

Representative Michael Callton, Chairperson  
Michigan House Committee on Health Policy  
Room 519  
House Office Building  
Lansing, Michigan

March 15, 2016

Representative Callton,

My name is Adel DiOrio. I am the Chair of Education and Advocacy for the Spina Bifida Association of Michigan (SBAofMI). Today, I am joined by Kate Pojeta (Advisory Committee Chair, SBAofMI) and Kasey Hilton (Advocacy Committee Member, SBAofMI). We represent the many Michigan families and individuals living with spina bifida, and we thank you for the opportunity to speak today in support of HB 5098 sponsored by Rep. Hank Vaupel.

According to the Michigan Department of Health and Human Services (accessed 10-11-2015), each year, 47 babies are born in Michigan with spina bifida. HB 5098 would place up-to-date, evidence-based, written information, and contact information for support programs and organizations in the hands of these parents when they need them.

As stated in the bill, information shall be given, "UPON RECEIPT OF A POSITIVE PRENATAL OR POSTNATAL TEST RESULT OR DIAGNOSIS OF SPINA BIFIDA." The opening statement of the bill is of great importance as it defines the time frame for access to critical information. Many families receive the diagnosis of spina bifida at the 18- or 19-week anatomy scan by ultrasound (the appointment at which families often learn the baby's gender). Fetal surgery (which is not the right choice for every family) must occur before the 26-week gestation mark, representing a remarkably short window of time in which to research, discuss, consult, and arrive at a decision regarding course of action and treatment. If information were delivered "to the parent of a *newborn* child with spina bifida" as the summary of HB 5098 denotes on the legislative website, it eliminates an option that the family and care team may deem the best option for that particular child and family.

Although spina bifida is the most common life-long disabling birth defect, it is still rare as compared to the many children not born with it. Therefore, doctors may seldom or never encounter a patient with it. And yet, life-saving and life-changing medical advancements for people with spina bifida are happening as we speak...effective interventions for hydrocephalus, mobility equipment, and surgical options that only recently became standard of care. Therefore, this bill is also in support of them, our valued medical community, providing them the support they need to have real-time access to timely, up-to-date, printable information to hand directly to the parents of a child with spina bifida at that emotional moment when they deliver the diagnosis.

The spina bifida community in Michigan and beyond have been eagerly awaiting the progress of this bill as it would be the first original legislation in direct support of persons with spina bifida. Kentucky recently passed a similar law (KRS 211.192) that added language to a bill requiring a similar provision of information upon diagnosis of Down Syndrome. Michigan stands to be the first State in the Union to pass original legislation in support of the spina bifida community.

In closing, the Spina Bifida Association of Michigan is in strong support of HB 5098 and anxiously looks forward to the opportunity to put these supports in place for all future Michigan families receiving the news that they will have a child with spina bifida and all of the people poised to deliver that diagnosis. We speak as the parents who received that news ourselves. Allow me to revisit our introductions as the bill we support today will directly impact families just like our own.



I am Adel, mother of Justin (diagnosed 10/25/2012 at 19 weeks gestation). I am joined today in support of HB 5098 by Kate, mother of Colten (diagnosed 09/18/2012 at 35 weeks gestation) and Kasey, mother of Carter (diagnosed 06/24/2014 at 19 weeks gestation). Thank you again for your consideration of this bill and your support for those living with spina bifida in Michigan.

Yours in service,



Adel DiOrio  
Chair of Education and Advocacy, Spina Bifida Association of Michigan