



Sickle Cell Foundation of Minnesota
P.O. Box 22306 | Minneapolis, MN 55422
Ph: (763) 607-5555

Improving the quality of life for individuals and
communities affected by sickle cell disease.

March 22, 2022

Senator Gregory D. Clausen (57, DFL)
95 University Ave W
St. Paul, MN 55155

Senator Clausen,

On behalf of the Sickle Cell Foundation of Minnesota, we want to extend our deepfelt appreciation for your work and commitment to HF3786/SF3566. As you may already be aware of, sickle cell disease (SCD) is the most common genetic blood disorder identified in newborn screening. It is also the most common blood disorder in the world! In addition to a laundry list of life-threatening complications, the hallmark of sickle cell disease remains its severe and debilitating pain episodes that can last from days to weeks, months, and even years. This common complication often results in increased hospital admissions and healthcare burdens.

While we understand the gravity of our current opioid addiction crisis, we also have a parallel crisis being experienced by sickle cell patients across the state of Minnesota. That crisis is the mis-management of sickle cell pain. Sickle cell pain is often under-treated and mis-treated by medical professionals with and without specialty training. We certainly recognize that not all mis-management is not attributed to racial bias, all too often there are elements of both conscious and unconscious medical bias as it relates to individuals with painful conditions such as SCD.

It is our sincere hope that HF3786/SF3566 will serve to address the real and perceived understandings of medical guidance as it related to patients with SCD who are in need of both short- and long-term opioid therapies. Given that I have a 25 year old son who lives with this disease, I have seen first hand the results of stigma and bias. I have also worked with countless individuals and families who have experienced helplessness that turned to hopelessness as a result of being forcibly tapered or flat out refused opioid treatments because of false assumptions of drug seeking or addiction. These decisions by medical professionals are leaving patients in a state of suffering both physically and mentally.

While the data is clear that individuals with SCD are less likely to experience drug addiction and/or overdose, that data has not been widely shared or is being disregarded by many physicians. In addition to pain management guidelines made available in 2020 by the American Hematology Society (ASH), we are hopeful that HF 3786 will protect medical providers by allowing them to apply their sickle cell expertise in a way that considers, without bias, the humane treatment and improved quality of life for individuals living with SCD. The sickle cell community is grateful for your support and commitment to HF3786/SF3566.

Sincerely,

Rae Blaylark

Rae Blaylark
President, Sickle Cell Foundation of MN

