sickle cell
communityconsortium

SICKLE CELL COMMUNITY CONSORTIUM
WWW.SICKLECELLCONSORTIUM.ORG

8TH ANNUAL WARRIORS CONVENTION

VIRTUAL VIA WHOVA

AUG
25-29

WE ARE RESILIENT

IN THE FIGHT OF OUR LIVES

8TH ANNUAL SICKLE CELL PATIENT & FAMILY SYMPOSIUM
www.sicklecellconvention.org

WARRIORS ARE RESILIENT!

WE ARE STRONGER TOGETHER!

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> Nothing for us without us. We are stronger together.

Dr. Lakiea Bailey
Founder

Letter From the Director

Welcome to the 8th Annual Sickle Cell Warrior Convention! We are delighted that you have chosen to join us for five days of education, engagement, entertainment, and fun! Before I write anything else, I want to first remind every warrior, caregiver, provider, and champion that we are a strong, resilient, unbreakable community. These are strange times, yet YOU ARE NOT ALONE.

We are living through the first global pandemic in any of our lifetimes and every aspect of our lives has changed. As we wait in our individual homes, separated by state lines and national borders, you are not alone. This community learned long ago that we are bonded by blood, united in passion, and STRONGER TOGETHER.

Over the next several days we will discuss a range of topics ranging from health concerns for warrior men and warrior women, sickle cell trait education, and the path to financial independence. We will engage in Community Conversations coving topics like “Curative Therapies: The Good, The Bad, The Ugly” and “Sickle Cell Holistic Health and Nutrition”. We are also excited to bring back the Murder Mystery, Make-Up and Advocacy, and Gaming Through the Pain, as well as to introduce the Warrior Block Party. This is a new time, with new challenges, requiring a new way of living and interacting with the world and we are glad that you’ve chosen to join as we host our second virtual Convention. Although we are separated by geography, our bond is strong and our will to thrive through any situation is stronger.

The Sickle Cell Consortium has adapted accordingly. Last year, we held the first fully virtual sickle cell convention and this year we are back again with fun, engagement, and entertainment with the help of Zoom and Whova.

AT - A - GLANCE

Wednesday, August 25

Pre-Con Networking Event

Thursday, August 26

- Morning Wholeness
- Opening Reception
- Community Conversations
- Community Lunch & Learn
- Healthy Cooking w/ Warriors
- Murder Mystery

Friday, August 27

- Morning Wholeness
- Community Conversations
- Community Lunch & Learn
- Make-Up Advocacy
- Gaming Through The Pain
- Paint & Chat
- Warriors After Dark

Saturday, August 28

- Morning Wholeness
- Community Conversations
- Community Lunch & Learn
- Community Block Party

Sunday, August 29

Closing of the 8th Annual Convention

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SC MAN
MEN'S TRACK

MIA ROBINSON
SC3 365
YOUNG ADULT TRACK

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AARON WASHINGTON
INTERN

SUPPORT TEAM

LANITA SMITH - SPEAKERS

ANDREW N. LEWIS - TECH

NIKO DURRETTEL - TECH

CHLOE ROSE - CHILDREN'S TRACK INTERN

WARRIORS CONVENTION TRACKS

TRAIT TRACK:

Hosted by The As One Foundation, the Trait Track is designed to engage trait warriors with educations and an understanding of all things sickle cell trait.

YOUNG ADULT TRACK

Young Adults Track- Hosted by SCA365, the Young Adult track is designed to empower the next generation of Warriors in showing up as their best selves by setting long-term and short-term goals, learning financial literacy, knowing what it means to advocate for yourself, and implementing safe boundaries to maintain good health. Young adults age 15 to 22 are invited to participate in daily sessions, each day from 3pm – 4pm EST.

MEN'S TRACK

Hosted by the Sickle Cell Men's Action Network (SC MAN), this track is dedicated to male warriors and caregivers living with sickle cell disease, or in the care of a warrior. The men will focus on general men's health, men and mental health, body building as a warrior, leading as head of the household, and more. Join this session each day from 1-2pm EST for these important discussions.

CHILDREN'S TRACK

The Children's Track is designed for young warriors and caregivers age 6-14. Hosted by SC3 Next Generation, the young warriors and caregivers will be guided through various activities focusing on health, hydration, and stress management. Each participant, who registers by the August 17th deadline, will receive a package in the mail containing all supplies necessary for these activities. Young warriors and caregivers are also eligible to request a Chromebook or tablet to help access the meeting and with future educational needs. To request a device, contact Lisa Rose at lisa.m.rose@live.com.

MORNING WHOLENESS

This morning session is hosted by the SC3 Mental Health & Wellness Initiative and will focus on mindfulness, breathing, and yoga, followed by a discussion each day on boundaries, self-care, and Wellness Recovery Action Plans (WRAP).

YOU ARE THE EXPERT

We are flipping the script and making the sickle cell warriors and caregivers the experts. The Convention Conversations are focused your experiences and journeys.

