

# Stories of Sickle Cell

## Resource Toolkit

Help us spread awareness about the diverse experiences of people with sickle cell disease (SCD).

In observation of Sickle Cell Awareness Month, CDC has launched the Stories of Sickle Cell project, which consists of personal stories of members of the SCD community. This project includes a video series, short stories, and a photoblog to share the unique identities of people living with SCD.

To encourage and support your efforts in sharing these stories, this toolkit includes

- Promotional announcements for the general public and healthcare providers,
- Social media posts, and
- Links to key resources and materials.

We hope you find these materials useful as you engage your community. Please forward this message and its attachments to members of your network so they may help us spread the word about these important resources.

For additional information and resources about SCD, visit [www.cdc.gov/ncbddd/sicklecell](http://www.cdc.gov/ncbddd/sicklecell).



**Centers for Disease Control  
and Prevention**  
National Center on Birth Defects and  
Developmental Disabilities

## Stories of Sickle Cell Resource Toolkit Announcement for the general public

Spread awareness about the Stories of Sickle Cell project by including the announcement below in a newsletter, publication, email, or web page.

People living with sickle cell disease (SCD) are more than just their disease. CDC is launching the [Stories of Sickle Cell](#) project, which aims to highlight the unique stories and diverse identities of those living with SCD. These individuals have real passions and dreams and experience struggles, successes, and failures just like everyone else. They live with SCD, but the disease doesn't define who they are and what they are able to achieve. Stories of Sickle Cell aims to provide a deeper understanding of people living with SCD to help take away the stigma attached to the disease and inspire action to support the SCD community. Below is more information about the resources in this project, which you can use and share with others.

### Stories of Sickle Cell

- **Videos:** Includes personal video interviews with members of the SCD community, including people with SCD, family members, and healthcare providers.
- **Short Stories:** Includes real stories of people with SCD.
- **Photoblog:** Includes a photo journey of the dynamic lives of those living with SCD.

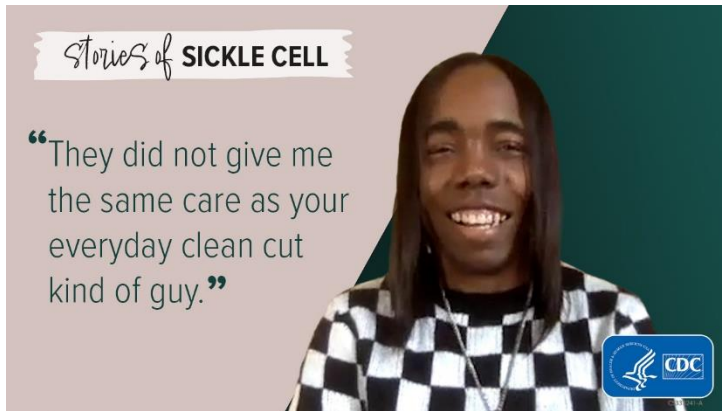


### Get to know some of the people highlighted in the project

#### Constance's Story

Constance D. Benson is a professional model and actress from Kennesaw, Georgia. She is the first person in the world to be cured of SCD via the [Sickle Cell Transplantation to Prevent Disease Exacerbation In Young Adults \(STRIDE\)](#) study in 2012. She shares her experience navigating life before and after her bone marrow transplant and relearning her identity outside of SCD. [Watch](#) her story of self-discovery.





### Tristan’s Story

Tristan was diagnosed with SCD at 6 months of age, and his mother was told he wouldn’t live past age 20. At age 9 Tristan experienced a stroke due to SCD and was paralyzed on the left side of his body. Despite his diagnosis and SCD complications at an early age, Tristan is now an accomplished actor, model, and fashion designer, all while being an international advocate and SCD warrior. [Watch](#) Tristan tell his story and [read](#) about it.

### **What You Can Do**

- Share the resources mentioned above on social media platforms, such as Facebook, Twitter, and Instagram.
- Read [other stories](#) of people living with SCD and check back often for future additions to the Stories of Sickle Cell series.
- Visit the [Office of Minority Health](#) website for more health information and resources for diverse groups.
- Learn more about SCD by visiting CDC’s [SCD website](#).
- Stay current on the latest news and updates by following us on Twitter [@CDC\\_NCBDDD](#).

