort in being a part of ASAP.

Impact Story #2: Kristen is an adult warrior who has been a part of A.S.A.P. for 6 years. She grew up in The Bahamas as a Sickle Cell SS patient and moved to the states for college. Growing up she felt lonely and misunderstood because she did not know anyone else who also suffered from this disease. Throughout her life she has hesitated to share her sickle cell condition for fear of being stigmatized. Kristen joined the support group and slowly began to open up and share. She developed new friendships and has been integral in advocating for other warriors. "With the exception of my family, I felt nobody really understood what I struggled with, both physically and emotionally. It wasn't until recent years, after I moved to South Florida, that I finally felt a sense of real community and was understood as a Sickle Cell warrior through ASAP."

Impact Story #3: Rachelle is a mother of an 8-year-old sickle cell warrior who has experienced pain crises that have put him in the ICU several times. She and her son have struggled with the mental effects of living with sickle cell. Rachelle came to A.S.A.P. looking for resources and found tangible coping methods to help her and her child deal with sickle cell disease. Rachelle's favorite sessions included mindfulness and art therapy as they taught her effective ways to center herself and implement tools she can use for the rest of her life. She expressed gratitude for the program's positive impact on her family's well-being and revealed the program could not have come at a better time.



SUPPORT THE CAUSE



SUPPORT ASAP

ASAP is honored and grateful for the businesses and individuals who have provided financial and in-kind support for our work. Your generosity has equipped us with the much-needed resources to make a significant impact within the Sickle Cell community at large. Our commitment to our mission, vision, and fiscal integrity is always our priority. We make giving easy by providing a host of different ways to contribute. The information and QR codes are listed below.

Our services are performed by volunteers and professionals alike, and we extend our services to all individuals and families impacted by Sickle Cell. We can continue to make a difference with faith in God and your help. ASAP is a 501 (c)(3) Organization, All Donations are 100% tax deductible. Thank you in advance for considering a generous donation to support the work of the Advancing Sickle Cell Advocacy Project (ASAP).

Make donations payable to: ADVANCING SICKLE CELL ADVOCACY INC. OR
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