Let's Talk About Pain, Insomnia, & Fatigue

Sickle Cell Holistic Health & Nutrition

Sickle Cell Symptoms & Side-Effects

The Power of Advocacy: Legislative, Health, Patient

Curative Therapies: The Good, The Bad, And The Ugly

Injustice In The Emergency Department, Sickle Cell Stigmatization & Social Justice

COMMUNITY CONVERSATIONS

AGENDA

WEDNESDAY | AUGUST 25, 2021

PRE-CON REGIONAL NETWORKING

11:00AM - 2:00PM EST
CONVENTION REGISTRATION/HELP DESK

Check-in on Wednesday, August 25th, between 11am and 2pm EST to let us know you're here and have any of your questions answered. This check-in will also confirm your attendance for the Thursday Lunch and Learn.

12:00PM - 3:00PM EST
CBO REGIONAL NETWORKING SESSIONS

Sickle cell patients, caregivers, providers, and others in the community are invited to check-in to the convention and then join their region to connect with others in the sickle cell community in their state (or surrounding states). Hosted by local CBOs, this is a time to get to know your fellow warriors and caregivers in your region.

Learn more about events & activities; hear from patients, caregivers, and CBOs; and discusses the cares and concerns of the sickle cell community in that region.

11:00 AM	**Morning Wholeness - Clayton Andrews, Marjorie Dejoie-Brewer, LaToyia Webb** Activity: Breathing, Mindfulness, & Yoga Discussion: Self Care
12:00 PM	**Opening Reception**
1:00 PM	**Breakout Sessions**
	The Warrior Entrepreneuer Sickle cell warriors are all things that all people are. Join us for a chat with warrior entrepreneurs as they share with us what it's like to be an entrepreneur with sickle cell.
	Trait Track - Dr. Tomia Austin, Farron Dozier, Mwape Miller, Maisha Pesante, Davard Darling, Sidney Alexandria Sickle Cell Trait: Benign or Not? Are you a trait warrior that has been told your only concern is having a baby with sickle cell disease? Have you ever wondered what sickle cell trait is and how it can affect our bodies? Do you live with trait and contemplate if any of the health concerns you have, connect back to this "benign" condition? Join us for an interactive conversation about all things sickle cell trait! Talking points include risks, protective factors, and possible complications for those living with trait. Recent COVID research will also be included.
	Movement & Health For Men - Chris Smith Join warrior Chris Smith as he walks warrior men through a session on movement and health.
2:00 PM	**COMMUNITY LUNCH & LEARN - SPONSORED BY VERTEX**
3:00 PM	**Young Adult Track: Vision Board Party Setting Goals - Mia Robinson** Young Adults are invited to join Mia Robinson of SCA365 as she guides are warriors and caregivers between ages 16 and 22 through visualization and affirmation. Check your registration kit for supplies.
	Children's Track Opening Activities - Lisa Rose
	Hydrate & Create W/ SC3 Next Generation This session is a Paint & Sip for children. Grab your painting kit from the registration package and your electrolyte hydration powder and join SC3 Next Generation as we paint, hydrate, and learn.
	Vision Board W/ Shamaine Charelle Discussion - The Power of Positive Thinking This Vision Board session is for our young warriors and caregivers to think about positive thinking and create their own vision boards with Shamaine Charelle.
4:00 PM	**Community Conversation - Sickle Cell, Holistic Health, & Nutrition**
5:00 PM	**Community Conversation - Let's Talk About Pain, Insomnia, & Fatigue**
6:00 PM	**Healthy Cooking with Warriors - DeMitrious Wyant** Join warrior chefs and dieticians as they prepare a healthy meals and chat about healthy eating and nutrients with sickle cell disease. Interested participants will receive a recipe card and shopping list to cook along at home. This has come to be one of the most requested sessions of the Warriors convention. This year we welcome back DeMitrious Wyant, sickle cell warrior, educator, musician, and chef on Thursday, August 26th, from 6-7 pm EST. Last year, Chef Wyant demonstrated how to make a blood boosting smoothie while hosting an open Q& A with the attendees. This year he has a bigger meal planned to teach the community how to eat for health.
7:00 PM	**Murder Mystery**

AGENDA
THURSDAY | AUGUST 26, 2021

DAY 2

AGENDA DAY 3

FRIDAY | AUGUST 27, 2021

11:00 AM **Morning Wholeness - Clayton Andrews, Heather Avant, Marjorie Dejoie-Brewer**
Activity: Breathing, Mindfulness, & Yoga
Discussion: Boundaries

12:00 PM **Community Conversation**
The Power of Advocacy: Legislative, Health, Patient

1:00 PM **Breakout Sessions**

Sickle Cell & Women's Health - Dr. Titilope Fasipe
This session focuses on the health concerns that affect warrior women. Come join the conversation to talk about everything from menses to menopause.

Trait Track - Dr. Tomia Austin, Maisha Pesante, Ritchie Johnson
Sickle Cell Trait: The Kidney Connection
Have you heard rumors regarding a link between cancer and sickle cell trait? Have you read recent headlines discussing kidney complications among trait warriors? Kidney complications are one of the most important areas of trait research today and this conversation will cover topics including the inability to concentrate urine, blood in the urine, and a rare but exclusively trait-focused cancer called Renal Medullary Carcinoma (RMC).

