

Keisha's Transfusions and Desferal™ Therapy

An Educational Coloring Book
for Children with Sickle Cell
Disease

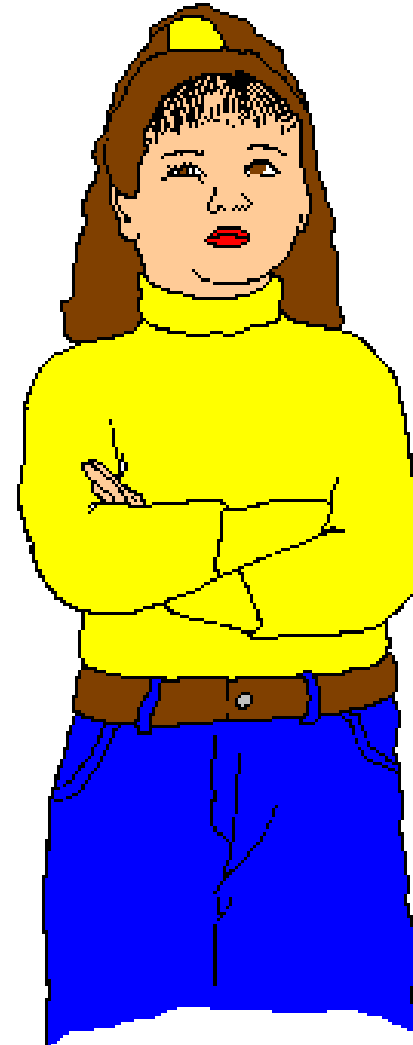
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Keisha's Transfusions and Desferal™ Therapy

- This publication was produced by the Georgia Comprehensive Sickle Cell Center, Atlanta, GA.
- Text by Beatrice E. Gee, M.D.
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- First edition, June 2000

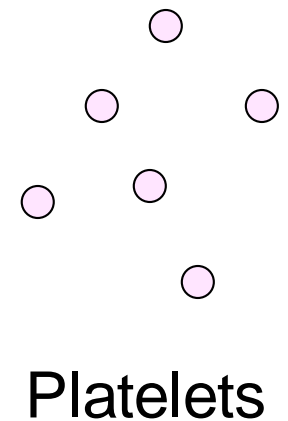
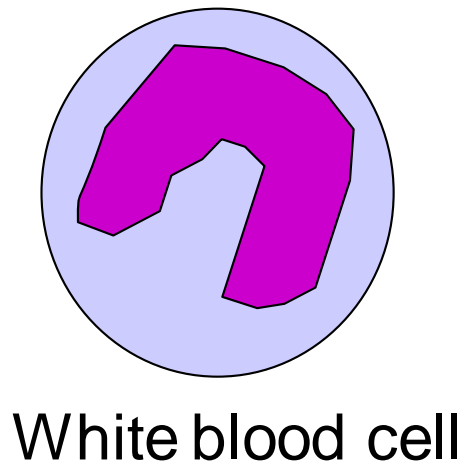
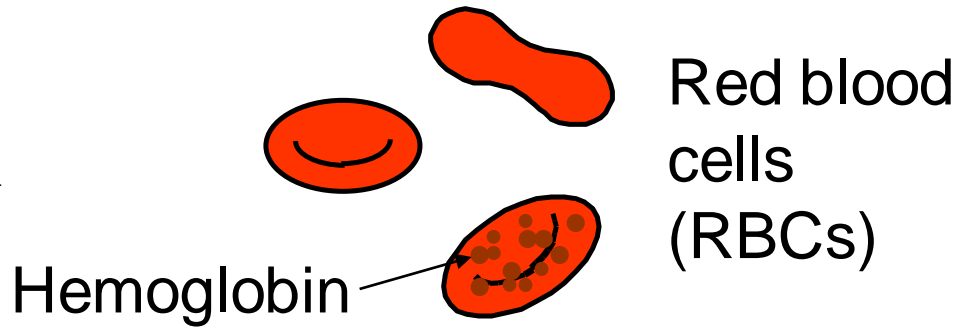
Keisha has sickle cell anemia

- Keisha is a lot like you or me.
- Most of the time, she feels great and does all the things other kids do.
- Sometimes, she might not feel well because of **sickle cell anemia**. This illness affects her red blood cells.



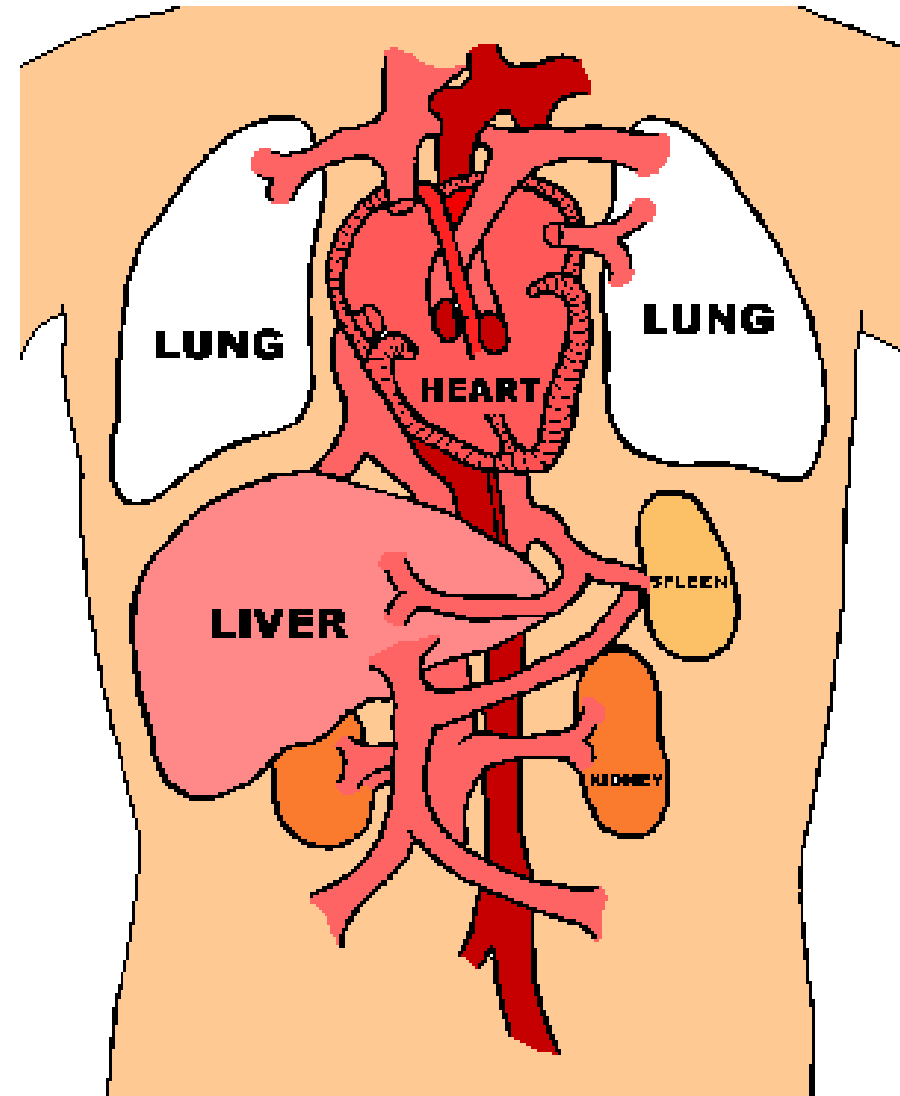
Red Blood Cells

- Blood contains **red blood cells**, white blood cells, and platelet cells.
- **Red blood cells** have **hemoglobin** in them.
- **Hemoglobin** helps each **red blood cell** carry **oxygen** throughout our body.



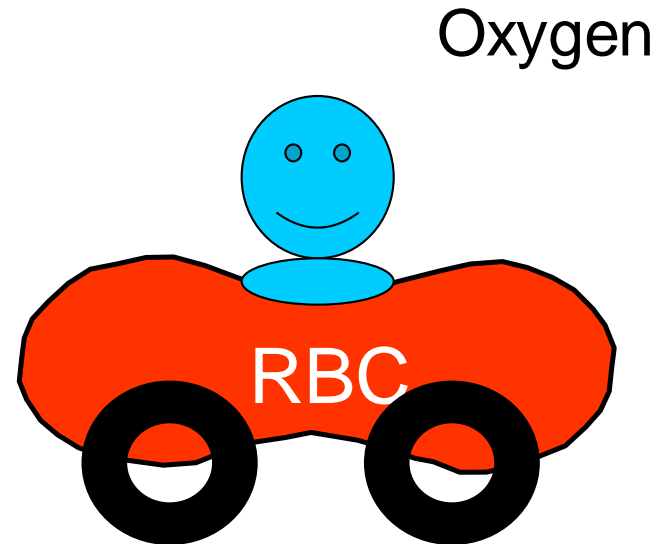
Blood and Blood vessels

- Our bodies need **oxygen** to stay healthy.
- **Blood** carries **oxygen** from place to place in our bodies, starting in the lung and going to all of the organs, like the heart and brain
- **Blood** circulates through our bodies in the **blood vessels**, which are like highways.



