

THE SICKLE CELL RAPPER

Fall 2015

UT KIDS Sickle Cell Center



Welcome Our Latest Member



Hello Sickle Cell Community!

My name is Alexis Boggess and I am the research project manager for hematology research studies at UTHSCSA. I've worked in clinical research for the past 8 years after graduating with my bachelors of science degree from Sam Houston State University in 2007 and recently completing my masters of science

degree in clinical research administration from George Washington University in May 2015.

I am Texas born and raised but have only lived in San Antonio for the last 4 years. In my spare time I like to stay active by hiking, kayaking and swimming. I also have an adorable 6 year old French Bulldog who requires lots of attention. Her name is Adalyn, Addy for short, and her favorite things are belly rubs and nap time.



I'm so happy to be working with the sickle cell community and can't wait to meet each of you as we open more research opportunities related to sickle cell.

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504 Program and Back to School Issues

Welcome back to school! In preparation for a safe and healthy school year, we wanted to briefly introduce the 504 program. The Texas Administrative Code states that sickle cell disease is a “health impairment” and therefore automatically qualifies students with sickle cell disease for certain accommodations, including a 504 Plan.

We believe that a child’s school experience is critical for growth and development, as well as promoting self-esteem during treatment and in the future. Therefore, we encourage you to reach out to your school staff to request a 504 meeting to evaluate the special needs for your child.

We encourage children to attend school on all days that are medically possible and to make school a priority. However, we recognize that certain accommodations must be made for repeated school absences. Below is a brief list of accommodations that can be helpful to include in your child’s plan:

- Access to the school nurse at all times.
- Ability to use the restroom as needed.
- Access to water throughout the day.
- Ability to take breaks from physical education as needed.
- Modified work or school schedule after prolonged hospitalizations.

We hope that attached information is helpful. If at any time you have questions or concerns, please do not hesitate to contact your treatment team social worker.

Megan Colletta, LCSW,
for more information ***(210.567.7477)***



Flow Cytometry Study

Dr. Frei-Jones is currently recruiting for the voluntary participation in a research study specific to the sickle cell community. This study uses a very sensitive test to look at red blood cells. Red blood cells carry oxygen throughout the body and people with sickle cell disease have red blood cells that change into a sickle shape. Sickled cells clog blood vessels and prevent oxygen from moving around the body. In order to help treat sickle cell disease, some patients need to receive blood transfusions.

The blood used in these transfusions is from blood donors. Doctors match the donor's blood to the blood of the person who needs the transfusion as much as they can, but no donor's blood is exactly like our own. Some patients who receive transfusions, over time, can develop antibodies to the donated blood. Normally, we think about antibodies helping us fight infections. The donated blood is not an infection, but it looks different than our own blood cells and our body reacts to this difference by making antibodies. These antibodies can make the transfusions not work well. In other words, the blood count or hemoglobin does not rise as it would in patients who do not have the antibodies. This research study uses a very sensitive test to look for antibodies that regular tests can sometimes miss. Our hope is to find a way to make transfusions safer even after many transfusions are given.

This study will use only leftover blood from tests drawn during a regular clinic visit or hospital stay. The leftover blood is sent to the American Red Cross for specialized testing. The results of this testing are given to Dr. Frei-Jones to look over. She will monitor the results over time and report any new findings to the study participant. No additional blood draws are needed to be part of this research study. Being part of the study is completely voluntary and you can request to leave the study at any point.

Please ask about the study at your next appointment, if you are interested. Dr. Frei-Jones is happy to answer any questions regarding voluntary participation in this study at your next clinic visit. If you would like to schedule a clinic visit to discuss your participation in this study please call Donna to schedule an appointment.

The Texas Interagency Task Force

The Texas Interagency of Children with Special Health Care Needs (CSHCN). The CSHCN also applies to adults over 21 with Cystic Fibrosis. The website is a great resource to share with your families, with content that includes articles, videos, and links to other websites. The website is available in English and Spanish and can be translated to other languages with a built-in Google Translator. The Diagnostic section is also a good resource for providers who may not be familiar with some medical conditions. It is pretty comprehensive, including diagnostic info, insurance/financial resources, family support resources, and assistance/advice for school plans. There is also a tab for special needs teens who are transitioning to the adult world, and a link to finding local groups and live support by county.



