

# Titus' Story

**Titus Ajayi lives in Northampton with his wife and four children. His youngest child Temitope, who is now 11 years old, has sickle cell disease. Titus' family discovered that Temitope had sickle cell disease when his wife was five months pregnant.**

My wife and I went for one of our regular antenatal check-ups where we found out that we would need to take a genotype test. It was at that point that the whole family found out that our son had sickle cell disease.

At diagnosis we were given a lot of options as to how to proceed. We were given information about what our child's quality of life could look like and the challenges that we would face as a family with our son living with sickle cell disease. However, for us, the only option was to continue with the pregnancy. We were given lots of support from the hospital staff, but it was a difficult time, and I would not like to go through it again.

After we made the decision to keep our son, we were given more information, but I also wanted to do research for myself to make sure that I understood as much as I could about the disease and to also try to be as prepared as I could be.

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**We didn't feel alone and there was a team of people around us, but because I wanted to know more, this is what led me to join the Sickle Cell Society, where I could meet others, listen to their experiences, and learn more for myself.**



It was back in 2015 that I read about hydroxycarbamide, and at an appointment with the specialist I asked them about the drug. They told me that in some cases it may not be the most suitable drug, but I asked if we could at least try it for my son.

In my mind, if it didn't work we could take him off it, but we would have at least tried. However, luckily, we didn't even need to think that because it did work for our son.

**Ever since then, his quality of life has just improved tremendously; on average he is now hospitalised only around once a year. We are able to manage his sickle cell pain at home.**

**I don't know where we would be without hydroxycarbamide; it has really been a huge help to us to know that we can rely on this medication. By and large, Temitope is living a normal life.**

I am originally from Nigeria, and if you have sickle cell disease others may not know that you have the disease and only know that you're sick. This is because of the stigma attached.

I just feel that although it can be hard sometimes, it's important to share your experiences and knowledge as you may help others.

There is so much information out there, but in my opinion, there can always be more. Sharing your experiences can only help to educate doctors, nurses and other families who want to learn and understand more.

This is a lifelong disease, but we are not the only family going through this. No child likes to take medication, but once our son got used to it, he is very good at taking it. He understands that without the medication he will be in pain and it makes him feel better in himself.

**It's just about being more open and helping educate others.**

**One thing that I cherish about the medication is that it can help him to live a 'normal' life and I am very, very grateful that this medication can allow him to do this.**

**Nova**  
Laboratories Ltd

*We can confirm that the above case study is genuine and true at the time of this interview – April 2021 – and has been approved by Titus. This case study is independent of Nova Laboratories Ltd.*

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