Red blood cells deliver oxygen

- **Red blood cells** are like cars on the highways inside your body.
- **Oxygen** is a passenger.
- Lots of red blood cells are necessary to take oxygen to every part of the body.



Sickle cell anemia

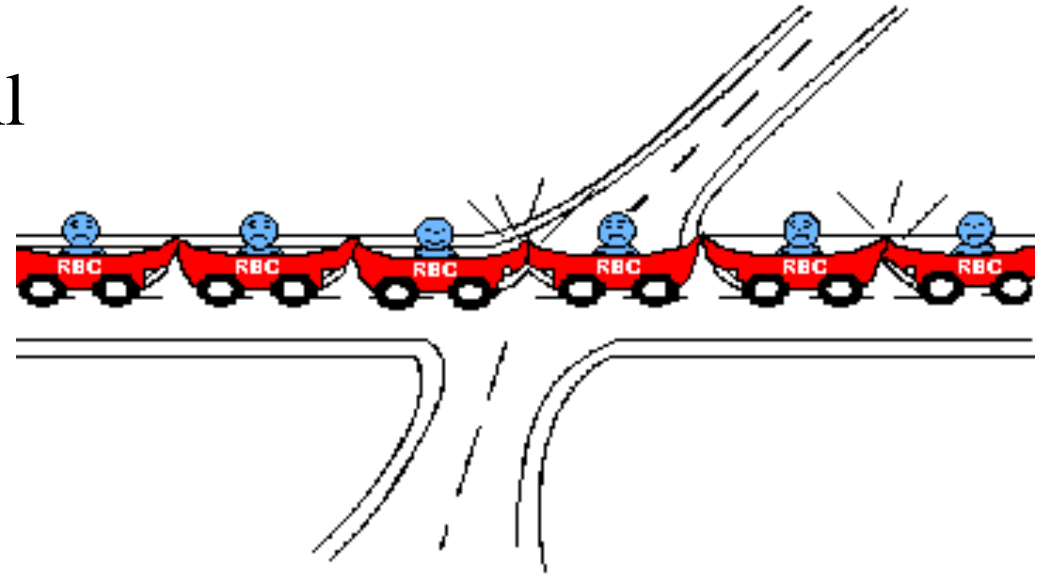
- In sickle cell anemia, red blood cells can become curved and pointy (like a sickle) and stiff.
- Sickle red blood cells don't always travel smoothly through the blood vessels, so traffic jams can occur on the highways.

Sickle: a tool with a curved blade, for cutting grass



Sickle cell traffic jams

- If sickle cell traffic jams occur, parts of the body will not get enough blood or oxygen.
- This can cause problems in the bones, spleen, lungs, kidneys, or brain.



Sickle cell pain

- This kind of problem doesn't happen all the time, but when it does, Keisha can feel pretty bad.
- Sometimes, her arms and legs can hurt a lot. This is called a pain episode or crisis.
- Pain may develop anywhere in the body.



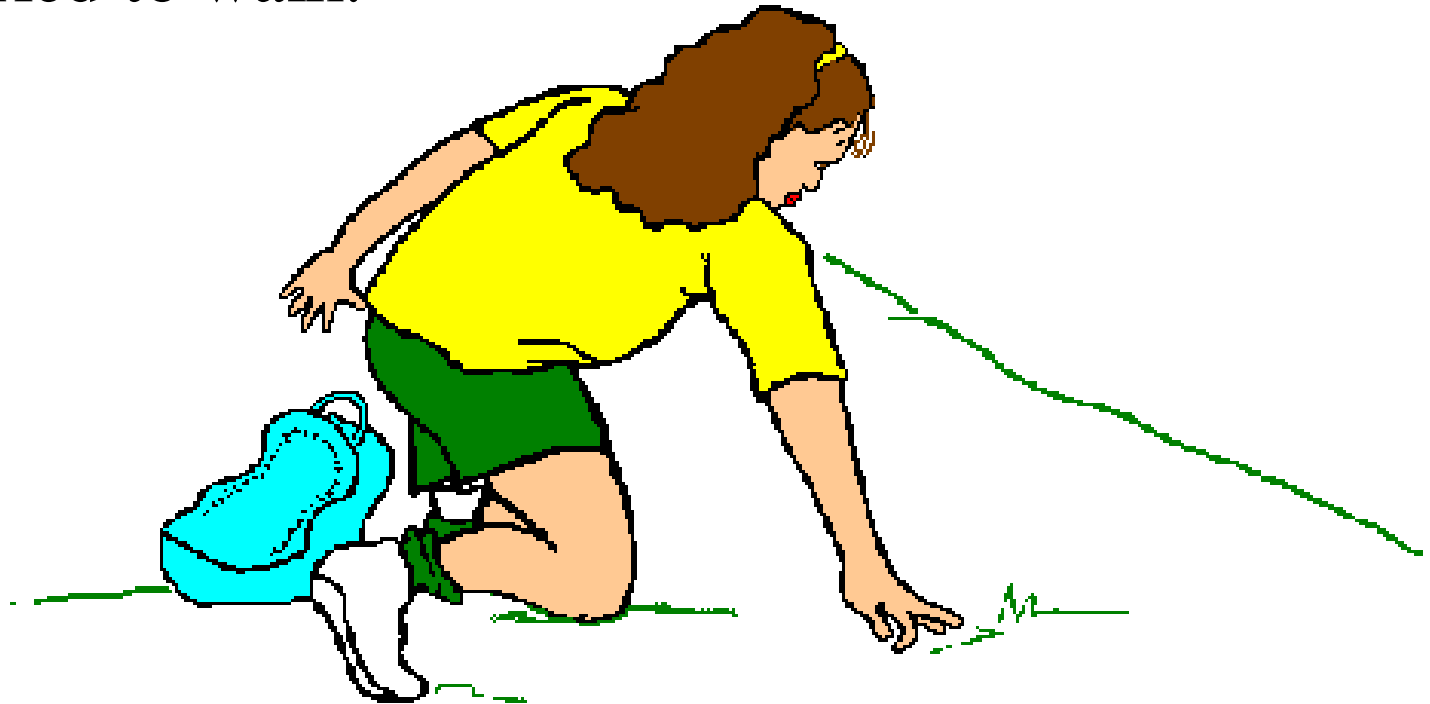
Pain treatment

- When Keisha has pain, she rests, drinks lots of fluids, and takes medicines like Tylenol, ibuprofen, or codeine. If the pain is really bad, she goes to the hospital.
- Sometimes, the pain goes away quickly. Other times, it lasts for many days.



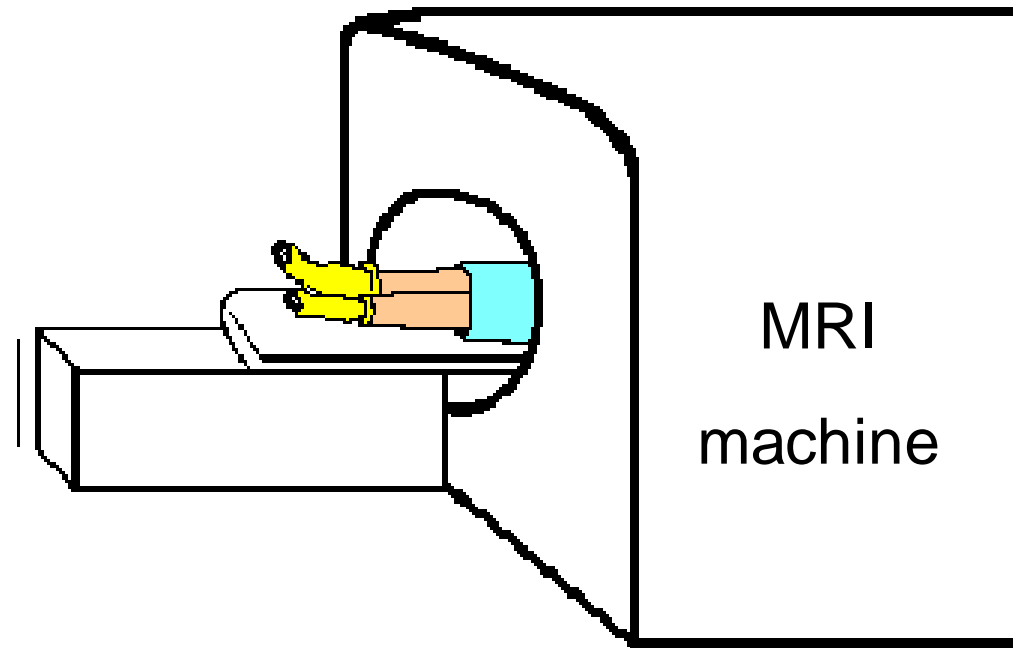
Keisha feels weak

- One day, Keisha felt different. She couldn't move her right hand very well and her right leg wasn't very strong when she tried to walk.



