



# Share Your Personal Sickle Cell Story!

If you live with sickle cell disease and would like to share your personal story with teens who also have sickle cell disease, we are looking for short stories to include in an SCD app made for teens called Pinpoint. We are looking for stories from people of all ages living with sickle cell.

## REQUIREMENTS

**Stories need to be both typed and recorded and submitted for consideration no later than May 15<sup>th</sup>.** If your story is selected for the app, you will be compensated \$75.00 once a contract is signed granting us permission to use your story. **Your story will not be used without your permission.** Additionally, if your story is not selected to be used, we are unable to provide compensation.

### Stories should:

- Be less than 2 minutes when read aloud
- Be recorded using either professional recording equipment or a smartphone

### Stories should NOT include any of the following personal details:

- your last name
- your home or work address
- the name of your employer
- the names of any friends, coworkers, classmates or family members

## HOW TO RECORD YOUR STORY

### OPTION A: Using professional recording equipment:

1. First, write out your story and save it as a Word Document or PDF (.doc, .docx, or .pdf).
  - a. In the first sentence, please state your first name and current age.
2. Record yourself reading your story three different times (3 separate files)
  - a. Read your story like you are telling it to a friend
3. Please save audio files as .wav files.
4. Email your typed story and 3 audio files to: [pinpointstudy@emichealth.com](mailto:pinpointstudy@emichealth.com)
  - a. If the files are too large to email, you can share them via Dropbox, Google Drive or other online file sharing program. If you have any technical difficulties, you can call our team for help at (888) 695-9650 or email us at [pinpointstudy@emichealth.com](mailto:pinpointstudy@emichealth.com).

## OPTION B: Using a smartphone:

1. First, write out your story and save it as a Word Document or PDF (.doc, .docx, or .pdf).
  - a. In the first sentence, please state your first name and current age.
2. Using either your phone's voice recorder app or the Awesome Voice Recorder app (free version is available on Google Play and the Apple App Store), record yourself reading your story three different times (3 separate files)
3. Tips for recording:
  - a. Hold your phone about a hand-length distance from your mouth
  - b. Record your story under a thick, heavy blanket or in a small closet with lots of clothing and the door closed
  - c. Read your story like you are telling it to a friend
4. Email your typed story and 3 audio files to: [pinpointstudy@emichealth.com](mailto:pinpointstudy@emichealth.com)
  - a. If the files are too large to email, you can share them via Dropbox, Google Drive or other online file sharing program. If you have any technical difficulties, you can call our team for help at (888) 695-9650 or email us at [pinpointstudy@emichealth.com](mailto:pinpointstudy@emichealth.com).



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## NEXT STEPS

After May 15<sup>th</sup>, our Pinpoint Study Research Team will select stories to include in the app. If your story is selected, we will notify you by email with a copy of a contract and release agreement. Please review the contract and agreement, sign and return them along with a picture of yourself (head shot) to be used with your story in the app.

Once your picture and the documents signed are returned, we will mail you your compensation of \$75.00. Again, we will not use your story without the your permission in the form of a signed contract and release agreement. Please note that there may be a need to re-record stories or to send an alternative photo of yourself in order to ensure the best sound and image quality.

## EXAMPLES OF PERSONAL STORIES

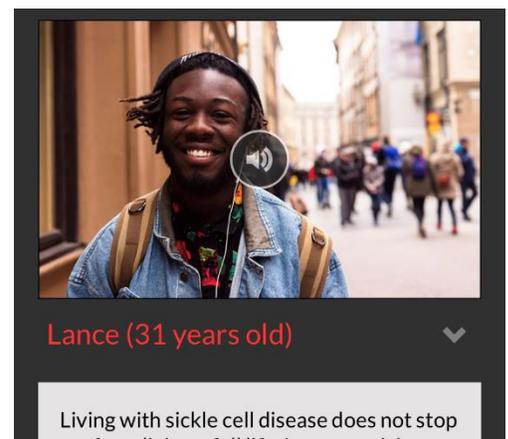
Here are some examples of personal stories, which we've already selected for Pinpoint, to give you a better idea of what kind of information others have shared in their stories.

### Example 1: Lance, 31 years old

Living with sickle cell disease does not stop me from living a full life. I am a musician and music producer. I am working towards a master's degree in clinical psychology and I am also engaged to be married.

I was diagnosed with sickle cell when I was 2 years old. No one in my family knew anything about the disease at the time and it was a major change for all of us. My mom had to quit her job to take care of me and my siblings thought I got special treatment from my parents because they got less time and attention. To me, it felt like my parents only cared about keeping me healthy while they helped my siblings focus on their goals and dreams.

My mom was a big support system for me, though. She made sure I was able to get necessary accommodations and time needed to make up assignments from missed days at school. She had a tutor come to my room for the times I was hospitalized. As I got older, I learned more about my disease and began to take charge of my life and my health. My mom showed me how to fill out paperwork and to order my own medications. I began to make my own doctor appointments and prepared to talk to the doctors myself.



Today, I am very involved in the sickle cell community. I volunteer for the Sickle Cell Disease Foundation of California and mentor teens with sickle cell disease. I helping them do things like get a driver's license, complete college applications, apply for scholarships and make the transition from pediatric to adult care.

My tips for those with sickle cell are to always be aware of signs of complications, they can happen at any moment. Do your research and know the disease and what you are dealing with. Lastly, don't let go of your dreams and don't let limitations hold you back. Have goals and make plans – sickle cell should not control you, it is just be something you live with.

**Example 2: Naomi – 13 years old**

My name is Naomi and I was diagnosed with sickle cell disease before I was even born. My parents had genetic testing done when I was still in the womb. When I was young, my parents kept me away from pools and playgrounds since I am more likely to get an infection. And they always knew the quickest route to the hospital from wherever we were, just in case. I was in and out of the hospital a lot when I was younger. That has changed as I've gotten older, although I still see my health care team regularly for check-ups. I am able to live a pretty normal life. I have lots of friends and rarely miss school. I love sports, especially dance. I hope to be a nurse one day. I know I can handle the hard times by staying strong and getting through to the good times. I'm not going to live short, I'm going to live long.