Men's Track: Men & Mental Health - Clayton Andrews
Clayton Andrews, warrior and mental health counselor, talks with the warrior and caregiver men about mental health.

Intro to the 1st Caregivers Summit - Carley Cole-Cavins

IEP & 504 Plans - Janeen Greene
Sickle Cell & School Policy

2:00 PM **COMMUNITY LUNCH & LEARN - SPONSORED BY BLUEBIRD BIO**

3:00 PM **Young Adult Track: The Keys to Financial Independence**
This session on Financial Independence for young adults. Check your registration package for the book "I Want More Pizza: Real World Money Skills For High School, College, And Beyond" and prepare to learn more about money management with SCA365.

Children's Track
Opening Activities - Lisa Rose

Health & Hydration W/ Keemaya - Andressa Ambrose
Join caregiver Andressa Ambrose as she leads young warriors and caregivers through activities on health and hydration with character Keemaya. The book with activities is in the registration package.

Managing Stress: Calming Jars W/ Carley Cole-Cavins
Join caregiver Carley Cole Cavins as she talks about managing stress and guides young warriors and caregivers through the steps to create calming jars. The supplies are in the registration package.

4:00 PM **Community Conversation - Injustice in the Emergency Department, Sickle Cell Stigmatization and Social Justice**

5:00 PM **Jazmine Rivera Beauty In Sickle Cell Make-up & Advocacy - Mikaya Warren**
The Jasmine Rivera Beauty Within Sickle Cell Initiative presents "Makeup and Advocacy". This session is led by a Warrior Make-up Artist Mikaya Warren who will lead a demonstration of detailing make-up artistry while simultaneously opening up chat about the power of advocacy as a collective.

Gaming Through The Pain
Sickle cell is a very painful disease, and we all have techniques that we use to manage it. Gaming has been identified by both male and female warriors of all ages as a great distraction technique for both acute and chronic pain. Join us as the Sickle Champions Men's Action Network (S.C. M.A.N.) hosts an online gaming segment to discuss effective distraction techniques, while joining other warriors and caregivers to play either Rocket League or Call of Duty! This session is open to all ages and gender identity. S.C. M.A.N., an initiative of the Sickle Cell Consortium, is pleased to create a safe and welcoming place where gamers can come together and play games while chatting about how to cope with pain.

6:00 PM **Community Paint & Chat - Mia Robinson**
During this workshop we will collectively participate in a Bob Ross moment as we paint with the tutorial of a warrior artist. Join artist Mia Robinson and get out your paint, brushes, and canvas to help get those creative juices flowing, while having conversation.

8:00 PM **Children's Track - SC3 Next Generation Dance Party**

9:00 PM **Warriors After Dark - WAD**

Women Only: Pajama Jam - Shamonica Wiggins, Dominique Goodsoon, Janeen Greene
This Warrior After Dark session is for women only. Join other warrior women for this self-care themed pajama jam.

Men Only: Living With Sickle Cell as the Head Of The Household - Sponsored By Chiesi
This Warrior After Dark is for men only. Join other male warriors and caregivers to network, bond, and discuss male mentoring.

CONVERSATION
AND FUN

11:00 AM	**Morning Wholeness - Clayton Andrews, Marjorie Dejoie-Brewer** Activity: Breathing, Mindfulness, & Yoga Discussion: Wellness Action Recovery Plan (WRAP)
12:00 PM	**Therapeutic Options for Sickle Cell Disease**
1:00 PM	**Breakout Sessions**
	Trait Track - Dr. Tomia Austin, Maisha Pesante, Tiffany Riley Sickle Cell Trait: Life, Action, Hydrate There are millions of Sickle Cell Trait Warriors nationally and hundreds of millions world wide. Most are not aware of their positive sickle cell trait status. Some won't be made aware until it's too late. Here we discuss the importance of sickle cell trait testing, education and hydration – especially for those who are physically active, including but not limited to athletes, those who do physical work and even hard-working caregivers who are also sickle cell trait warriors.
	Men's Track: Welcome to SC MAN - Ade Adeyokunnu & Kadeem Gayle Join this session to learn more about the Sickle Champions Mens Action Network (SC MAN) from the leaders of SC MAN.
2:00 PM	**COMMUNITY LUNCH & LEARN - SPONSORED BY AGIOS**
3:00 PM	**Young Adult Track: Self Advocacy & Boundaries**
	Children's Track Opening Activities - Lisa Rose
	Broken Crayons Still Color - Duchess Grace
	Writing Your Story - Angel Woods
4:00 PM	**Community Conversation - Sickle Cell Symptoms & Side-effects**
5:00 PM	**Community Conversation - Curative Therapies: The Good, The Bad, & The Ugly**
7:00 PM	**Community Block Party - Sponsored By Fulcrum** This fun event will feature music, dancing, and games with DJ Don Perignon and P. Skillz and special guest Warrior artists AR The Prophet and Charlie Blakk. Thanks to our Sponsor Falcrum we are able to recreate an in person common community function to a digital and engaging party that brings us together again.

