

## ● Medication Schedule:

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**Try using one of these apps to help you remember to take your medicine:**

- (1) MyMedSchedule Mobile
- (2) Mango Health Medication Manager
- (3) MedCoach Medication Reminder
- (4) MediSafe Meds & Pill Reminder

## ● Notes

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## ✓ Checklist:

- ☐ Get your child's prescription filled and look into auto-refill options since they will have to take it every day.
- ☐ Schedule a visit to have your child's labs drawn.
- ☐ Plan where and how your child will store and remember to take Hydroxyurea.
- ☐ Schedule a follow up visit with your child's doctor.
- ☐ Note any side-effects (e.g. nail bed darkening, stomach upset) or problem (e.g. trouble getting medication) so you can discuss them with your child's doctor by phone or at your child's next appointment.

## ● Goals Before Next Visit

- 1 

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- 2 

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- 3 

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## ● Next Appointment Time

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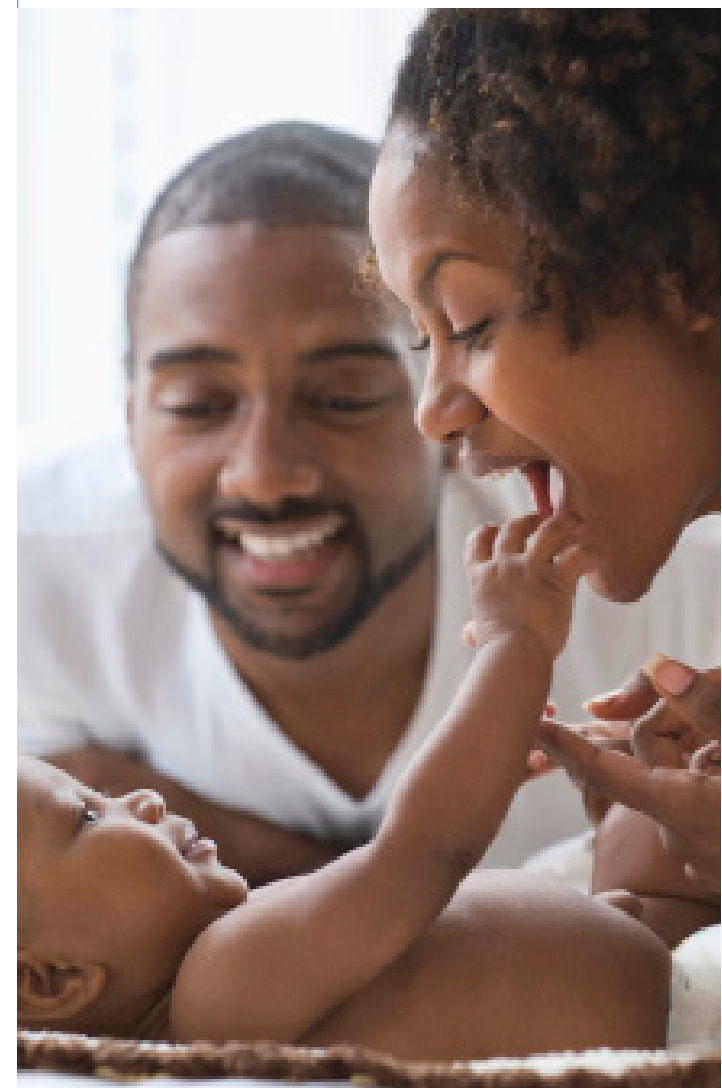
## ● Tips

- Being honest will keep your child safe. Talk with your doctor about any problems or side effects your child experiences.
- There are many tools to help your child be successful including medication reminder apps, calendars to track appointments and refills, and pill boxes.
- If your child's stomach gets upset, try taking it with food.

## ● Other Helpful Sources

[www.nhlbi.nih.gov/sites/www.nhlbi.nih.gov/files/SCD Infographic on Hydroxyurea.pdf](http://www.nhlbi.nih.gov/sites/www.nhlbi.nih.gov/files/SCD%20Infographic%20on%20Hydroxyurea.pdf)

<sup>2</sup> [www.stjude.org/content/dam/en\\_US/shared/www/patient-support/hematology-literature/hydroxyurea-treatment-for-sickle-cell-disease.pdf](http://www.stjude.org/content/dam/en_US/shared/www/patient-support/hematology-literature/hydroxyurea-treatment-for-sickle-cell-disease.pdf)



# HELP SCD

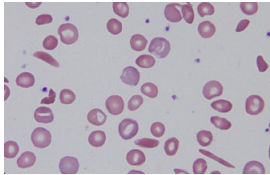
Helping you understand sickle cell disease & hydroxyurea treatment

## What is hydroxyurea?

Hydroxyurea is an oral medicine that can reduce many SCD related problems (i.e. pain, organ damage, need for blood transfusions, hospitalizations).

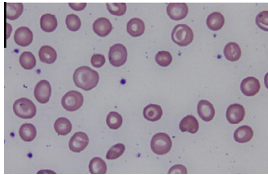
## How does hydroxyurea work?