## Stories of Sickle Cell Resource Toolkit Announcement for healthcare providers

Spread awareness about the Stories of Sickle Cell project by including the announcement below in a newsletter, publication, email, or web page.

People living with sickle cell disease (SCD) may experience difficulties in receiving proper healthcare treatment due to structural inequities. These inequities can lead to implicit biases, including perceiving patients as drug-seeking and doubting their reports of severity of pain.

CDC is launching the [Stories of Sickle Cell](#) project, which aims to

- Highlight the diverse identities across the SCD community, which can help challenge sweeping implicit biases,
- Share less-frequently discussed realities of SCD, such as the effects of systemic racism and health disparities, and
- Build empathy, which is an important step in improving treatment of people living with SCD, such as in the healthcare setting.

Below is more information about the resources included in this project, which you can use and share with others.

### Stories of Sickle Cell

- **Videos:** Includes personal video interviews with members of the SCD community, including people with SCD, family members, and healthcare providers.
- **Short Stories:** Includes real stories of people with SCD.
- **Photoblog:** Includes a photo journey of the dynamic lives of those living with SCD.

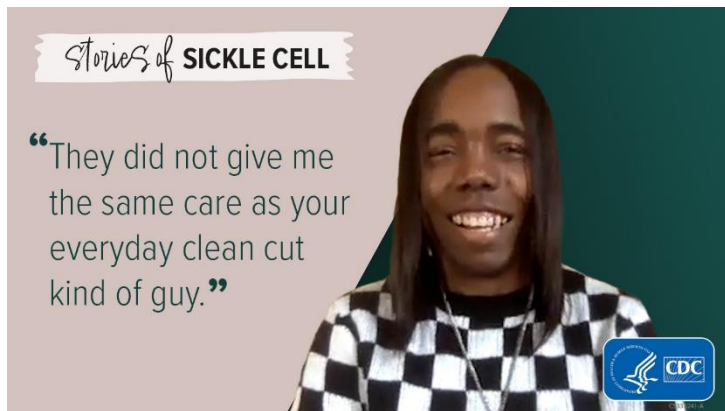


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### Tristan's Story

Tristan was diagnosed with SCD at 6 months of age, and his mother was told he wouldn't live past age 20. At age 9, Tristan experienced a stroke due to SCD and was paralyzed on the left side of his body. Despite his diagnosis and SCD complications at an early age, Tristan is now an accomplished actor, fashion designer, and advocate of the lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ) SCD community. [Watch](#) Tristan share his experiences of receiving care as a gay man and [read](#) more about him.

### **What You Can Do**

- Share the resources mentioned above with patients, with colleagues, with your community, and on social media.
- Read [other stories](#) of people living with SCD and check back often for future additions to the Stories of Sickle Cell series.
- Visit the [Office of Minority Health](#) website for more health information and resources for diverse groups.
- Learn more about SCD by visiting CDC's [SCD website](#).
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# Stories of Sickle Cell Resource Toolkit

## Social media posts

Share the messages below, which are intended for people with SCD, SCD organizations, healthcare providers, public health officials, and the public to use on their social media channels. Use the **#StoriesofSCD** hashtag.

### General

- People with sickle cell disease (SCD) are more than just their disease. Stories of Sickle Cell aims to highlight the unique stories and diverse identities of those living with SCD. Learn more here: [#StoriesofSCD](https://go.usa.gov/xhWWV)
- In observation of #SickleCellAwarenessMonth, CDC has launched the Stories of Sickle Cell project, which consists of a photoblog, personal stories, and videos of members of the sickle cell community. Check out their stories here: [#StoriesofSCD](https://go.usa.gov/xhWWV)
- If you are living with sickle cell disease (SCD), you are not alone. SCD may not always be visible to others and can lead to feelings of isolation. #StoriesofSCD features people who are going through the same thing as you. Watch their stories here: [#StoriesofSCD](https://go.usa.gov/xhWWV)
- People with #SickleCell often face dehumanizing treatment because of preconceived notions about the disease, which can lead to a lower quality of life. #StoriesofSCD humanizes people who have this blood disorder through storytelling. More here: [#StoriesofSCD](https://go.usa.gov/xhWWV)