DAY
4 - 5

Sunday

1:00 PM	Close of the 8th Annual Convention "Sickle Cell Disease: The International Experience"
	SC3 Next Generation Meeting

AGENDA

SATURDAY | AUGUST 28, 2021
SUNDAY | AUGUST 29, 2021

Warriors Battling Sickle Cell Together

Fulcrum Therapeutics is very pleased to support the 8th Annual Warrior's Convention and the important work of the Sickle Cell Community Consortium. Your dedication and commitment inspire us every day!

Fulcrum
Therapeutics

About Fulcrum Therapeutics

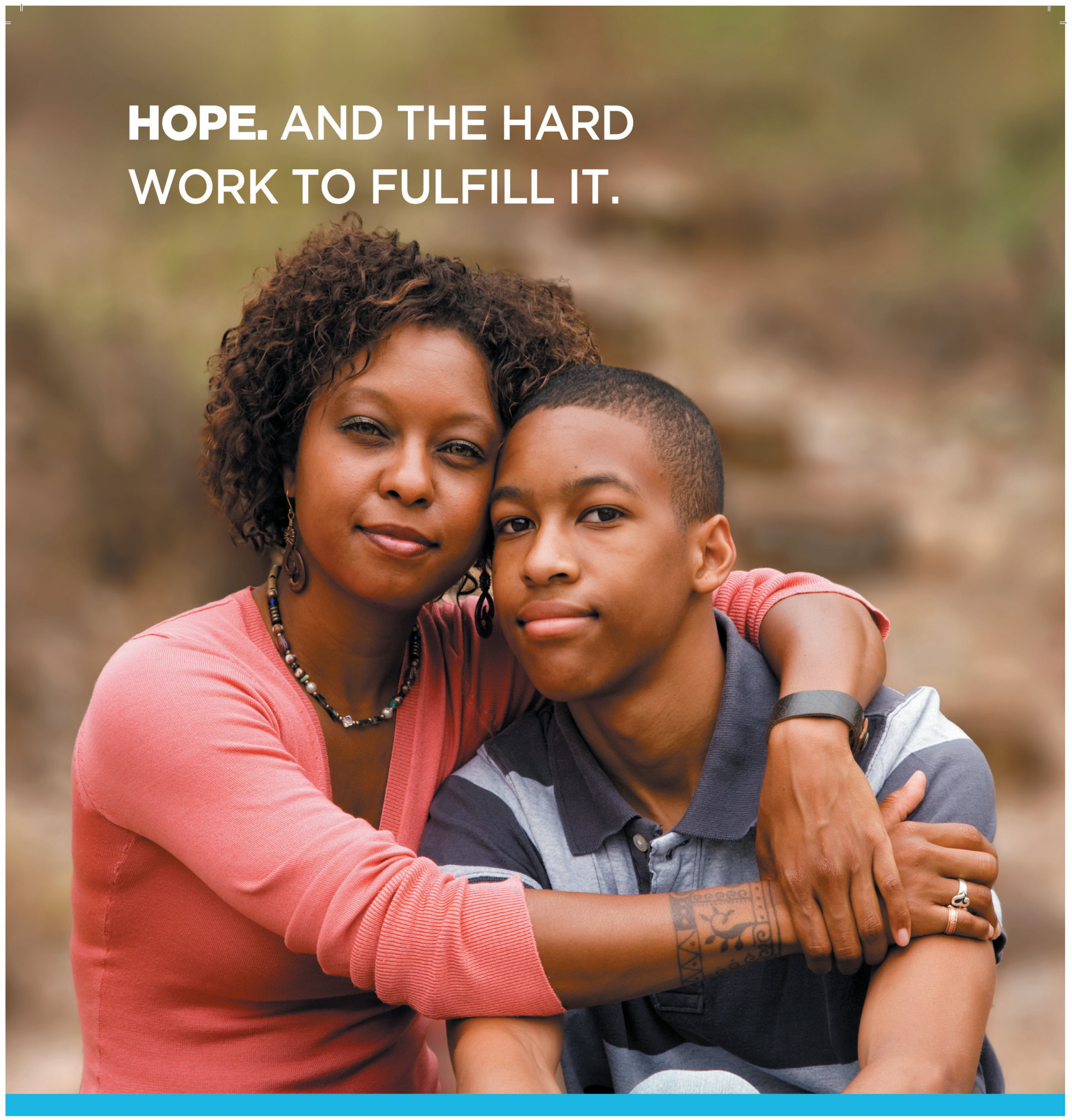
Fulcrum Therapeutics is a clinical-stage biopharmaceutical company focused on improving the lives of patients with genetically defined rare diseases in areas of high unmet medical need. We are committed to advancing promising research to develop treatments for many serious genetic diseases including sickle cell disease and facioscapulohumeral muscular dystrophy. To learn more, visit **fulcrumtx.com**.

