

Do-Not-Resuscitate Orders, Michigan Schools, and One Boy's Journey with His Family

Our journey to legitimize the status and implementation of Do-Not-Resuscitate (DNR) orders in all schools in the State of Michigan for children who are terminally ill with life-threatening disorders but are not actively dying. Efforts are being undertaken to amend the Michigan DNR Procedures Act, which does not currently address pediatric DNRs or the educational setting. These efforts passed the Michigan Senate unanimously in 2018 but did not make it to the House before the Congressional session ended. The process has now been restarted in the Michigan House of Representatives with House Bills 5417, 5418, and 5419 (2020).

For more information:

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Blog:

A Very Post-Modern Family – Life, Love, and Loss in a World Gone Slightly Mad

A blog by Dawn Krause journaling a family's efforts to raise a family that includes a terminally ill child. (Who has now passed on.) Come along on the journey with us...

<http://averypostmodernfamily.blogspot.com/>

Facebook Pediatric Do Not Resuscitate parents group:

<https://www.facebook.com/groups/539638029533333/>

This is a private Facebook group for parents only. In this group we are discussing the issues and problems surrounding end of life decisions and advance directives for our children. We also support one another, post articles, and share information.



William Douglas Pickett

3/12/04 – 11/5/15

Testimony in support of House Bills 5147, 5148, and 5149 (2020)

My name is Dawn Krause and I am from Saline. I am married and have three children. I work as a research administrator at the University of Michigan. I received two degrees from Michigan State University; one in Eastern European History and one in Interdisciplinary Studies in Social Sciences with a cognate in International Political Science. Willy's father works in law enforcement and has a degree in anthropology. My husband has a PhD in American Studies and is a professor at Central Michigan University. I give you this background only to explain how no life experience, job, or level of education could ever prepare you for what we have had to go through.

My middle son, William, (Willy), was born March 12, 2004. My pregnancy with him was normal and uneventful as were his first four months of life. On July 9th, 2004 after a grand mal seizure he was diagnosed with lissencephaly. Lissencephaly is a rare neuromigrational disorder in which the brain does not form correctly during gestation. Lissencephaly literally means smooth brain. Willy had no gyri or ridges which are what gives you your motor skills. At diagnosis, we were given an approximate 2-year life span for Willy. We were told to take him home and be prepared to deal with complex seizures and respiratory issues and basically try to keep him comfortable while we waited for the end.

The early years were the most difficult. We were learning how to take care of this very sick baby and doing everything we could to keep him alive. Every time he was sick we thought it was the end. Mott Children's Hospital became our second home. The stress of the entire situation was devastating to our family, our other children, our jobs, our finances, and to our marriage.

After a while we started to pick up some confidence and hope. Willy started to have longer periods of improved health. We enrolled him in the Early On program and the therapists and teachers there taught us how to take care of him and give him quality of life. They opened up a new world for us. A world where special education meant a life for Willy. A life of his own where he still had goals. They had equipment at school that we could have never afforded to have at home. They had specialists there who had

studied how to educate and work with this very special population of students. He couldn't walk or talk. But they focused on what he could do not what he couldn't do. Sometimes their goals were lofty which made us laugh. We joked that we really just wanted him to poop and breathe. (Constipation was a large part of our lives and caused a lot of problems for Willy.) They wanted more for him. He learned to hold his head up. He learned to make choices with his eyes. He enjoyed swimming in the therapy pool which was not only fun for him but good for his muscles. He received physical, occupational, music, and vision therapies. They went on outings in the town. They did crafts. They listened to stories. He worked hard during therapy sessions and would come home exhausted. He was healthier when he was in school because he worked himself. It is a much healthier lifestyle than just lying around at home. After years of working with occupational therapy he learned how to hold a toy on his own. He learned how to roll over.

I mentioned lissencephaly is a regressive disorder. This means Willy's performance peaked at a very young age and started to decline slowly every day thereafter. Mind you, it's a slow regression and we had a lot of really good years in there. But his disorder, along with severe seizures, pulmonary issues, and cerebral palsy, was slowly destroying his muscles. Any skills he had (swallowing, holding a toy, rolling over, holding his head up,) were slowly going away. Eventually we had to put a feeding tube in so he could get enough nutrition. Your muscles control everything, how you eat, suck, swallow, breathe, urinate, have bowel functions, and more. The respiratory muscles become badly damaged in kids with these disorders and they often times succumb to respiratory distress as a result of pneumonia.

Throughout Willy's life, the educators and therapists working with us just kept changing the goals. Adapting. Meeting him where he was at. He continued to hit goals and milestones and then he'd regress and lose some skill or function. We'd celebrate the gains, no matter how small, and we'd grieve the losses. For the most part, he continued to be a happy boy, enjoying music, the pool at his school, outings with his class, snuggling with his loved ones, and his iPad with his shows.

