



Sickle Cell Foundation of PBC & Treasure Coast, Inc.

NEWSLETTER

INSIDE THIS ISSUE

PG. 2

"Go-bags" – What They Are & Why They're Important

PG. 3

Upcoming Events & Tip of the Month

PG. 4

Poster Child & Annual 5k Run/Walk Highlight

MARCH

M	T	W	T	F	S	S
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31					

March Sickle Cell Calendar

March 7, 2020	Eva Mack Gala
May 2020	Mother's Appreciation
June 19, 2020	World Sickle Cell Day
Sept. 12, 2020	Sickle Cell-cebration Walk
Oct. 24, 2020	Red Hat Affair

**“When life
keeps
throwing you
stones, keep
finding the
diamonds.”**

“GO-BAG”

There is little that is greater than the feeling you get when you realize you have everything you need in the most trying of times. For sickle cell patients, “go-bags” contribute to being prepared in a major way. A "go-bag" includes all the essentials one would need for an immediate trip to the emergency room or a sudden hospital stay.

Sickle cell patients can especially benefit from having a go bag and being prepared for emergencies. They often go into crisis at the most inconvenient times. During the pain they experience, some patients are unable to move, let alone pack a whole bag; and if you're a college student living alone, a frantic and nervous parent or anyone in between, getting to the hospital is the only major concern. Having a bag that is packed and ready in case a crisis arises can be key in those situations.

Some examples of items to put in your "go-bag" include socks, a change of clothes, a blanket, toothbrush and toothpaste, deodorant, phone charger, a small amount of cash, a book or any small form of entertainment, a bottle of water/Gatorade, hematology orders and any form of positive encouragement. The number of different items that can be put in your go-bag may vary depending on your specific needs and size of the bag. The most important aspect of the "go-bag" is just to have one.

- Dameneka Afrika, BSW
SCF Case Manager



DIY “Go-Bag”

Here are some items that you'd want to include in your “go-bag”:

- Hematology orders
- Change of clothes
- Socks
- Toothbrush
- Toothpaste
- Deodorant
- A blanket
- Phone charger
- Water/Gatorade
- Other small toiletries



Tip of the Month

It's Spring Time!

- Check the weather.
- Dress comfortably.
- Plan your schedule around peak allergy hours.
- Wash your hands often.
- STAY HYDRATED!

In the coming warm months, be sure to dress for the weather, but still bring a jacket for inside temperatures that are cooler, and an umbrella in case it rains. The weather is sometimes unpredictable and it's better to have it and not need it than need it and not have it!

UPCOMING EVENTS

March 7th

Eva Mack Gala

Hilton Palm Beach Airport

Call (561) 833-3113 for details!

April 15th

Poster Child Application Due!

See pg. 4 for details

May 2020

Sickle Cell Mother's Appreciation

June 19, 2020

World Sickle Cell Day

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POSTER CHILD WANTED

The Sickle Cell Foundation is looking for a new poster child!

Living with sickle cell disease is difficult; it's important that people understand the struggles children have in their everyday life. The poster child will represent the Foundation and its cause by performing the following duties:

- Attend events hosted by the Sickle Cell Foundation
- Speak about own personal experience with sickle cell disease

The poster child chosen must be between the ages of 8-17 and have an outgoing personality. They must also have sickle cell disease (any type).

The poster child is a valued position. As the face of the Sickle Cell Foundation and an advocate of its cause, the duty to spread awareness and knowledge on the disease is respected.

Contact the office at (561) 833-3113 for more information!

NEW MEDICATIONS

OXBRYTA (Voxelotor)

The Food and Drug Administration (FDA) approved this new drug for sickle cell in mid-November of 2019. The medication, a pill taken once daily, is said to “block a process in blood cells that can lead to anemia and organ damage.” (Loftus, 2019)

Only for ages 12 and up, the drug is one of the first to treat the underlying causes of sickle cell anemia.

For more information, visit: oxbryta.com

ADAKEVO (Crizanizumab-tmca)

The FDA approved this medication around the same time as Oxbryta. Adakevo is indicated to reduce the number of vaso-occlusive crises in adults and pediatric patients aged 16 and up. The medication is given through an IV infusion once a month.

For more information, visit:

us.adakevo.com/sickle-cell-disease

COVID-19 & Sickle Cell Disease

Frequently Asked Questions

How can I get myself and my family prepared?

- Please check to see if you have refilled all your (your child's) medication and are not about to run out.
- Contact your (your child's) doctor to ask about getting extra medications to have on hand in case there is an outbreak of COVID-19 in your community and you need to stay home for a long period of time. Some pharmacies are offering home delivery.
- Be sure you have over-the-counter medicines and medical supplies (e.g. tissues) to treat fever (e.g. Tylenol) and other symptoms.
- Make sure you have a thermometer to take your temperature.
- Take your prescribed medications for sickle cell disease. These medications will help keep your body in the best possible condition to fight off infection.
- Have enough household items and groceries on hand so that you will be prepared to stay at home for a period of time that could be many weeks.
- Stay in touch with others by phone or email. You may need to ask for help from friends, family, neighbors, etc. if you become ill.
- Think ahead about who will watch your children, other loved ones, or pets if you become too sick.
- Find out if working from home is an option.

What can I do to prevent the spread of COVID-19?

- Stay home as much as possible. Do not leave home unless absolutely necessary.
- Wash your hands with soap and water for 20 seconds (don't stop until you finish singing the "Alphabet song") or use hand sanitizer with at least 60% alcohol.

- If you feel sick, call your medical provider immediately.
- Avoid touching your face.
- Avoid being close to people who are visibly sick, coughing, or sneezing.
- Greet one another from a distance (no hugs or handshakes).
- Disinfect frequently touched objects and surfaces. The virus can live on these surfaces and get transmitted this way.
- Cover your cough or sneeze with a tissue you can discard, then immediately wash your hands.

Have any individuals with sickle cell disease been diagnosed with COVID-19?

- Yes, we are aware that some have. We are not aware of any deaths among those living with sickle cell disease. This could change.

I feel fine so far. Is there anything I can do to help others?

- If you know others living with sickle cell disease, contact them by phone, text or social media. Make sure they are doing ok and see if they need help or reassurance. It is a stressful time for a lot of us. If you know people who are willing to donate blood, encourage them.

SOURCE:

<https://www.sicklecelldisease.org/2020/03/17/health-alert-for-patients-and-caregivers/>

**Always remember, you are not alone!
The SCF is here to help.
For more information, contact
Dameneka Afrika (Case Manager) at
(561) 396-9197.**