ANNUAL LEADERSHIP SUMMIT

- Held every March in Atlanta, GA
- Attended by Consortium partners
  CBO partners
  Independent patient/caregiver leaders

- CBO & Advocacy Best Practices
- Research & Legislative Updates
- SC3 Business Meeting
- Partner Services
- Creative Content

- Home of the Annual General Assembly of Patients, Caregivers, and CBOs



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If you live with sickle cell, it's your time to experience less sickling with Oxbryta, the first of its kind, tablet specifically designed to treat sickle cell. For patients 12 years and older.

Ask your doctor if Oxbryta is right for you.

ARELYS
actual sickle cell patient
on Oxbryta

For access to Full Prescribing Information, please contact GBT at (833) 428-4968 or 181 Oyster Point Blvd., South San Francisco, CA 94080

INDICATION

What is OXBRYTA?

OXBRYTA is a prescription medicine used for the treatment of sickle cell disease in adults and children 12 years of age and older.

It is not known if OXBRYTA is safe and effective in children below 12 years of age.

This indication is approved under accelerated approval based on increase in hemoglobin (Hb). Continued approval for this indication may be contingent upon verification and description of clinical benefit in confirmatory trial(s).

IMPORTANT SAFETY INFORMATION

Do not take OXBRYTA if you have had an allergic reaction to voxelotor or any of the ingredients in OXBRYTA. See the end of the patient leaflet for a list of the ingredients in OXBRYTA.

If you are receiving exchange transfusions, talk to your healthcare provider about possible difficulties with the interpretation of certain blood tests when taking OXBRYTA.

Before taking OXBRYTA, tell your healthcare provider about all of your medical conditions, including if you:

- have liver problems
- are pregnant or plan to become pregnant. It is not known if OXBRYTA can harm your unborn baby
- are breastfeeding or plan to breastfeed. It is not known if OXBRYTA can pass into your breastmilk and if it can harm your baby. Do not breastfeed during treatment with OXBRYTA and for at least 2 weeks after the last dose

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Some medicines may affect how OXBRYTA works. OXBRYTA may also affect how other medicines work.

What are the possible side effects of OXBRYTA?
OXBRYTA can cause serious side effects, including:

- **Serious allergic reactions.** Tell your healthcare provider or get emergency medical help right away if you get:
  - rash
  - hives
  - shortness of breath
  - swelling of the face

The most common side effects of OXBRYTA include:

- headache
- diarrhea
- stomach (abdominal) pain
- nausea
- tiredness
- rash
- fever

These are not all the possible side effects of OXBRYTA.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088. You may also report side effects to Global Blood Therapeutics, Inc. at 1-833-428-4968 (1-833-GBT-4YOU).

Keep OXBRYTA and all medicines out of the reach of children.

For more information about Oxbryta, please see the Patient Information on the next page of this publication and talk to your HCP.

GBT

PATIENT INFORMATION
OXBRYTA® (ox brye ta)
(voxelotor) tablets

What is OXBRYTA?

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If you are receiving exchange transfusions, talk to your healthcare provider about possible difficulties with the interpretation of certain blood tests when taking OXBRYTA.

Before taking OXBRYTA, tell your healthcare provider about all of your medical conditions, including if you:

- have liver problems.
- are pregnant or plan to become pregnant. It is not known if OXBRYTA can harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if OXBRYTA can pass into your breastmilk and if it can harm your baby. Do not breastfeed during treatment with OXBRYTA and for at least 2 weeks after the last dose.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. Some medicines may affect how OXBRYTA works. OXBRYTA may also affect how other medicines work.

Keep a list of all your medicines and show it to your healthcare provider.

How should I take OXBRYTA?

- Take OXBRYTA exactly as your healthcare provider tells you.
- Do not change your dose or stop taking OXBRYTA unless your healthcare provider tells you to.
- Take OXBRYTA 1 time each day. Swallow each OXBRYTA tablet whole.
  Do not cut, crush or chew the tablets.
    - Your healthcare provider may change your dose if needed.
- Your healthcare provider may also prescribe hydroxyurea during treatment with OXBRYTA.
- Take OXBRYTA with or without food.
- If you forget to take a dose of OXBRYTA, skip that dose and return to your normal dosing schedule the next day.

What are the possible side effects of OXBRYTA?

OXBRYTA can cause serious side effects, including:

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How should I store OXBRYTA?

- Store OXBRYTA at or below 86°F (30°C).
- OXBRYTA comes in a child-resistant package.
- The bottle contains a desiccant to help keep your medicine dry (protect it from moisture) and polyester coil. Do not eat.

Keep OXBRYTA and all medicines out of the reach of children.

General information about the safe and effective use of OXBRYTA.

Medicines are sometimes prescribed for purposes other than those listed in a Patient Information leaflet. Do not use OXBRYTA for a condition for which it was not prescribed. Do not give OXBRYTA to other people, even if they have the same symptoms that you have. It may harm them. You can ask your healthcare provider or pharmacist for information about OXBRYTA that is written for health professionals.

What are the ingredients of OXBRYTA?