A graphic of a yellow bulletin board with a red pushpin on the left, a yellow pushpin at the top, and a blue pushpin on the right. A piece of paper with the word 'The' is pinned at the top, and a larger yellow banner with the words 'Bulletin Board' is pinned across the middle.

- ◇ Have a week's worth of any medication? Time to call your pharmacy for refill. Pain medication are not refilled after hours, holidays, or weekends. Please remember that some pain prescription's (hydrocodone/morphine) cannot be refilled by a phone call nor e-submitted via computer and we can no longer give refills on these medications.
- ◇ **New pain medication policy:** Morphine/Dilaudid—we will be implementing a new policy which will require patients who need these medications on a daily basis to be seen once a month and agree to a use contract. These are very powerful pain medications and new regulations by the State of Texas make it more challenging to prescribe these medications. We are trying to ensure that children taking these medications are carefully monitored and don't run out of the medicines they need.
- ◇ Hydroxyurea: If your child is on **hydroxyurea**, he or she needs to be seen every 3 months to make sure that it is the right dose and effective. Children grow very fast and we need to keep up! Hydroxyurea has been a life changer for many of our children with sickle cell disease but it too has many side effects that the team needs to be on top of to ensure that your child stays as healthy as possible.
- ◇ Did you know that we are starting children on hydroxyurea as young as 9 months old? We feel very strongly that the children that are starting hydroxyurea as an infant will grow up with less complications and organ damage due to the disease. However, it is never too late to start hydroxyurea! For more information google "Baby HUG study."



VOICE CRISIS ALERT APP

Very cool new tool for talking about Sickle Cell Pain Management — Check out the “VOICE Crisis Alert” App designed just for Sickle Cell Disease. Crisisvoice.com Ask us about it during your clinic visit.

Free App—create your own avatar!



VOICE Crisis Alert
a crisis tracking and
communication app

Download it from
APP STORE

Download it from
ANDROID MARKET

Track your pain

Your site(s) of pain and severity are recorded along with the date, time, and attempted interventions. No pen, no, paper... just tap.

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- ◇ ****New Number**** To change, cancel or make an appointment call **210-743-2300**.
- ◇ Please use doctor on call phone number **1-800-239-9769** for **TRUE** emergencies running out of medication is not considered an emergency.
- ◇ Back to school, please remember to go to the school nurse and complete a school medication form. Please give the school nurse our fax number **210-702-6014**.
- ◇ **Mario's Pharmacy is moving in October.** The building where Mario's Pharmacy is located has been sold. Mario is joining Stonegate Pharmacy on Broadway. New address is 2515 Broadway St, San Antonio, TX 78215. Phone number will still be **210-354-0101**. They will still be Making liquid hydroxyurea and offer delivery.
- ◇ Adults Feeling blue? There are times when "adults" need someone to talk to about life issues. Center for Health Care Services (Mental Health) takes Medicaid insurance. Intake phone number is **210-261-1250**. It is a "walk in" basis; first come first served. At registration you will need to have: proof of ID, proof of income and proof of residency.



Current News

September is Sickle Cell Awareness Month — Join us on Friday, September 18, 6-8 p.m. at the Witte Museum on 3801 Broadway St. Free Parking is available at the Brackenridge Park parking garage. RSVP by September 11, 2015 to Rebecca Solis at **210-743-2315**

THIS WILL REPLACE OUR ANNUAL CHRISTMAS PARTY.

JK Family Fit Day – Saturday, September 26 8AM-3PM—Sponsored by the Alan Ardoin Foundation, a local San Antonio organization that is raising awareness and funds for Sickle Cell Research. Check out their website — www.aaronardoinfoundation.org
Event is located at JKFitness 3603 Paesanos Pkwy, San Antonio, TX 78231.
Let Dr. Frei-Jones know if you are interested in participating.

Sickle Cell Camp: We want to take this opportunity to thank a generous donation from the Junior League of San Antonio which allowed us to be able to transport the campers to and from Camp Cell-A-Bration. We truly appreciate how many requests are made daily to them and are so thankful that our request was chosen! This gift was also made possible by the generosity of the University Health System Foundation.



Physician

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Nurse

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**Important Phone
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Social Worker

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Psychologist

Leanne Embry, Ph.D.

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Admin Assistant Sr.

Marisol Fernandez

Office 210-567-7480



Doctor On-Call

1-800-239-9769

Appointments

210-743-2300

Fax

210-702-6014