### Videos

- The Stories of Sickle Cell project gives people living with sickle cell disease a platform to tell their stories on their own terms. Watch them share their stories here: [#StoriesofSCD](https://go.usa.gov/xhWWH)
- Sickle cell disease was once a big part of Constance's identity. She is learning to navigate life without pain after being cured by a medical procedure called a bone marrow transplant. Check out her story here: [#StoriesofSCD](https://go.usa.gov/xhWWH)
- Tristan is an accomplished actor, fashion designer, and advocate of the LGBTQ sickle cell community. Watch Tristan share his experiences of receiving care as a gay man: [#StoriesofSCD](https://go.usa.gov/xhWWH)

### Short Stories

- Meet Lance. Lance is engaged, in graduate school pursuing a master's degree, and a talented musician and music producer. He is also living with #SickleCell. Read Lance's story here: [#StoriesofSCD](https://go.usa.gov/xhWWJ)
- "Having sickle cell disease is what led me into the healthcare field, even though my mother didn't want me to pursue nursing. She thought it was too strenuous and wanted me to have a sit-down job." Read more about Tasha's story here: [#StoriesofSCD](https://go.usa.gov/xhWWJ)

### Photoblog

- #SickleCell has many faces. See the wide range of identities represented among members of the sickle cell disease community by viewing the #StoriesofSCD photoblog here: [#StoriesofSCD](https://go.usa.gov/xhWZc)
- #StoriesofSCD aims to highlight the unique stories and diverse identities of those living with the disease. Learn about the dynamic lives of these people through the photoblog here: [#StoriesofSCD](https://go.usa.gov/xhWZc)

## Stories of Sickle Cell Resource Toolkit

### SCD resources and materials

Access SCD resources and materials anytime via the following web pages:

<b>Sickle cell disease</b>	<a href="http://www.cdc.gov/ncbddd/sicklecell">www.cdc.gov/ncbddd/sicklecell</a>
<b>Sickle cell trait</b>	<a href="http://www.cdc.gov/ncbddd/sicklecell/traits.html">www.cdc.gov/ncbddd/sicklecell/traits.html</a>
<b>Real stories of people living with SCD</b>	<a href="http://www.cdc.gov/ncbddd/sicklecell/stories.html">www.cdc.gov/ncbddd/sicklecell/stories.html</a>
<b>Infographics</b>	<a href="http://www.cdc.gov/ncbddd/sicklecell/materials/infographics.html">www.cdc.gov/ncbddd/sicklecell/materials/infographics.html</a>
<b>Fact sheets</b>	<a href="http://www.cdc.gov/ncbddd/sicklecell/materials/factsheets.html">www.cdc.gov/ncbddd/sicklecell/materials/factsheets.html</a>
<b>Steps to Better Health for People with SCD toolkit</b>	<a href="http://www.cdc.gov/ncbddd/sicklecell/betterhealthtoolkit/index.html">www.cdc.gov/ncbddd/sicklecell/betterhealthtoolkit/index.html</a>
<b>Videos and podcasts</b>	<a href="http://www.cdc.gov/ncbddd/sicklecell/materials/video.html">www.cdc.gov/ncbddd/sicklecell/materials/video.html</a>
<b>Web buttons</b>	<a href="http://www.cdc.gov/ncbddd/sicklecell/buttons.html">www.cdc.gov/ncbddd/sicklecell/buttons.html</a>
<b>Webinars</b>	<a href="http://www.cdc.gov/ncbddd/hemoglobinopathies/scdc-webinars.html">www.cdc.gov/ncbddd/hemoglobinopathies/scdc-webinars.html</a>
<b>Health disparities</b>	<a href="http://www.cdcfoundation.org/sites/default/files/files/SickleCellDisease-HealthDisparities-FactSheet021618.pdf">www.cdcfoundation.org/sites/default/files/files/SickleCellDisease-HealthDisparities-FactSheet021618.pdf</a>
<b>Publications</b>	<a href="http://www.cdc.gov/ncbddd/sicklecell/articles.html">www.cdc.gov/ncbddd/sicklecell/articles.html</a>
<b>Spanish SCD website</b>	<a href="http://www.cdc.gov/ncbddd/spanish/sicklecell">www.cdc.gov/ncbddd/spanish/sicklecell</a>