

Testimony in Support of HB-5417, 5418, and 5419
Debra Chopp, JD

Mr. Chairman and honorable members of this committee:

My name is Debra Chopp. I am the director of the Pediatric Advocacy Clinic at the University of Michigan Law School. I am here in my capacity as attorney for Dawn Krause, dedicated and tenacious mother of Willy Pickett, and other families with terminally ill children to support House Bills 5417, 5418, and 5419.

History: I am honored to take part in this effort. A few years ago, I was litigating against the Washtenaw County ISD in an effort to overturn the ISD's policies with regard to honoring DNR orders in the school setting. I am so glad to have joined forces with Dr. Menzel, as a partner instead of an adversary, to ensure the protection of children and school personnel throughout the state of Michigan, and not just in one school district. I am thrilled with our collaboration and inspired by the parents, educators, doctors, and nurses around us who are passionate about this issue.

I support these 3 bills for the following reasons:

1. Parents already have the right to make medical decisions for their children, including the right to sign Do-Not- Resuscitate orders on their behalf. These bills reaffirm that right and make clear that the right carries over to guardians of wards as well. These bills contain safeguards to ensure that the decision is ratified by the child's or ward's attending physician.
2. Bills provide much needed clarity and uniformity throughout the state. When my students and I were trying to get a sense of the scope of this problem, we sent a FOIA request to every ISD in Michigan. We received responses from almost all 57, describing the policies they have or don't have with regard to honoring DNR orders in the school setting. There are at least 9 different policies in effect in the 57 ISDs throughout the state placing varying obligations on parents, superintendents, principals and school nurses, and courts. This leaves parents – uniquely stressed and vulnerable parents given the medical state of their children – with considerable uncertainty. These bills today eliminate the uncertainty. The bills allow parents and guardians the freedom to make medical decisions in the best interests of their children and give clear instructions to schools.
3. Bills relieve burden on families caring for terminally ill children. They will no longer need to try and discern the policy of their district before sending their medically fragile children to school and, more importantly, those living in districts that require a court order before a DNR order will be honored, will not need to hire a lawyer to figure out how to get an order requiring the school to honor the DNR.
4. Finally, these bills address a practical problem that schools throughout the state face. Children with life-threatening disabilities attend our public schools. Under federal law, public schools may not turn away a child on the basis of his or her disability. These children are entitled to a free, appropriate

public education. The bills we are debating today do not – indeed they cannot – change that. What they do is provide clarity for the schools charged with educating these vulnerable children.

Thank you. I am happy to answer any questions.

Debra Chopp

Director, Pediatric Advocacy Clinic

University of Michigan

dchopp@umich.edu

734-763-1948