Hydroxyurea works by increasing hemoglobin F<sup>1</sup> and lowering the amount of sickle hemoglobin.



**Before  
Hydroxyurea**

More sickled RBC's;  
Less normal RBC's



**After  
Hydroxyurea**

Less sickled RBC's;  
More normal RBC's

## How often do you need to take it?

Your child needs to take it every day for it to work. Your dose or how much you take may change based on your lab results. Hydroxyurea takes about 6 months to build up in the body.

<sup>1</sup> HbF stands for fetal hemoglobin. It helps newborn babies keep from having health issues during the first 6 months. In those with Sickle Cell, if they have an increased amount of HbF, red blood cells are less likely to change into the sickle or banana shape.<sup>2</sup>

<sup>2</sup> [www.stjude.org/content/dam/en\\_US/shared/patient-support/hematology-literature/hydroxyurea-treatment-for-sickle-cell-disease.pdf](http://www.stjude.org/content/dam/en_US/shared/patient-support/hematology-literature/hydroxyurea-treatment-for-sickle-cell-disease.pdf)



## Frequently Asked Questions

### Is this new, untested treatment?

Hydroxyurea has been used for SCD for over thirty years. There have been several research studies that have shown that Hydroxyurea is both safe and helpful for adults and very young children with SCD.

### Can it damage my child's organs?

No - in fact Hydroxyurea prevents organ damage usually caused by sickle cell.

### Will it put my child at risk of cancer?

While Hydroxyurea was first used as a treatment for cancer, today it is given at a much lower dose to children with sickle cell disease and does not cause the usual side effects seen with cancer treatment (hair loss, vomiting, weakness, or loss of appetite).

### Is it covered by my health insurance?

Yes, but pre-authorization may be needed. Your doctor can help with this.

## Continued...

### Will my child's hair fall out?

While Hydroxyurea is an extremely strong medication, hair loss/thinning is rare, and does not occur in most patients.

### Does it come in liquid form?

Yes, but only some pharmacies carry it

### What if we miss a dose?

Taking the medication every day is important.

- Do not take an extra dose.

Talk with your doctor about what to do.

*"My daughter had three hospitalizations over a four month period. After the last one, she was put on Hydroxyurea. Not only did she have fewer pain crisis episodes, they were less intense, lasted fewer days, and she stayed out of the hospital for three years!"*



## Remembering to Take Your Medication Can be Challenging.

Try Using One of These Apps:

MyMedSchedule  
Mobile



itunes



google play

Mango Health  
Medication  
Manager



itunes



google play

MedCoach  
Medication  
Reminder



itunes



google play

MediSafe Meds  
& Pill Reminder



itunes



google play

### ✓ Checklist:



Get your prescription filled and look into auto-refill options since you will have to take it every day.



Schedule a visit to have your labs drawn.



Plan where and how you will store and remember to take Hydroxyurea.



Schedule a follow up visit with your doctor.



Note any side-effects (e.g. nail bed darkening, stomach upset) or problem (e.g. trouble getting medication) so you can discuss them with your doctor by phone or at your next appointment.

### ● Goal Before Next Visit (e.g. pill case, refill)

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### ● Medication Schedule:

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### ● Next Appointment Time

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#### What if I miss a dose?

Taking Hydroxyurea every day is key. If a dose is missed it is not recommended that you take another dose. Contact your doctor's office.

### ● Tips

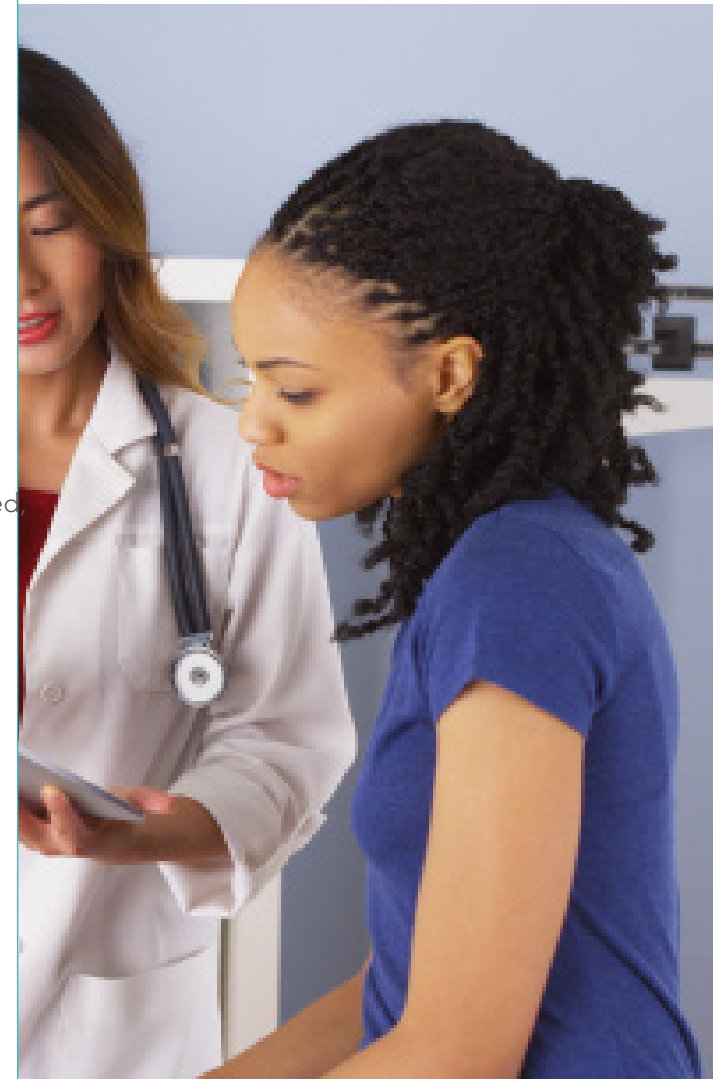
- 1 Being honest will keep you safe. Talk with your doctor about any problems or side effects.
- 2 There are many tools to help you be successful including medication reminder apps, calendars to track appointments and refills, and pill boxes.
- 3 If your stomach gets upset, try taking it with food.