What happened to Keisha?

- Keisha went straight to her Sickle Cell Clinic. She was examined and some tests were performed.
- A special test called an **MRI** showed that a place in Keisha's brain had a problem because not enough blood could get to it.
- This is called a **stroke**.



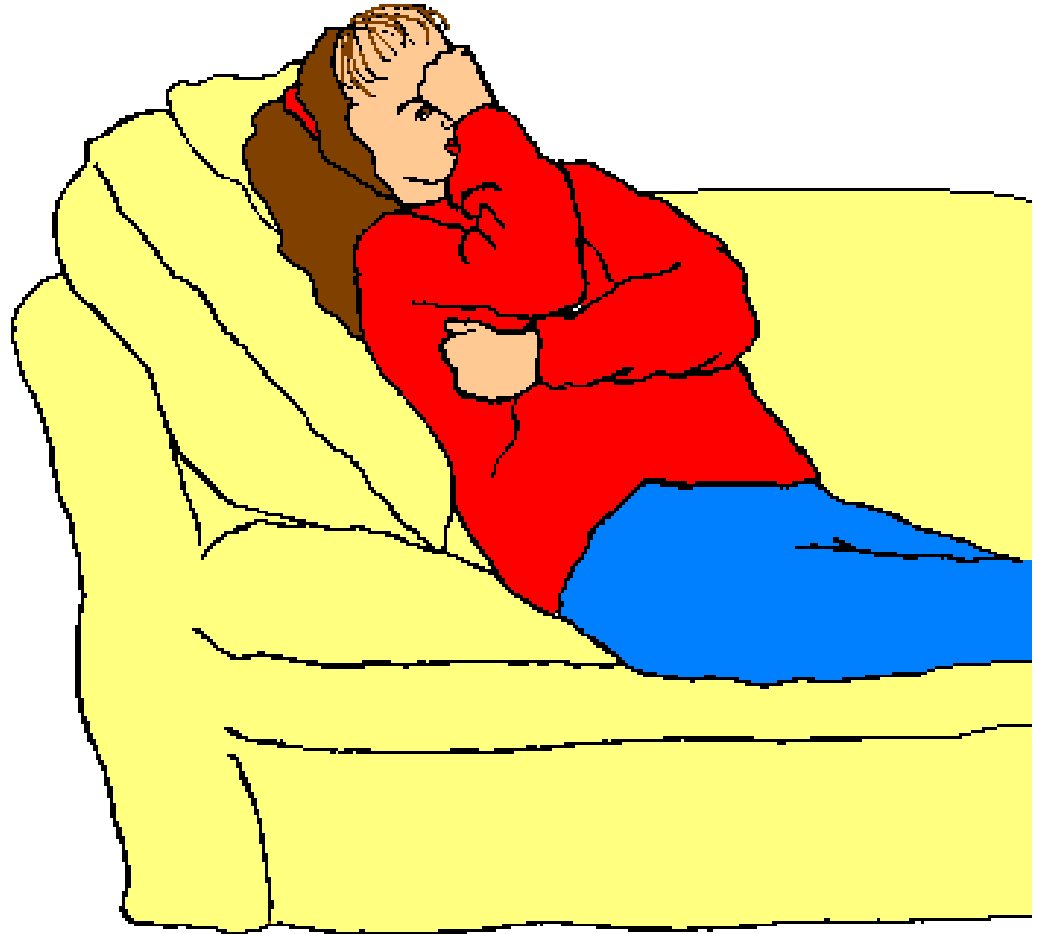
What is a stroke?

- A stroke happens if blood vessels in a part of the brain get completely blocked. No blood or oxygen can get to that part of the brain.
- The brain gets hurt when there is not enough oxygen.



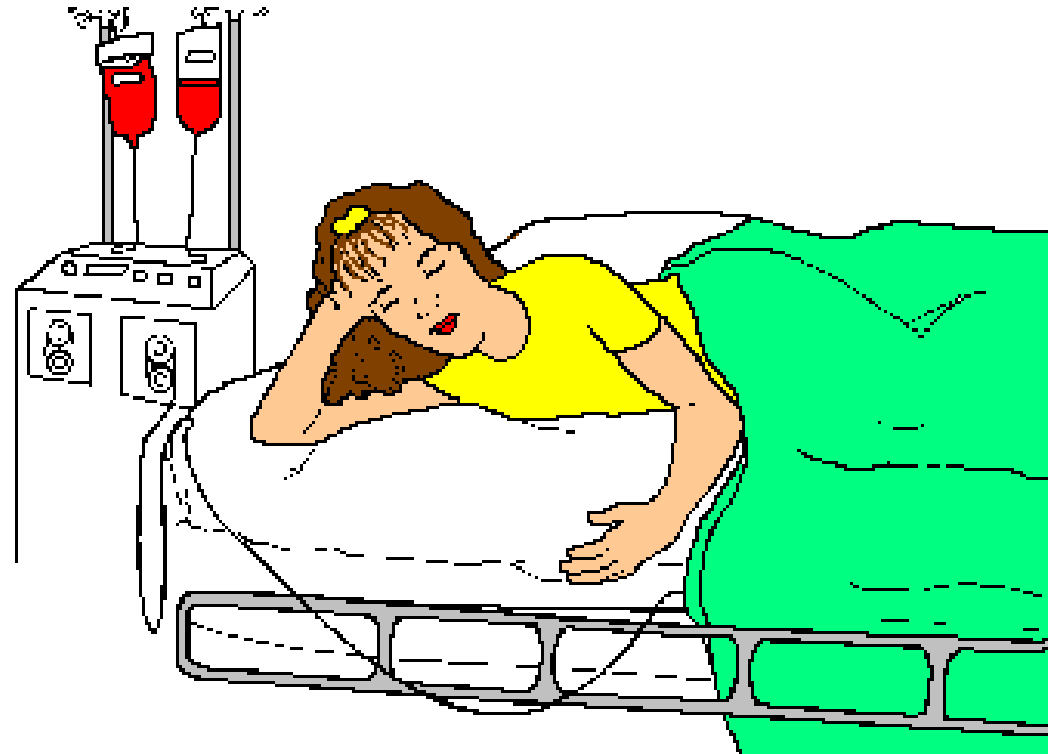
What is a stroke?

- Depending on which part of the brain is injured, people may experience weakness, fainting, seizures, problems talking or seeing, or trouble with memory or learning.



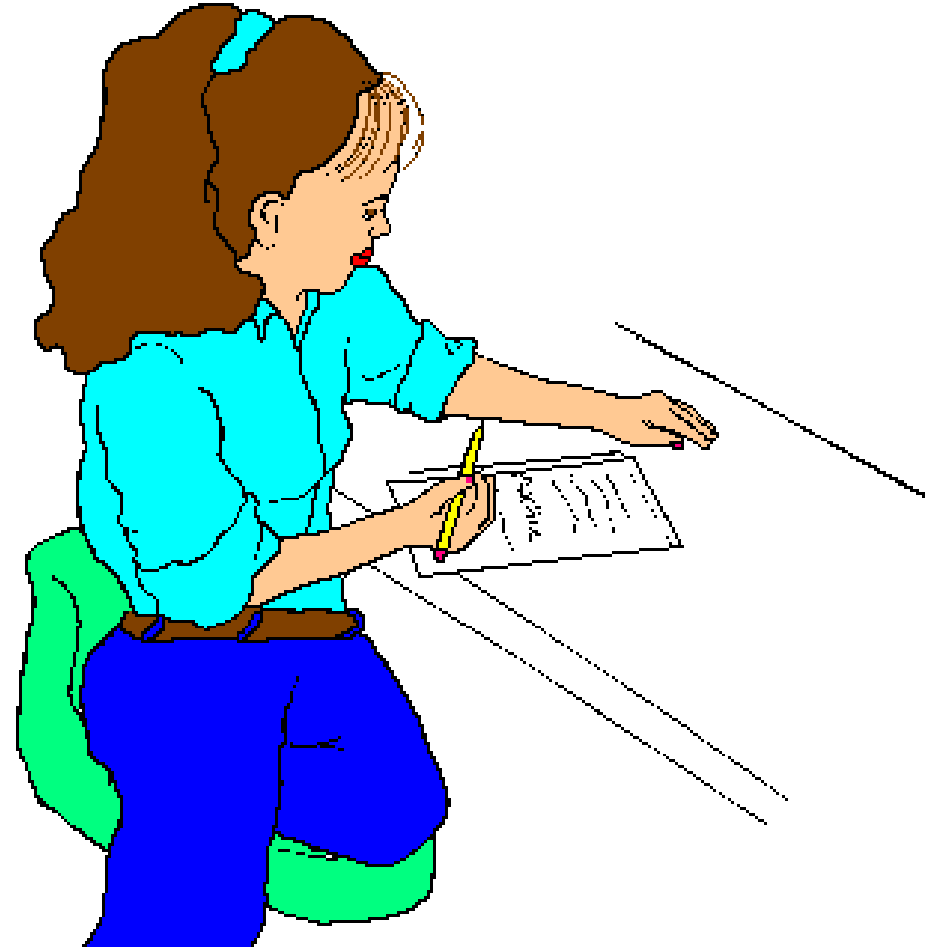
Keisha gets an exchange transfusion

- To help Keisha after the stroke, she got a special kind of blood transfusion, called an **exchange transfusion**.
- Most of her own sickle cells were removed and replaced by other red blood cells
- Healthier red blood cells try to go to the part of her brain where the stroke occurred.