Active Ingredient: voxelotor

Inactive Ingredients: colloidal silicon dioxide, croscarmellose sodium, magnesium stearate, microcrystalline cellulose, and sodium lauryl sulfate. The film coating contains: polyethylene glycol 3350, polyvinyl alcohol, talc, titanium dioxide, and yellow iron oxide.

Manufactured for: Global Blood Therapeutics, Inc. South San Francisco, CA 94080, USA.

For more information, call 1-833-428-4968 (1-833-GBT-4YOU) or go to www.OXBRYTA.com.

This Patient Information has been approved by the U.S. Food and Drug Administration.

Issued: 01/2021

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2020 BLAST TO THE PAST

In 2014 the Sickle Cell Consortium was created to identify the problems, needs, and gaps in the sickle cell community and then develop solutions to address these patient/caregiver-identified concerns. In recognition of the challenges that the COVID-19 pandemic presented, our standard protocol of outlining community problems, needs, and gaps at the annual Leadership Summit was instead replaced with a series of community assessment meetings to define the needs of the sickle cell community. We met with patients, parents, the mental health initiative, educators, and community-based organizations, and collectively, these groups identified a specific set of resources and support needed to continue to thrive past COVID-19.

Specifically, four major categories of need were identified: social services, mental health support, education support, and access to care. We have spent the last several weeks creating projects and programs to address these needs.

To learn more, visit www.sicklecellconsortium.org/COVID19.

EDUCATION SUPPORT

Sickle cell families directly identified specific needs and support services to help navigate the education of young warriors and caregivers. A new Board of Educators and Longterm Home-schoolers was developed after an exhaustive series of assessment and advisory meetings with educators, administrators, warrior parents, and parents raising warriors. This Board recommended that families focus on ensuring that school-age children focus on meeting education benchmarks for their advancing grade level. Working in partnership with HOPE for SCD and Cleverly Changing, we've developed a platform to provide education support and resources to ensure that our warriors and young caregivers are prepared to advance to the next grade level in the fall. We've compiled a database of existing resources and developed a protocol to provide education assistance. For more information, to connect with the Parent-to-Parent network, sign-up for tutoring help, or find daily low-tech activities with HOPE for SCD, visit https://sicklecellconsortium.org/education-support/.

MENTAL HEALTH SUPPORT

The Consortium Mental Health Initiative team organized a series of webinars and community chats to discuss numerous mental health topics, from "Anxiety & Fear" to "PTSD in Isolation". These sessions are now available online via the Sickle Cell Consortium YouTube page along with a list of online mental health resources and references. To decrease feelings of isolation, we also developed a series of Warrior Games & Challenges, designed to promote community engagement and interactivity.

The Sickle Cell Mental Health Initiative of the Sickle Cell Community Consortium is committed to working with the patients, caregivers, and community-based organizations (CBOs) of the sickle cell community to provide MENTAL HEALTH SUPPORT amid COVID-19.

Check-in with mental health experts to learn more about the mental health concerns facing the sickle cell community, participate in Community Conversations with warrior and caregiver panelists as we share our daily mental health experiences, sign-up for small community chats with mental health counselors, and chase away boredom and feelings of isolation by competing in a various array of Warrior Games!

We are eager to work with mental health professionals interested in helping our patient and caregiver community during this time.

sickle cell
communityconsortium

UNITY
PROGRESS
COMMITMENT

SOCIAL SERVICES

Social services are, of course, a major identified need. We recognize that patients and families may need assistance obtaining cleaning supplies, food, water, basic medical supplies, and other services. We have compiled a list of existing resources and are daily searching for more to add. Visit the resource map, click on your state to be taken to resources in your state. Links for national resources are added weekly. The Consortium network of CBO partners and leaders are preparing to address community needs and have organized a process to do this efficiently. The community's greatest need in this category is simply access to resources. The Consortium and our partners are working diligently to identify resources to address these needs.

The patients, caregivers, and CBO partners of the Sickle Cell Consortium are eager to connect with any individual or entity able to provide assistance or resources in any of these areas as we work to address the growing needs of the sickle cell community.

Please address ideas, thoughts, or concerns to Dr. Lakiea Bailey (director@sicklecellconsortium.org) or Sharonda Hudson-Sikes (ssikes@sicklecellconsortium.org).

EDUCATION SUPPORT FOR FAMILIES DURING COVID-19

The Sickle Cell Consortium Board of Educators and Long-term Homeschoolers recognize how difficult it can be to suddenly find yourself thrust into a "distant learning" environment and we want to help. Although we cannot ensure that all schoolwork assignments are completed for every child in every home, we can provide assistance to help ensure that your child meets the benchmarks for their grade level.

The Sickle Cell Consortium has partnered with Hope for SCD and Cleverly Changing to pride Educational Support to Warrior families.

Cleverly Changing

HOPE for SCD

Mental Health Support

May is Mental Health Awareness Month. The Mental Health Initiative of Sickle Cell Community Consortium is committed to working towards the stigmatization of mental illness and will continue to promote mental health awareness in May and all year long. Visit www.sicklecellconsortium.org/mental-health to learn more about this patient-led initiative.

