



Explaining  
**BLOOD**  
**TRANSFUSIONS**  
to a Child with  
**SICKLE CELL DISEASE**

# Words of Encouragement

*Dear Caregiver:*

*Guiding a child through sickle treatments can feel overwhelming. There are so many choices to make and so much information to learn about your options. The unknown can cause anxiety – for both you and your child. The Sickle Cell Disease Association of America is here to support you and your family as you navigate this journey.*

*One of the most common treatments for sickle cell disease is blood transfusion. In the following pages, parents and caregivers will learn more about the procedure and understand what to expect. It's normal for a child to feel anxious leading up to treatment.*

*One of the most important things for your child to understand is that the goal of this treatment is to help them feel better. Many adults and children have found relief from blood transfusions. Your health care provider recommended it because they expect it to help your child too.*

*Your child will likely have as many questions about this treatment as you do. Gently explain the facts to them and listen to their fears and concerns. It may be helpful to share some general information about sickle cell disease (SCD). Key facts include:*

- *SCD is a blood disease that affects people of all races.*
- *SCD is in your genes. It is not contagious.*
- *Sickle Cell Trait (SCT) means a person has inherited the sickle cell gene from one or both of their parents; people with SCT usually do not have any sickle cell symptoms.*
- *If both parents have the genetic trait, they can have a child with SCD.*
- *It's best to get tested to know for sure if a child has SCD.*

*We hope this brochure helps you calm a nervous mind and brings your family confidence as you prepare for the transfusion.*

## **Regina Hartfield**

President and Chief Executive Officer  
Sickle Cell Disease Association of America, Inc.



**“Being a sickle cell warrior means being brave. Wear your strength like a badge of honor so others can stand tall too.”**

# What you need to know...

## ABOUT BLOOD TRANSFUSIONS AND SICKLE CELL DISEASE

You are receiving this brochure because your child has been diagnosed with sickle cell disease (SCD) and your child may need **blood transfusions as treatment**. Blood transfusions prevent the sickled (banana shaped) red blood cells (RBC) from getting stuck in the blood vessels and provide healthy red blood cells to bring oxygen to every part of the body.

Blood transfusions play an important role in the management of SCD in children. Reasons your child might receive a transfusion include the **prevention of stroke and pain episodes**. Sometimes blood transfusions are given for other reasons as well.

Strokes occur in **11% of children** with **sickle cell anemia (SCA)** and often times there are no visible stroke symptoms.<sup>1</sup> **Children with SCD** are **300 times** more likely to experience a stroke than healthy children.<sup>2</sup>

Blood transfusions are **standard of care for preventing strokes** in children, and your child may need them throughout their lifetime. Regular transfusion therapy has been shown to **reduce the risk of stroke** in sickle cell patients by **90%**.<sup>3</sup>

Blood transfusions are also used to **treat pain** that your child may experience from SCD, and blood transfusions have been shown to reduce the number of patient visits to the hospital due to a pain episode.<sup>4</sup> Your child may need long-term blood transfusions for other sickle complications which you should discuss with your doctor.

## THERE ARE DIFFERENT WAYS TO GET A BLOOD TRANSFUSION

**Simple Blood Transfusion:** a blood transfusion that involves giving your child blood from someone who donated it. The healthy donor RBCs are able to carry oxygen to all parts of their body and decrease the number of sickled red blood cells. Depending on the amount of RBCs to transfuse, a simple transfusion can take several hours or an all-day clinic visit.

**Exchange Blood Transfusion:** this procedure involves slowly removing a portion of your child's RBCs and replacing them with a donor's RBCs. An exchange transfusion is sometimes done with an automated system using an apheresis machine. An exchange transfusion can take up to 8 hours. If an apheresis machine is used, it may only take a few hours.

*Please speak with your doctor to discuss which treatment is right for your child.*

# Preparing for a blood transfusion

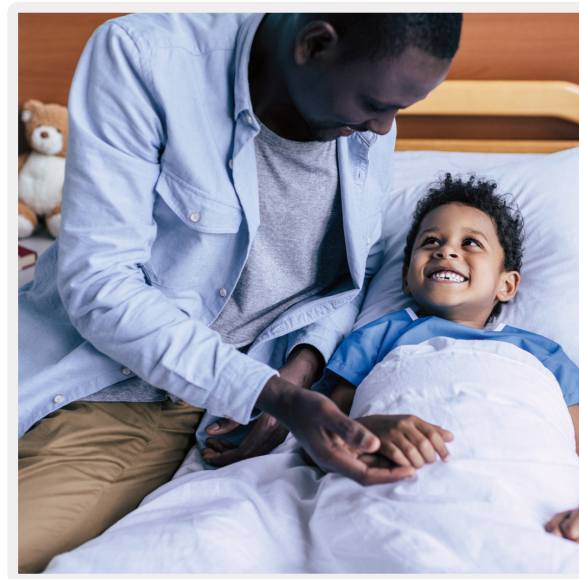
We understand that this may be a stressful time for you and your child, and we would like to make the process of a blood transfusion as simple as possible. The accompanying brochure **“Transfusions to the Rescue! New Blood = Stronger You”** is provided for you to use with your child to help explain why they may need a transfusion and help prepare them for the day of the transfusion. **Only a doctor can know when your child might need a transfusion.**

## PRIOR TO THE BLOOD TRANSFUSION

- 🩸 A blood sample from your child will need to be taken within 3 days of the transfusion to determine the blood type (ABO group) and Rh type (positive or negative). Blood will be taken from a vein in his or her arm.
- 🩸 Your child’s blood will be matched with donor blood to find a compatible blood type for the transfusion. If your child receives blood that is not compatible, they may have a transfusion reaction which can occur immediately or several days later.
- 🩸 The donated blood your child receives will have been tested to confirm there is no evidence of certain infections such as hepatitis B and C viruses and human immunodeficiency virus (HIV). The blood donors are healthy volunteers who give their blood to help patients and they are not paid for their important service.
- 🩸 It would be helpful if you could make a list of all the places your child has ever received a blood transfusion. The doctor needs this information to know if your child has possibly developed a reaction to blood or something called antibodies in the past. This will allow the doctor to provide the best matched blood for your child.
- 🩸 Hospitals will require a consent discussion and form to be signed before a blood transfusion. This is the time for you to ask any questions about what may happen to your child. The consent form needs to be signed by a parent or guardian.
- 🩸 If you plan to stay with your child, who will be awake during the procedure, talk with your doctor so that the staff will expect you.