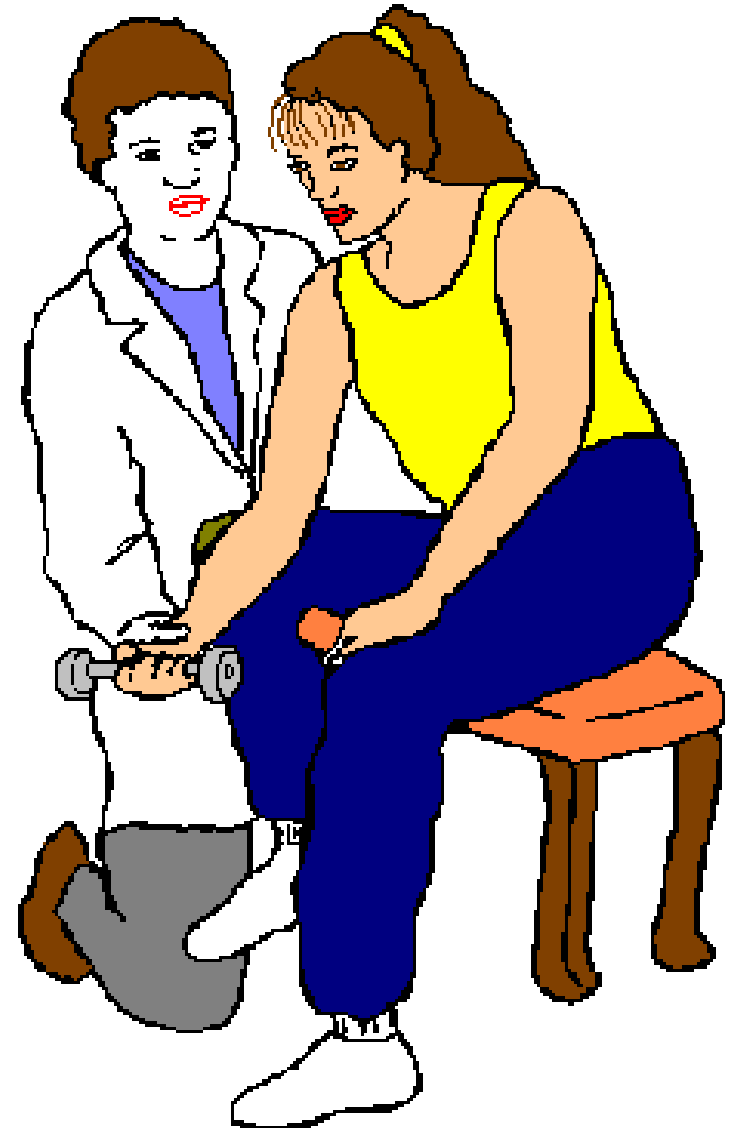
Keisha feels better

- After a few weeks, Keisha feels like her old self again. Her strength is almost back to normal but it's a little hard for her to write.
- After a stroke, people may continue to have weakness or trouble remembering or learning. The brain has a harder time healing than other parts of the body.



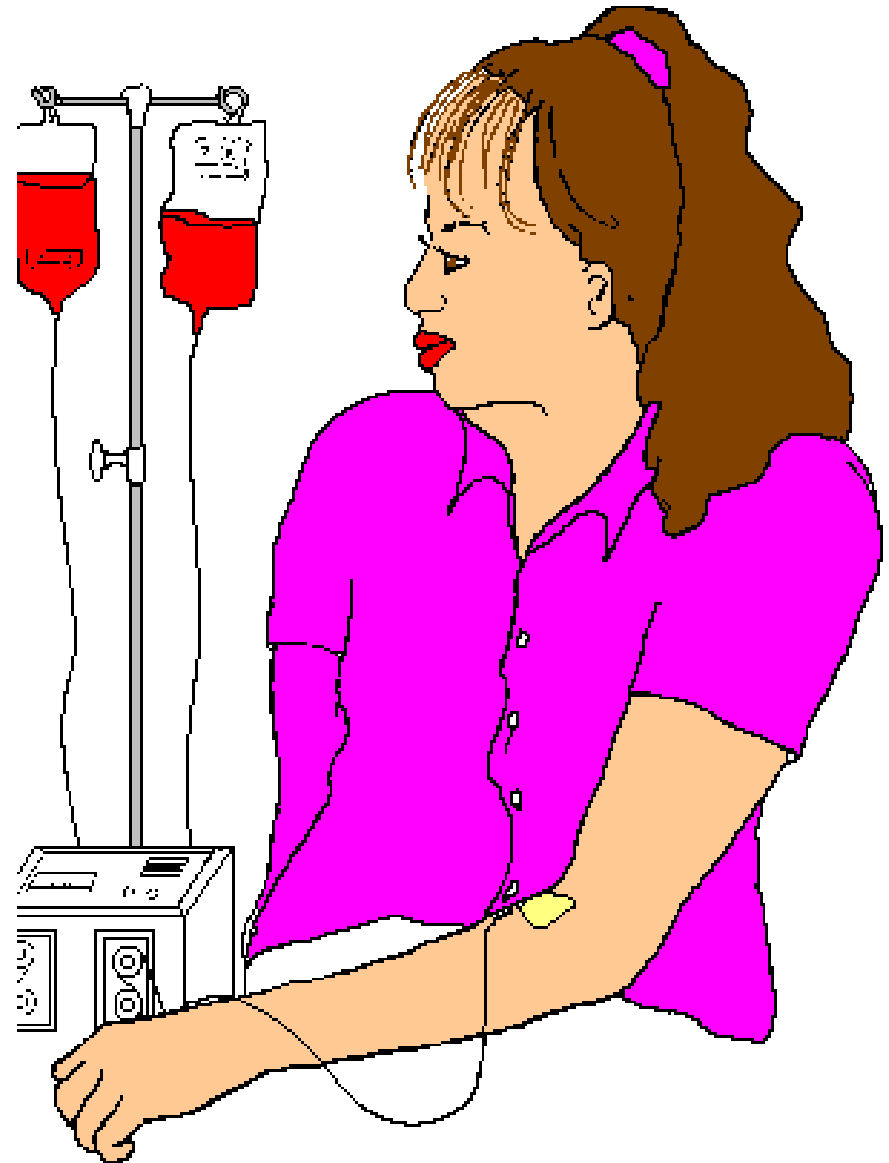
Physical and Occupational Therapy

- Keisha sees a therapist every week to help her hand work better.
- Special exercises with a therapist can help people get their strength and coordination back after a stroke.



Keisha gets monthly transfusions

- To prevent another stroke, Keisha's doctors recommended that she receive red blood cell transfusions every month.
- These transfusions give her less blood than the exchange transfusion and do not require a big pump. She does need to get an IV and stay for half a day in the Transfusion Clinic.



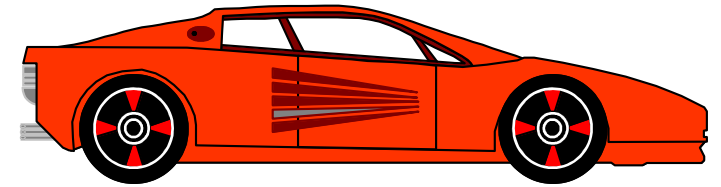
Transfusions aren't so bad

- It can be a hassle to come every month for transfusions, but Keisha goes to school and does normal things all the rest of the time and she feels pretty good.
- Transfusions help her not have so many pain episodes.



A problem with transfusions

- Even though transfusions are helpful, they can also cause a big problem.
- After receiving many transfusions over two years, Keisha's body will get more **iron** than it can use.
- Extra iron is what's leftover after the red cell cars get old and worn out.



