

## ● 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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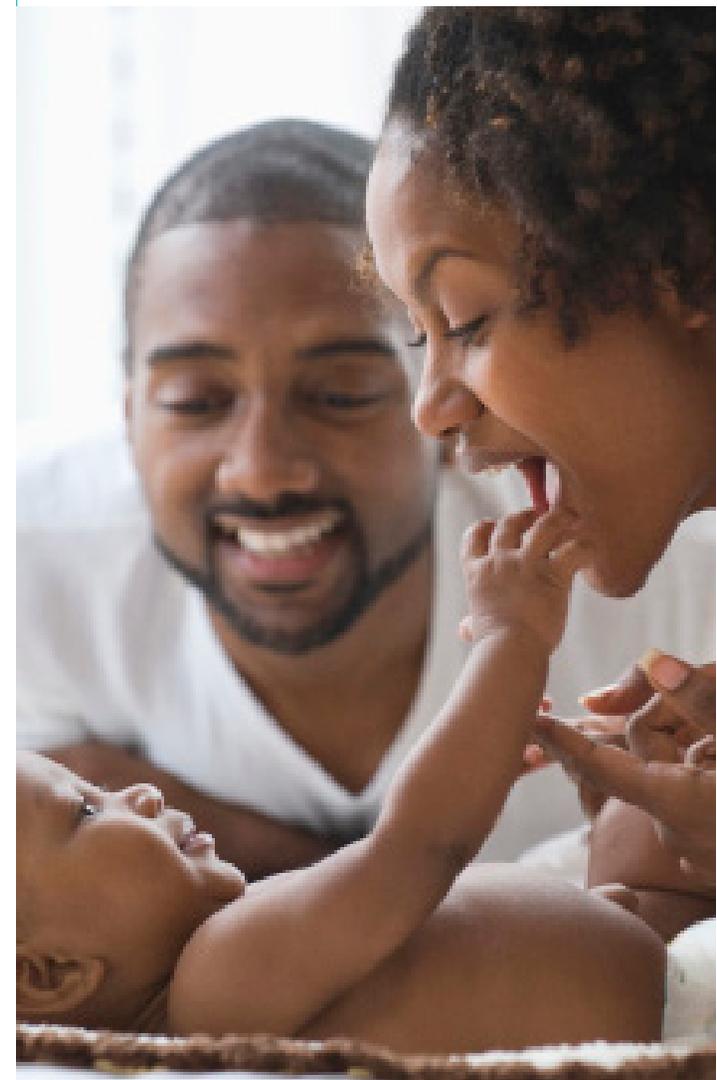
## ● Tips

- 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

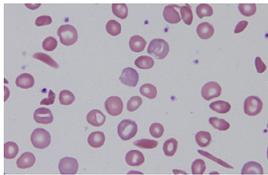
Helping you understand sickle cell disease & hydroxyurea treatment

### 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).

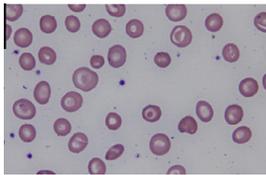
### How does hydroxyurea work?

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!"*