# What happens during the blood transfusion?

- 1 Your child can sit comfortably in a reclining chair or lie down on a bed and watch a movie or listen to music.
- 2 The IV for the transfusion is typically placed in the arm or hand, although it can be done in other places if finding a vein is difficult. A small needle is used to administer the start of the IV which can cause a little bit of pain. To reduce discomfort, a nurse might put some numbing cream on your child's skin a half hour before inserting the needle.
- 3 Nurses will check that the name and identification numbers on your child's armband to match what is written on the blood bag.
- 4 The blood is then given from the bag through a tube into your child's vein. The nurse will measure your child's blood pressure, body temperature, and pulse before, during, and after the transfusion.



**Your child also will be watched closely for any signs of an allergic reaction or other type of reaction, including rash, fever, headache, or swelling.**

## After the transfusion

A healthcare provider will watch your child for any signs of unexpected reactions. These are most likely to occur within the first 15 minutes. Tell your child to let the healthcare provider know right away if he or she starts feeling like something isn't right in their body. If you are with your child let your nurse know any changes you have observed as well.

**If your child is going home, the tiny plastic tube is removed from the vein and a bandage is placed over the area. The site may be slightly sore or tingly for a while.**

# Useful Stats<sup>5,6</sup>



# 100,000

Americans live with SCD,  
the most common inherited  
blood disorder.

1 out of 13

African-Americans carry  
the SCD trait



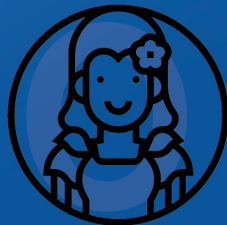
1 out of 365

African-American babies  
have SCD



1 out of 16,300

Hispanic-American babies  
have SCD



29,000 Units

of RBCs are needed every  
day in America



# Frequently Asked Questions

## What steps are taken to make sure transfusions are safe?

Some people worry about getting diseases from infected blood, but the United States has one of the safest blood supplies in the world. Many organizations, including community blood banks and the federal government, work hard to make sure that the blood supply is safe. The risk of getting a disease like HIV or hepatitis through a transfusion is extremely low in the United States today because of very stringent blood screening. Also, the needles and other equipment used are sterile and used only on one person, and then thrown away in special containers.

## Are there alternative therapies to blood transfusions?

There are other treatments that are being evaluated that may be helpful to your child. Your doctor can discuss these options with you.

### Ref:

1. Guilliams KP, Fields ME, Ragan DK, et al. Red cell exchange transfusions lower cerebral blood flow and oxygen extraction fraction in pediatric sickle cell anemia. *Blood*. 2018;131(9):1012-1021.
2. Sickle cell disease and stroke screening. Patient brochure. Children's National. Accessed November 21, 2022. <https://childrensnational.org/departments/center-for-cancer-and-blood-disorders/programs-and-services/blood-disorders/programs-and-services/sickle-cell-disease-program>.
3. Lee MT, Piomelli S, Granger S, et al. Stroke prevention trial in sickle cell anemia (STOP): extended follow-up and final results. *Blood*. 2006;108(3):847-852.
4. Mize L, Burgett S, Xu J, Rothman J, Shah N. The use of chronic transfusions in sickle cell disease for non-stroke related indications. *Blood*. 2014;124(21):4934.
5. Data and Statistics on Sickle Cell Disease. Centers for Disease Control and Prevention. Updated May 2, 2022. Accessed November 21, 2022. <https://www.cdc.gov/ncbddd/sicklecell/data.html>.
6. Facts about blood needs. American Red Cross. Accessed November 21, 2022. <https://www.redcrossblood.org/donate-blood/how-to-donate/how-blood-donations-help/blood-needs-blood-supply.html>.

# AN ONGOING PARTNERSHIP

In 2020, SCDA and Hemanext Inc., a privately held medical technology company, formed a new alliance designed to enhance the lives of people living with sickle cell disease through educational materials. SCDA thanks Hemanext for sponsoring the development of this brochure.



**SCDA's mission** is to advocate for people affected by sickle cell conditions and empower community-based organizations to maximize quality of life and raise public consciousness while advancing the search for a universal cure.

THIS BROCHURE AND THE ACCOMPANYING BOOKLET FOR CHILDREN ARE THE **FIRST IN A SERIES OF EDUCATIONAL BROCHURES** AND PROGRAMS, GRASSROOTS EVENTS AND PUBLIC-AWARENESS CAMPAIGNS THAT SERVE AS THE FOUNDATION FOR THE PARTNERSHIP.

IN THE SPIRIT OF COLLABORATION, WE WELCOME YOUR FEEDBACK ON THIS BROCHURE AND FUTURE MATERIALS THAT OUR PARTNERSHIP WILL PRODUCE TO SUPPORT OUR COMMUNITY. PLEASE SEND YOUR COMMENTS AND SUGGESTIONS TO [SCD@SICKLECELLDISEASE.ORG](mailto:SCD@SICKLECELLDISEASE.ORG). THANK YOU.