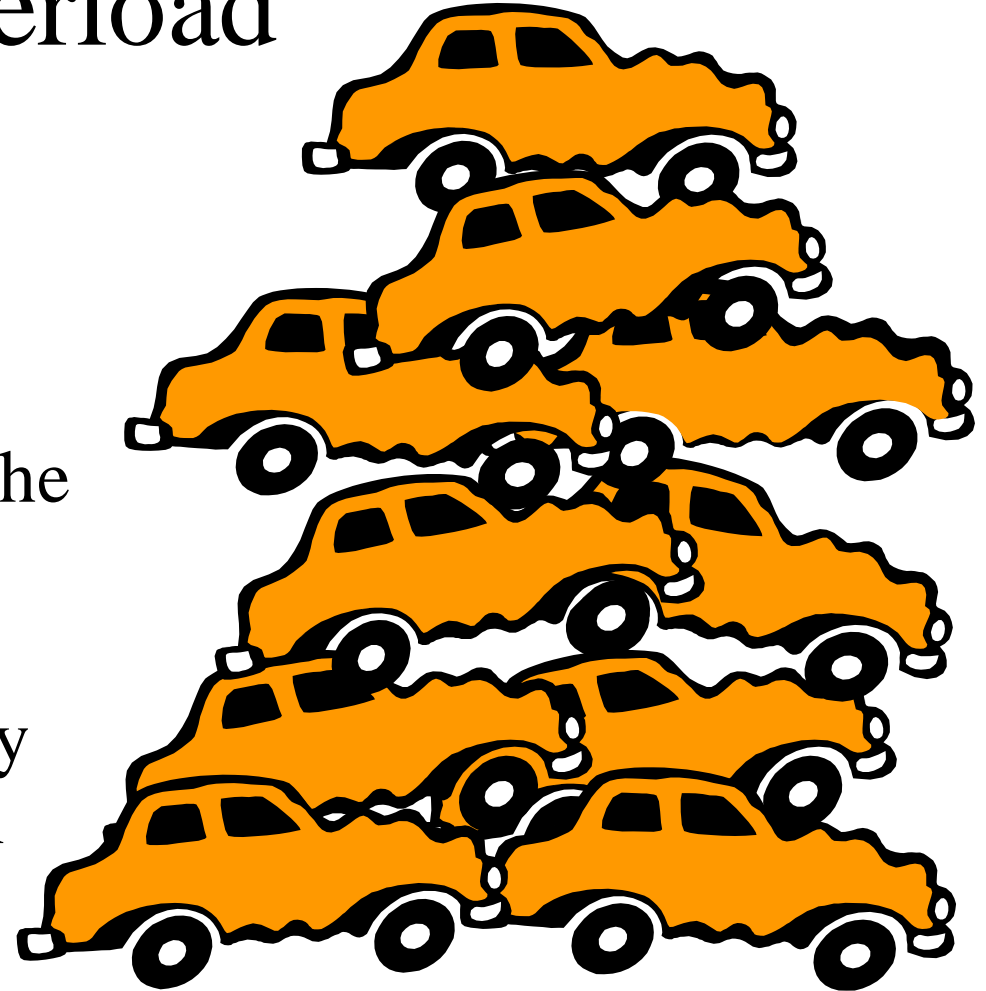
New red cells



Old red cells:
leftover Iron

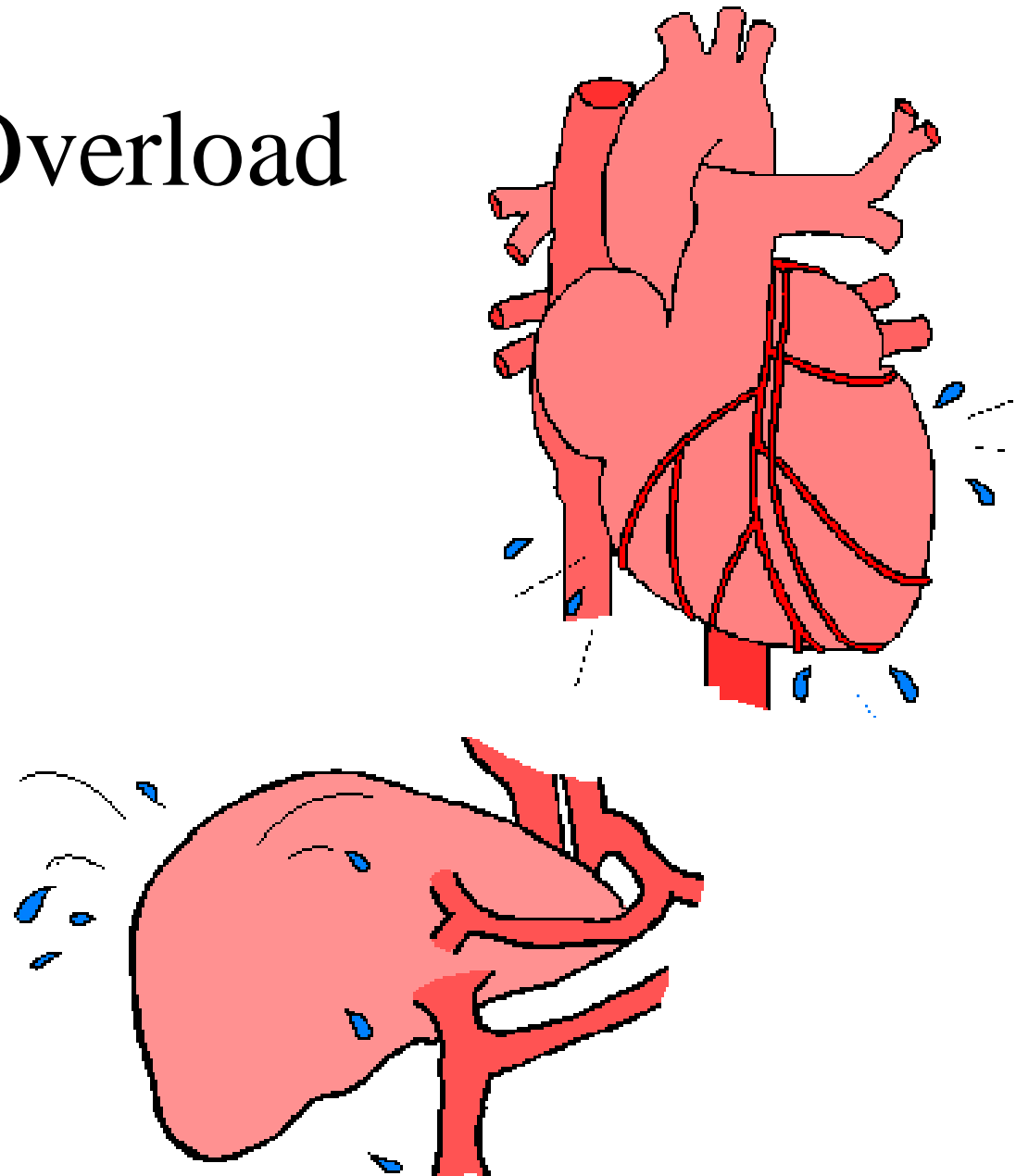
Iron Overload

- Everybody needs iron to stay healthy but too much causes problems.
- The rusty old cars pile up in the heart, liver, and hormone-producing organs.
- The body does not have a way to get rid of iron except when there is bleeding.



Iron Overload

- Keisha doesn't feel any different from having too much iron.
- Even though she feels fine now, if she doesn't get medicine to help remove iron, her heart will become weak and her liver will not work well.

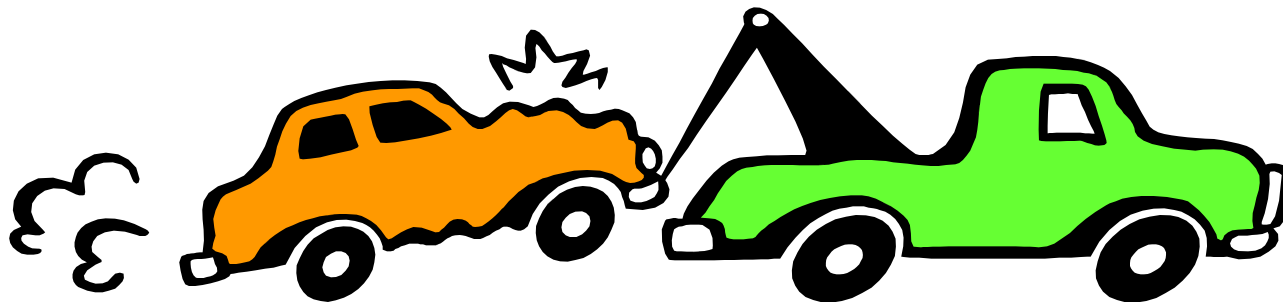


Iron Chelation Therapy

- **Deferoxamine** (or DESFERAL) is a medicine which removes iron from the body. This is called **Iron Chelation Therapy**.

