

Health Equity Showcase, February 2019

## What's the project?

A workgroup formed in December 2017 to:

- identify unmet needs of the sickle cell community in Minnesota
- identify the role of MDH in addressing these unmet needs
- provide input to MDH leadership about the issues and potential solutions and roles for MDH

The workgroup convened a stakeholder forum to bring together the impacted community, medical and public health professionals, government partners, researchers, and other interested individuals.

## Why is it important?

The life expectancy of individuals with SCD is reduced compared to persons without SCD and has actually decreased.

Some of the challenges experienced by individuals with SCD include:

- Poor clinical outcomes
- Lack of medical specialists for adult patients
- Emergency room and pain management issues
- Silent strokes in children leading to cognitive impairment
- Reproductive issues
- Suboptimal vaccination rates
- Lack of treatment options

Project title: Sickle Cell Disease Workgroup

## How did you accomplish it?

### Who were your partners?

The planning team included individuals from MDH, DHS, the Sickle Cell Foundation of Minnesota (SCFM), and a medical provider.

Eighty-seven individuals registered including;

- 27 members of the community
- 25 government officials
- 26 health care providers
- 8 researchers

The event included speakers from state (MDH, DHS) and federal (CDC) agencies, the SCFM, a medical provider, the American Society of Hematology (ASH), and individuals impacted by SCD.

## Lessons Learned

- 1) Community engagement was instrumental in getting a high level of community participation
- 2) Attendees most valued the stories from community members and the presentations by the Sickle Cell Foundation of Minnesota and the medical provider
- 3) More lead time prior to the event is needed to increase provider engagement and community awareness
- 4) Need to allow more time in the agenda for discussion and reflection

## Results and Next Steps

The event enabled the impacted community to engage and discuss with providers, public health professionals, and other members of the community; evaluations of the event were very positive.

A report will summarize the event, focusing on feedback from small table conversations where participants addressed questions about which issues the community felt were most important, how those issues might be addressed, and what role stakeholders might play in addressing the issues.

In the short-term, one issue that should be addressed is the emergency department (ED) experience and treatment of individuals suffering pain crises due to SCD. The group has already begun discussion about the need for guidelines for SCD pain management in the ED. Community member participation will be important in developing guidance, as well as keeping abreast of national guidelines currently in development by ASH.

We will be working with the planning group and other stakeholders to develop and implement a strategic communication plan to raise awareness of the report among critical decision makers.

## Team Members

Rae Blaylark, Stephen Nelson, Joanne Bartkus, Ruth Lynfield, Ellie Garrett, Jeff Schiff, Helen Jackson Lockett-El, Nicole Brown, Jennifer Hauser, Amy Dahle, Mary Manning, Jessica Cavazos, Bridget Busacker, Maggie Dreon



Caption: Individuals living with SCD, caregivers, community, providers, and public health professionals dig into the issues facing the SCD community during in-depth discussions.