Coping with Anxiety & Fear from Quaratine - Dr. Gayle Rogers
Tuesday, April 21st @ | Webinar Discussion with Q & A
Wednesday, April 22nd | Community Chat

The Caregiver Experience - Carley Cole Cavins
Tuesday, April 28th | Webinar Discussion with Q & A
Wednesday, April 29th | Community Chat

Depression & The Sickle Cell Warrior
Tuesday, May 5th | Webinar Discussion with Q & A
Wednesday, May 6th | Community Chat

Trauma, Quaratine, & Isolation
Tuesday, May 12th | Webinar Discussion - Gayle Rogers
Wednesday, May 13th | Community Chat
Thursday, May 14th | A Discussion on Healing - Lori Punch

Mental Health, Grief, & Sickle Cell Disease
Tuesday, May 19th | Webinar with Q & A
Wednesday, May 20th | Community

TUESDAY, MAY 19TH @ 7PM E
WEBINAR WITH Q & A

WEDNESDAY, MAY 20TH
COMMUNITY

Dr. Gayle Rogers

TUESDAY, APRIL 21ST @ 7PM EST
WEBINAR WITH Q & A

WEDNESDAY, APRIL 22ND @ 7PM EST
PANEL & OPEN DISCUSSION

Patients and science are at the center of everything we do.

At Sanofi Genzyme, we are inspired to push scientific boundaries to develop treatments for people with sickle cell disease and other rare blood disorders, providing hope to patients and their families.

SANOFI GENZYME

Novartis Oncology

Novartis proudly joins Sickle Cell Community and the 8th Annual Warriors Convention

Your dedication to helping patients with Sickle Cell is applauded.

At Novartis, our mission is to discover new ways to improve and extend people's lives. We use science-based innovation to address some of society's most challenging health care issues. We discover and develop breakthrough treatments and find new ways to deliver them to as many people as possible.

We are passionate about what we do and the impact we have on society, especially patients, including those living with Sickle Cell. We are Novartis, and we are reimagining medicine.

NOVARTIS

Novartis Pharmaceuticals Corporation
East Hanover, New Jersey 07936-1080 8/21 T-ONC-1159958

WE ARE THE CURE
BE THE MATCH

- A Grant from National Marrow Donor Program (NMDP), following the direction of Be The Match to encourage Black individuals between the ages of 18-44 to sign up and join the Bone Marrow registry.
- Currently Blacks only represent 4% of the national donor registry offering a 23% chance of identifying a matching blood stem donor.
- The NMDP is working to increase the number of Black Americans donating.
- Patients with Sickle Cell Disease are less likely to find a match on the registry because of this lack of diversity.
- Training Opportunity
- The Sickle Cell Consortium decided to take this Grant from Be The Match and turn it into a pilot training program for Credential Partners ONLY of the Sickle Cell Consortium.
- As part of training, SC3 sent out an RFP to increase the number of Black Americans in the National Marrow Donor Program (NMDP: dba Be The Match) registry.
- This pilot training program was designed to help partners become better acquainted with the RFP process.
- Independent Patient and Caregivers (IPAC) and Community-Based Organizations were eligible to apply and submit RFP.

WE ARE THE SICKLE CELL COMMUNITY CONSORTIUM

We are a registered 501(c)3 non-profit +organization.
Our tax ID number is 47-4771677.
The Sickle Cell Community Consortium is a US-based non-profit formed in 2014 to “harness and amplify the power of the patient voice”. The Consortium is comprised of sickle cell community-based organizations (CBOs), patient and caregiver advocates, community partners and medical and research advisers. These stakeholders collectively form the General Assembly of CBOs and Advocates, the decision-making body of the Consortium. The Consortium acts as an organizing entity providing the framework for the stakeholders of the General Assembly to apply a model of Collective Impact to define problems and gaps in the sickle cell community, identify strategies to address those needs and gaps, and determine the CBO, Community, and Corporate partnerships best equipped to implement those strategies to achieve significant and sustainable change.

OUR HISTORY

In February of 2014, during the FDA Patient-Focused Drug Development Initiative, a group of community-based organization leaders and patient advisors met to lay the foundation of what would become the Sickle Cell Community Consortium. Organized by Dr. Lakiea Bailey, this group made the collective decision to join efforts to create a unified platform to bring the sickle cell patient to the forefront of all matters regarding health, research, advocacy, education and awareness.

Over the span of the 18 months that followed, Dr. Bailey, Velvet Brown-Watts and Kena Drew would build upon this foundation to develop a cohesive, 501(c)(3) not-for-profit, created to harness and amplify the sickle cell patient voice.

Organized in a manner similar to the United Nations, Consortium Partner CBOs from all over the Country retain their individual autonomy, while uniting to apply a model of Collective Impact to tackle deeply rooted social, medical and legislative problems and barriers. The CBOs, along with Community Partners and Patient/Family Advisors, work together to identify and directly address community needs. The General Assembly, comprised of Partner CBOs and Advisors, form the decision-making body of the Consortium tasked with forming mutually beneficial partnerships to develop and execute strategies and solutions to address the needs, gaps and problems identified by the collective sickle cell community.