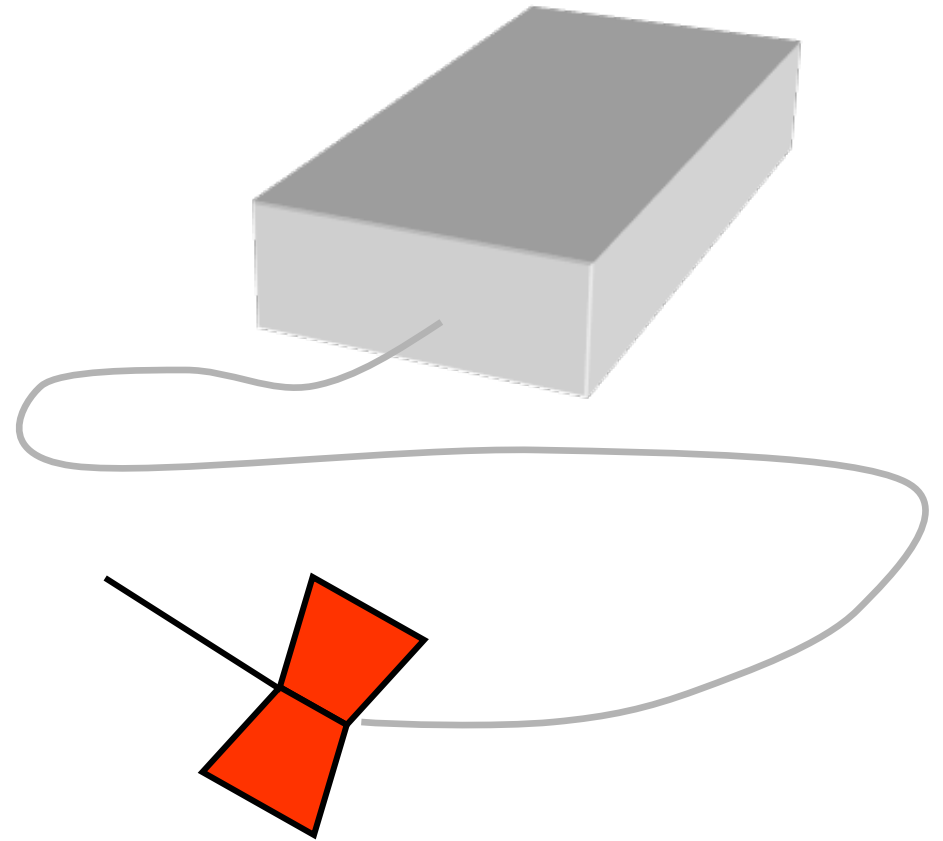
Extra iron

Desferal



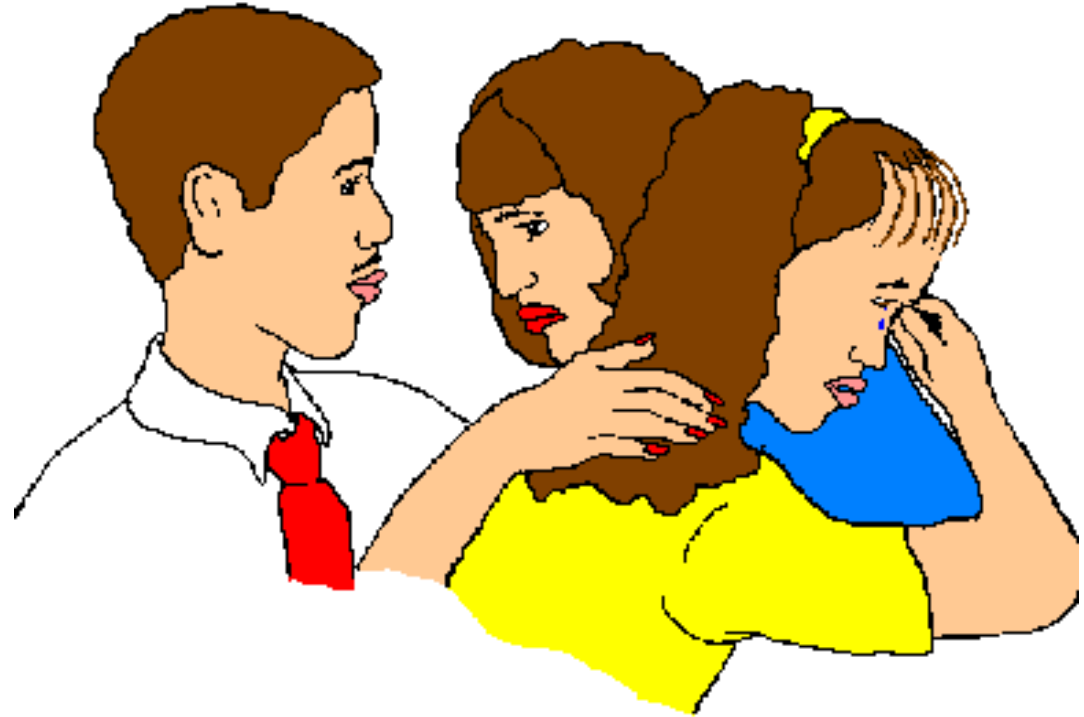
Desferal

- Desferal doesn't come as a pill and it doesn't last very long in the body.
- Desferal needs to be given using a small pump
 - a needle is placed under the skin
 - 10-12 hours each night
 - at least 5 nights each week



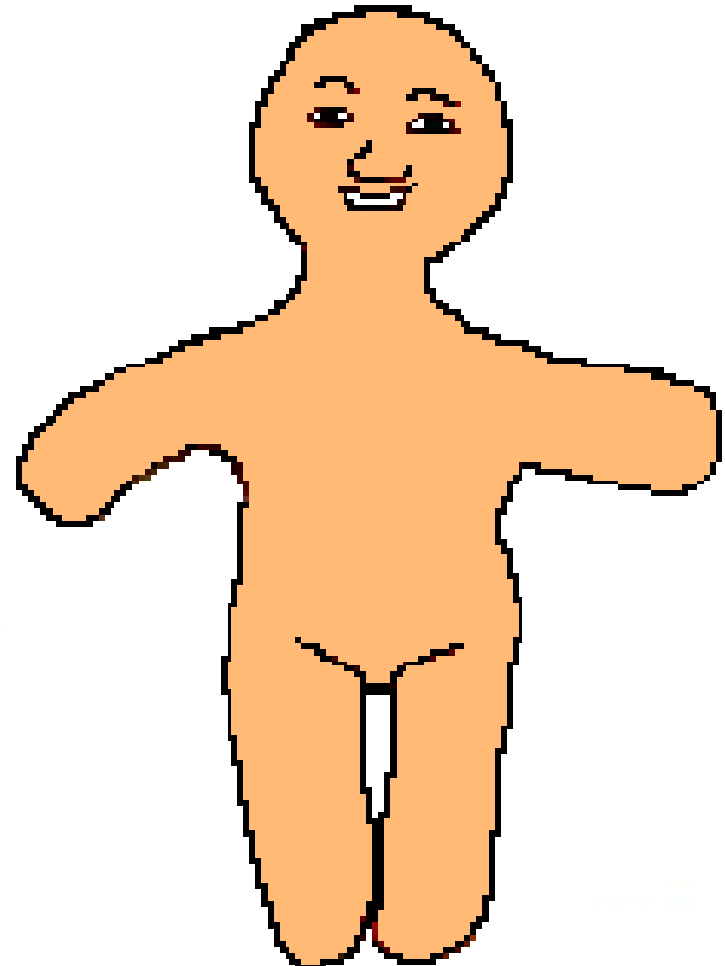
Keisha is scared about Desferal

- At first, Keisha is really scared about getting her Desferal infusions.
- She is used to one IV each month, but needing a needle stick every week night makes her really worried.
- Her Mom and Dad are nervous, too.