### ● Other Helpful Sources

[www.nhlbi.nih.gov/sites/www.nhlbi.nih.gov/files/SCD\\_Infographic\\_on\\_Hydroxyurea.pdf](http://www.nhlbi.nih.gov/sites/www.nhlbi.nih.gov/files/SCD_Infographic_on_Hydroxyurea.pdf)

<sup>2</sup> [www.stjude.org/content/dam/en\\_US/shared/www/patient-support/hematology-literature/hydroxyurea-treatment-for-sickle-cell-disease.pdf](http://www.stjude.org/content/dam/en_US/shared/www/patient-support/hematology-literature/hydroxyurea-treatment-for-sickle-cell-disease.pdf)

## Recurring Visit



# HELP SCD

Helping you understand sickle cell disease & hydroxyurea treatment



## Now that you have decided to take Hydroxyurea:

Remember you need to take it every day for it to work. Your dose or how much you take may change based on your lab results. Hydroxyurea takes about 6 months to build up in the body.



## Common Questions Asked by SCD Patients Taking Hydroxyurea:

### Is it safe to get pregnant?

More information is needed to understand the effect of Hydroxyurea on the developing fetus. Because we are not sure, we recommend that people taking Hydroxyurea use precautions to avoid pregnancy (both males and females) until we have more information. If someone on Hydroxyurea would like to start a family, they should talk to their doctor about stopping Hydroxyurea.

## Continued...

### What are some common side-effects?

Upset stomach or slight nausea may occur, however, taking medicine with food usually makes this better. Darkening of nail beds is harmless and may occur in some patients.

### What if I experience a fever or a cold?

Hydroxyurea is a daily medication. You should typically take it even if you have a fever or cold, but talk with your doctor.

### Can it damage my organs?

No – Some studies suggest Hydroxyurea prevents organ damage usually caused by sickle cell.

### Does it come in liquid form?

Yes, but only some pharmacies carry it.

### Does it put me at risk of cancer?


While Hydroxyurea was first used as a treatment for cancer, today it is given at a much lower dose to individuals with sickle cell disease. It does not cause the usual side effects seen with cancer treatment (vomiting, weakness, or loss of appetite).

### Should I take it if I have pain?


Hydroxyurea is a daily medication used to help prevent sickle cell complications. It has to build up in your system to work. Be sure to contact your doctor about your symptoms.

### What about hair loss?

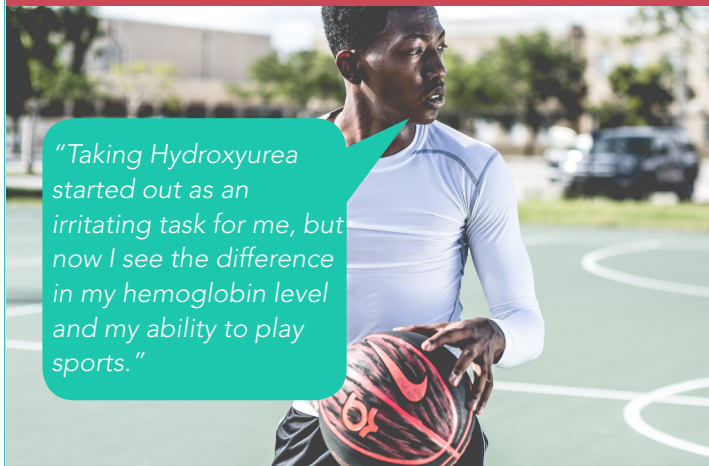
Hair loss is not a common side effect. Although rare, hair thinning can occur in some patients.



"Before HU I was hospitalized on average 2-3 times a year. Since HU I have not been hospitalized in over 3 years."



"My daughter had three hospitalizations over a four month period. After the last one, she was put on Hydroxyurea. Now she has stayed out of the hospital for three years!"



"Taking Hydroxyurea started out as an irritating task for me, but now I see the difference in my hemoglobin level and my ability to play sports."