Joined by a diverse Board and Staff of patients, caregivers and supporters, the Consortium provides the infrastructure to coordinate the activities of strategic partnerships, provide training and support to Partner CBOs, and push forward collective Consortium platforms and initiatives. In 2015, we focused was on organizing and providing support for patients and families to “Show Up and Speak Up” at sickle cell and/or rare patient meetings and conferences. Then, 2016 we will built upon this by also working to actively further sickle cell research and clinical trials through our Patient-Centered Outcomes Initiative (PCOI 2016).

OUR ORGANIZATION

The Consortium is organized in a manner similar to the United Nations. The General Assembly of CBOs is the decision-making body of the Consortium. It is this group that applies the model of Collective Impact to collectively identify the problems, needs and gaps in the sickle cell consortium; develop creative, collaborative solutions to these problems; and then form partnerships to execute these solutions. Committees and project managers that will then execute these solutions are determined during our annual General Assembly of CBOs. This meeting occurs every March in Atlanta, Georgia. The president of the General Assembly is elected for a two-year term. This person also sits on the Board of Directors during their term. The Board person acts as oversight for their specific area.


sickle cell
Georgia Health Policy Center 25
REdHHoTT
NOVARTIS

The STEP Project
Solutions To Empower Patients

Blood Transfusions
× How, Why, When?

Instructor:
Dr. James Eckman, MD


SEPTEMBER IS SICKLE CELL
Awareness Month

sickle cell
WWW.SICKLECELLCONSORTIUM.ORG

sickle cell awareness

SOMEONE IN THIS HOUSE HAS SICKLE CELL DISEASE

THOSE WHO ARE IMMUNOCOMPROMISED ARE MORE LIKELY TO CONTRACT CORONAVIRUS (COVID-19) AND EXPERIENCE LIFE-THREATENING COMPLICATIONS.

DUE TO THE WIDESPREAD OUTBREAK OF THIS VIRUS WE ARE USING AN ABUNDANCE OF CAUTION THROUGH PRACTICING SELF-ISOLATION AND SOCIAL DISTANCING. WE APPRECIATE YOUR UNDERSTANDING AND COOPERATION

PLEASE LEAVE PACKAGES/DELIVERIES ON THE DOORSTEP

IF YOU NEED US PLEASE CALL__________


SICKLE CELL COMMUNITY CONSORTIUM
5TH ANNUAL LEADERSHIP
DIGITAL
11-13 JUNE 2020
Summit & General Assembly of Patients, Caregivers, & CBOs
REGISTER TODAY!
For more inforamtion www.sicklecellconsortium.org

Warrior

Unity


STAY HOME
sickle cell
COVID-19 TIPS
Practice social distancing, wear facial coverings, and follow proper prevention hygiene, such as washing your hands frequently and using alcohol-based (at least 60% alcohol) hand sanitizer when soap and water is not available.

sickle cell
VIRTUAL GRADUATION FOR THE
CLASS OF 2020
SIGNUP TODAY TO BE INCLUDED IN THE YEARBOOK!
https://tinyurl.com/SC3-2020graduation


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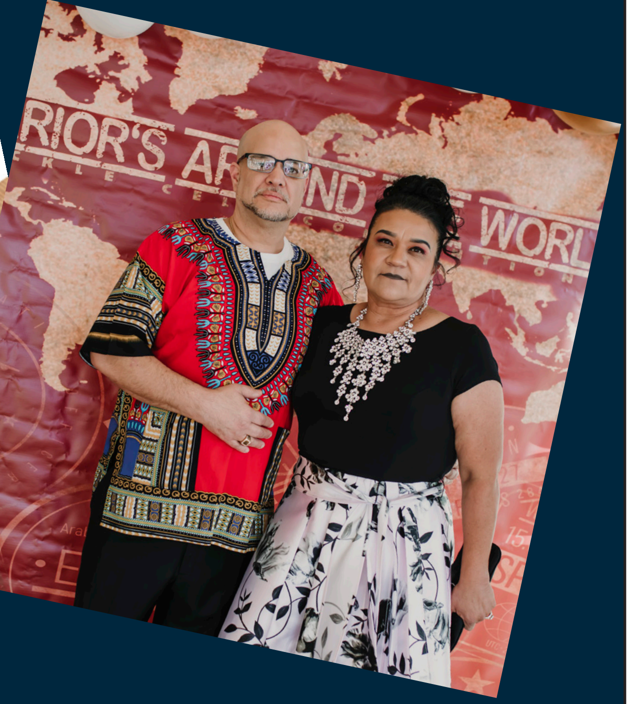
READ-A-THON
APRIL 20 - JUNE 1
PRIZES: 1ST - $100 GIFTCARD, 2ND - $50 GIFTCARD, 3RD - $25 GIFTCARD
FOR MORE INFORMATION/DETAILS
WWW.SICKLECELLCONSORTIUM.ORG

Winner



i am resilient