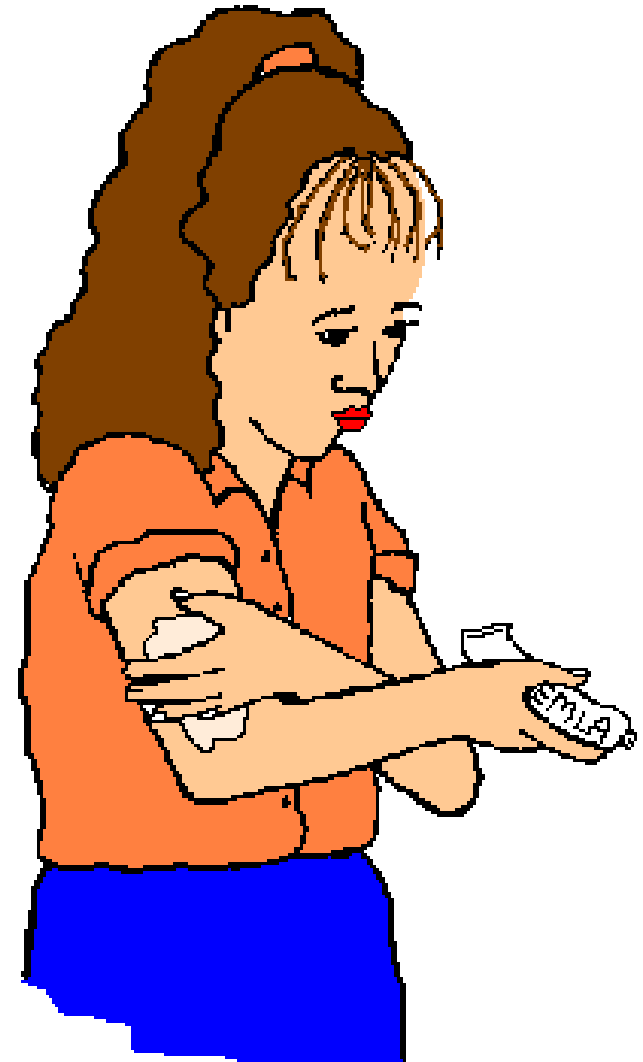
Keisha practices giving an infusion

- Before her first Desferal treatment, Keisha and her parents practice using the equipment with a doll named Ms. Desferal.
- Keisha practices giving Ms. Desferal a lot of infusions.
- She is a little less scared.



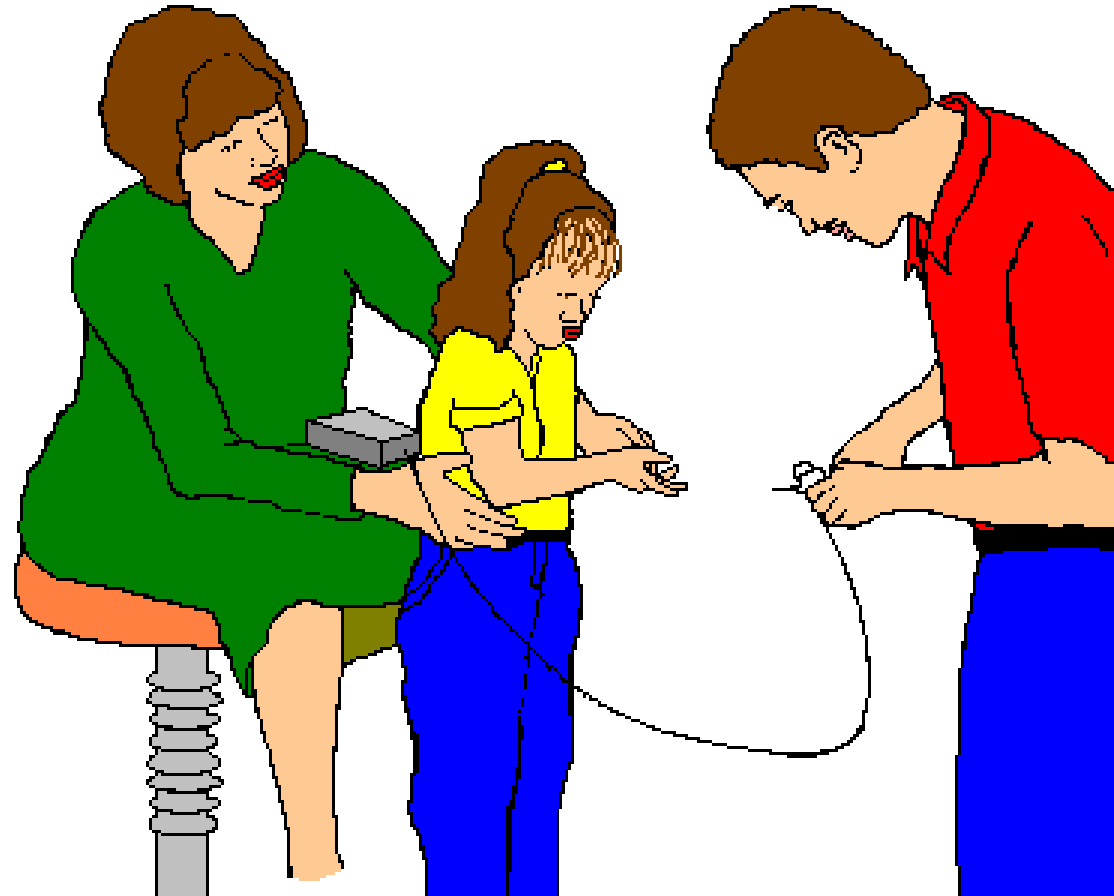
EMLA helps make the skin numb

- To help make the skin numb (tingly) and not feel the needle so much, Keisha puts EMLA cream on her skin 1 hour before it's time to start her infusion.



Keisha uses her Desferal

- Keisha's Mom and Dad learn how to give her Desferal infusions.
- Her skin gets a little sore sometimes, but it's not as bad as she thought it would be.



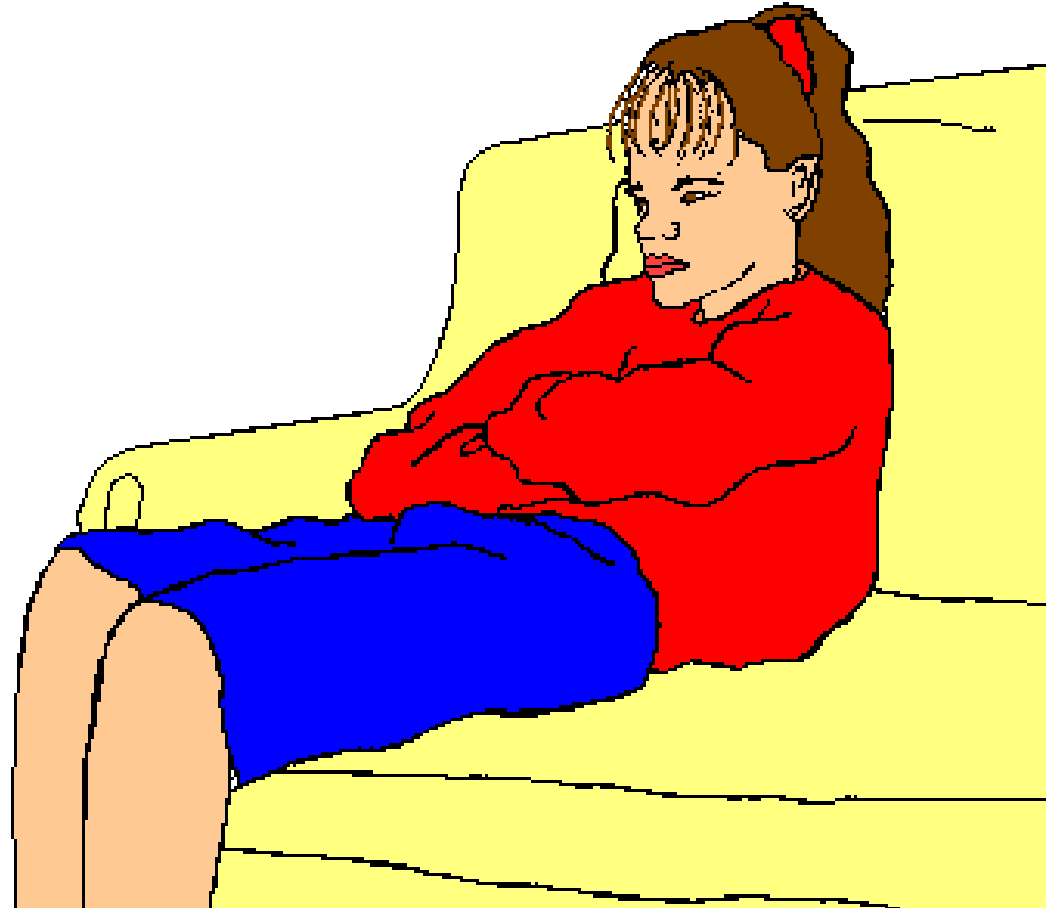
Keeping track of Desferal

- Keisha has a calendar to keep track of the days she uses Desferal.
- Sometimes, she doesn't feel like using Desferal. If she skips a day, she knows she has to make it up on the weekend.
- She tries really hard not to miss more than 2 days a week.

