

Working With Your Home Clinic

This installment of Sick Cells' Local Advocacy Toolkit is focused on creating systemic change. This means addressing issues within the hospital or hospital system that affect more than one person. To do this, you need to build a group of dedicated advocates who are willing to speak up for the needs and rights of the sickle cell disease community in their area.

1 Find a champion

- In order to make an impact at your local hospital or clinic, **you will need to have a good relationship with someone you consider to be a “champion” of your cause.** Do you have a *doctor, nurse, social worker, or other medical provider* you see frequently who knows you and understands you? It may also be a *hospital administrator* you've gotten to know through your work on a community advisory board or diversity, equity & inclusion committee.
 - It's important to remember that building relationships takes time, but it's important to do that.
- **Approach them with an idea.** One good idea is to look at the relationship between the emergency department (ED) and the sickle cell disease care team (if the hospital has one). Do they communicate? Are they keeping each other informed? Making sure the ED and sickle cell disease (SCD) team collaborate is crucial to receiving the care you deserve when you are admitted.
 - Unsure where to start? In many hospitals, SCD is one step down in the triage ladder from stroke and heart attack. Talking to your SCD and ED teams about how SCD is triaged is a great place to start.

Find the right data

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- **Because hospitals operate as a business, data-driven improvement is very important.** When it comes to patient feedback and hospital ratings, many medical centers and their staff think they are doing better than they actually are.
- While your personal experiences are incredibly important and should stay central to your requests, data is often needed to support what you, and others in the community, have experienced. **With the right data, we can show which problems exist and how bad they are.** Whether the issues at the hospital are due to discrimination, bias, understaffing, or lack of knowledge, creating stronger policies for treating individuals with sickle cell helps to reduce bias in this setting.



Case Study: Children's Wisconsin

Children's Wisconsin, a hospital in Milwaukee, wanted to study how well their Emergency Department (ED) protocols for sickle cell disease were working. They led a [study](#) for two years in seven different hospitals to figure it out. They studied how quickly children in sickle cell crisis were admitted and how quickly they received their first

dose of pain medication. They found that their existing policies were not working as well as they had hoped, but having the data to prove it helped them create better policies. Now, time to admission and time to first dose is much shorter than before and they have created additional policies.



- **There are many places to find data, and many different types to use.**
 - Having data on your specific hospital is helpful, but is not always available. Here are some ways you can find if there is local data on sickle cell disease in your area:
 - Connect with a local community based organization (CBO). They may have information or standing relationships with local hospitals and clinics.
 - Ask a local public library for help finding information on sickle cell disease studies in your area.
 - Browse Sick Cells' [Sickle Cell Resources](#) and [Advocacy Tools](#) pages on our website to find existing public data about sickle cell disease.

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Use existing systems

• Patient portal

- Make sure you and other patients you know are signed up
- Check that your information is up-to-date. If it's not, request that it is updated.



• Quality & Safety Board

- Hospitals will often have a quality or quality & safety board. These boards track target goals of the hospitals, such as: rate of readmission, length of stay, cost per stay, and more. If you can prove to them that the hospital's care of SCD patients is lacking and preventing them from reaching their goals, you might be able to recruit more champions.



• Electronic Medical Records

- Electronic medical records (EMRs) are a digital version of someone's paper chart and records. If your home hospital or clinic treats many individuals with SCD, you can work with your champion to request that a standardized EMR be added to everyone's chart. This will make it easy for the ED doctor or nurse to see the care that you normally receive and make sure that they know who your primary care provider is.



• Patient Feedback Forms

- Many hospitals have patient feedback forms that allow patients to share their experiences and provide recommendations on how their care could be better. Work with your champion to make sure your group's feedback form is seen and addressed. On these forms, you can ask for hospital-wide changes that will lead to increased access to care. For example, requesting evening and weekend appointments.



• Diversity, Equity & Inclusion Boards

- Many hospitals have diversity boards that try to engage with minority and underserved communities. Search your hospital's website for "diversity," "inclusion", and "equity," to see if such a group exists. Sometimes, they'll have spots for patient advocates or community members. If you have the time, you can apply to join. If they don't allow non-staff to join, you can also ask the board if you and other advocates can present about sickle cell disease to them. This is a great way to raise awareness and educate.



Contributors



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Francesca Valentine, MSN, RN is a nurse, the clinical adviser for Sick Cells, and a carrier of sickle cell trait. Francesca received her diploma in nursing in 1982. She continued her education years later to receive her bachelor in nursing in 1996 and Master of Science in Nursing in 2014. She has dedicated her life to ensuring quality care for Veterans and their families. Mother to Sick Cells co-founders Marqus and Ashley, Francesca is a fierce advocate for Marqus and other children with SCD who have crossed her path.