

# Sickle Cell Disease – A Community Approach

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## Sickle Cell:

- Sickle Cell Disease (SCD) is defined by the CDC as a group of inherited red blood cell disorders where the cells sickle and die early causing blockages in small blood vessels and anemia.
- There are six types of SCD: HbSS, HbSC, HbS beta thalassemia, HbSD, HbSE, HbSO.
- It is determined by a blood test and is part of the routine newborn screen in Indiana.
- Treatment varies and symptom management is most important, with the goals to try and reduce pain, manage anemia, and prevent infections.
- This is a lifelong disease that affects 1 out of every 365 African American births, and 1 out of every 16,300 Hispanic births. It is a lifelong condition that requires long-term management and care.

## Community Actors in Ft. Wayne

- Martin Center: a 50-year-old non-profit aimed at bettering the lives of those living with sickle cell. Stationed in Indy looking to expand into Ft. Wayne
- Timothy Lymon Group: A small nonprofit in Fort Wayne run by the Lymon family that works to support those with sickle cell and run a support group for both children and adults.
- Lutheran Health Pediatric Hematology and Oncology: The physician out of this office is part of the Indiana Sickle Cell Consortium and is passionate about working with sickle cell patients in the area. They are the only major pediatric provider in the area for it.
- Family medicine, St. Joseph Hospital: The biggest adult provider for sickle cell is a group of resident medical students with a few wanting to focus on sickle cell disease.

## Goals:

- Quantify those living with sickle cell in Ft. Wayne.
- Identify their needs.
- Assess the amount of medical providers in the area.
- Expand the support group operating in Ft. Wayne.
- Expand testing for adults for sickle cell.

## Actions:

- Attended a support group meeting and worked with them to understand their goals and creating a flyer to advertise them
- Passing out fliers to 600 housing units with the blessing of Ft. Wayne Housing Authority and circulating it to Dr. Offices.
- Research the number of those living in the area with sickle cell
- Reach out to all the doctors offices in Ft. Wayne to see who majorly provides for it.

## Research:

- While it is known that there is an SCD population in Ft. Wayne, there were no direct studies or published reports about it by the State Department of Health. The closest the project got was a rough estimate by the Lutheran Provider that ~150 people live with SCD.
- There is a decrease in the mortality rate of children with SCD from 1979-2005, as treatment options improve for that population, however the same study found that the adult mortality rate increased in a way that may reflect poor access to care and high-quality treatment for SCD. (Lanzkron, Carroll & Haywood 2013).
- SCD is a drastically underfunded nation wide, with limited specialized treatment centers, and symptom management—in particular pain management—is not properly understood by general practitioners (Lee, et. al, 2019).
- Nationally, the Sickle Cell Disease Association of America is the only national community based-organization for SCD treatment and focuses on quality of life improvement.
- There is a significant gap in national survey data, creating a gap in knowledge needed to create policy and improve health policy (Hulihan, et. al, 2017).
- There is a need to reduce physician bias, as it had been found to influence the quality of care for SCD. (Masese, et. al 2019; Lee et. al 2019).

## Recommendations

- To continue to raise awareness the goal would be to have a fundraiser or community event that could be supported by a local hospital and partnered by our community actors.
- Pass out informational brochures about SCD to physician offices, urgent cares, ER waiting rooms.
- Help create an educational program about SCD and living with the disease to give to children during their health classes and to those coming to the Lymon support group.
- Create a HIPAA compliant survey to attempt to objectively quantify the number of people living with SCD in Ft. Wayne and present that number to the city council.
- Organize workshops for medical personnel, especially urgent care and ER, about SCD.
- Work with schools and school nurses to make sure the holistic needs of children living with SCD can be met.

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