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				

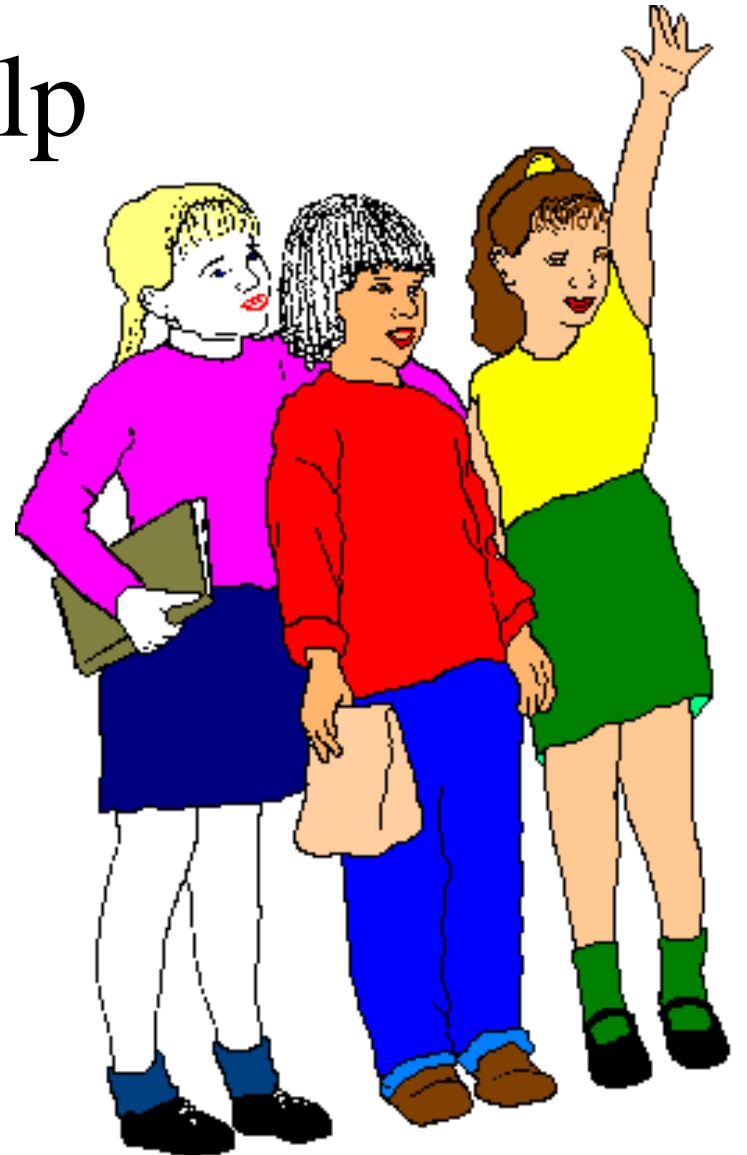
Keisha feels sad sometimes

- Some days, Keisha feels pretty sad about all of the things she has to do.
- It's not fair that she has to be different from other kids.



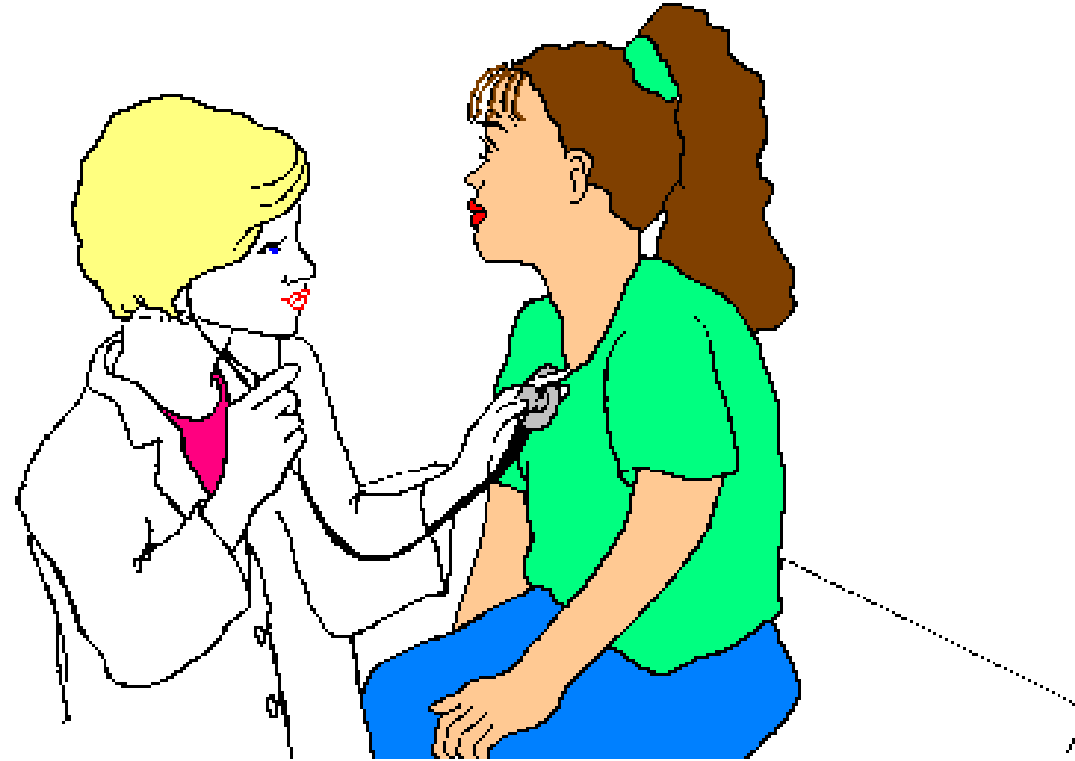
Friends help

- When Keisha is feeling sad about her medical treatments, it helps to talk to other kids who also get transfusions and use Desferal.
- It's important for her to remember that these treatments are helping her stay strong and healthy.



Clinic visits

- Keisha goes to the Sickle Cell Clinic every 3 months to get a check-up.
- Her doctors and nurses make sure that everything is going well.
- They tell her what a great job she is doing with her treatments and help out if there are problems.



Keisha is a STAR!!!

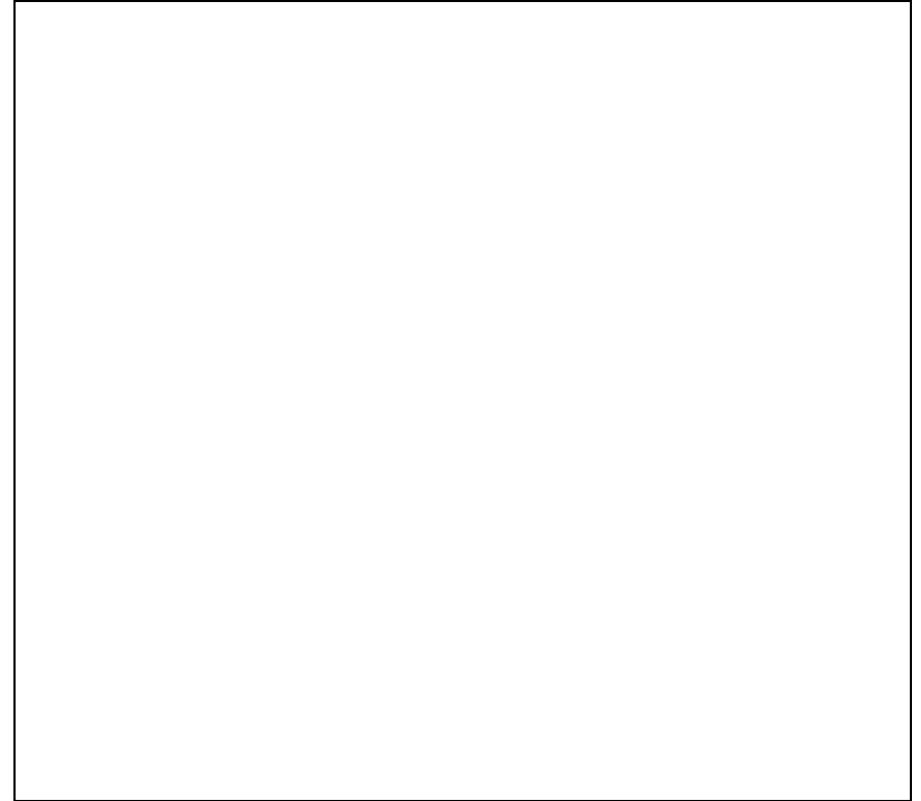
- Even though it's really hard work, Keisha tries really hard and takes her Desferal at least 5 days each week.
- Keisha is doing great with Desferal and she is keeping herself healthy.



You are a STAR, too!

- My name is

- I should use Desferal
_____ nights a week
- Using Desferal regularly is important for keeping you healthy and strong. Keep up the good work!



(Draw a picture of yourself here)

Many people are here to help

- Your family, friends and health care staff are all here to help you do the best you can and stay healthy.



For more information

- For more information about sickle cell anemia, stroke, transfusions, or Desferal, you can contact
 - your doctor
 - nearest sickle cell or hematology clinic
 - The Sickle Cell Disease Association of America
 - National Institutes of Health
- You can use a computer to check the Internet:
 - The Georgia Comprehensive Sickle Cell Center
<http://www.emory.edu/PEDS/SICKLE>
 - National Institutes of Health
<http://www.nih.gov>
- Call us!
 - Georgia Comprehensive Sickle Cell Center: 404-616-3572