Willy's lung function started to go seriously downhill somewhere around 2009. We wound up in an on again-off again cycle of hospitalizations that lasted over three

years. Usually he'd start with a cold or snuffle and the next thing you know we were in the intensive care unit and he was fighting for his life. Until then, we had maintained a very pro-active and aggressive approach to his care. Even though he had been given an approximate life expectancy of 2 and he was now 7, his life had been much better than we ever could have anticipated. When the hospice and palliative care teams would come visit our hospital rooms we promptly sent them away. We knew Willy had a lot of life left to live.

In late fall of 2012, Willy had been having some increased breathing and swallowing issues due to the continued regression and his obstructive sleep apnea. We had an appointment with Dr. Charles Koopman, a pediatric otolaryngologist, to see what our options were. The options that were presented to us for improved breathing and swallowing were not good. All of them required some form of complicated surgery. The only real viable option for us was a tracheostomy which, on one hand would have made life a little easier, and on another hand would have seriously increased the complication factor.

We decided against the trach. That night when we got home, I couldn't help but think that it was the "beginning of the end." There were no more procedures or life-saving surgeries that were options. It became a situation where we would just use what we had to keep him comfortable. His regression had made it to that crucial juncture where we realistically couldn't do much more to keep him alive and try the best we could to maintain a good quality of life.

Dr. Koopman introduced us to the phrase "terminally ill but not actively dying." This phrase would become the basis for all the decisions we made from then on. Willy was terminally ill. Not like when your great-grandmother has lived a good, long life and, at 99, has end stage cancer. In that situation, physicians can hazard a good guess as to how long she will have to live and know what her life will be like in those final days and weeks. In that situation, great-grandma would be actively dying.

The onset of the ACA allowed for concurrent curative and hospice care in pediatric cases like these. By providing coverage for curative and hospice care simultaneously, the ACA makes it clear that some disorders, especially in these pediatric cases, are different in that although they are terminal, they are not actively

dying. These patients require comfort measures that hospice provides and also curative care that comes from specialty clinic visits.

In June of 2013 Willy was in the hospital for increased seizure activity. This wasn't something new. He'd grow or a medicine he was on would lose its efficacy. Hormones change. We were always looking for the right concoction of medications that would keep his seizures at bay but not drug him out. I'll leave out the details but during this hospital stay, it was presented to us once again that we could consider palliative care or hospice services. Not only had we tried almost everything we were willing to try, Willy had gone quite a bit downhill in the years preceding. It was time for my husband and myself to have the talk about where we go from here and was it time to consider palliative care or hospice services.

With our goal being the best quality of life possible for the time that Willy had left (remember – he was not actively dying at this point,) we decided to go home from the hospital on hospice services. Willy would still be able to attend school. We would have some support by way of having supplies delivered, oxygen in the home, morphine and other comfort measure drugs. All of our medications would be ordered by the nurse who came once a week to check on Willy and delivered right to our home. If Willy became ill, a call to hospice would send out the nurse or the doctor. If Willy needed antibiotics we could get them. If Willy took a turn for the worse, we could either provide the comfort measures we had in the home or we could change our minds and head for the hospital for more aggressive treatment. We were also able to still see our physiatrist and our neurologist in clinic for curative care. If we could have designed a perfect set-up for our imperfect situation, this would be it.

We worked with a team of professionals to create a care plan which included a "do not resuscitate" (DNR) order. The decision to add the DNR into Willy's care plan was no less agonizing just because we knew it was the right thing to do. Taking all of the facts into consideration we knew it was time. Every time Willy was sick he came back to us a different boy. Less of his old self and more of a tired and uncomfortable one. We knew that should something happen where his heart stopped beating and resuscitation was an option, we would not want that for him. We would want comfort measures. We would want him to be surrounded by people who love him, whether at

home or at school, holding his hands and staying by his side. Once we made this decision we never looked back. At the time, Willy was attending Haisley Elementary in Ann Arbor, Michigan and they honored his DNR. We had a team meeting to put protocols in place and off to school he went.

The next school year we made the decision to transfer Willy to the Washtenaw Intermediate School District. They have a specialized special needs program and there were more services available for Willy including a very warm therapy pool which we knew he would love. We were sad to leave Haisley but, again, keeping in mind quality of life, we knew it was the right decision.

When we found out that the WISD would not honor his DNR we were crushed. We would have been devastated if something had happened at school and resuscitation was attempted. I am very sure this is a difficult concept to understand for parents and adults who do not live in a world where children are terminally ill. But we did live in that world and it was not acceptable that a school district could overrule our decision with regards to our DNR.

We decided to still send Willy even though we knew they would not honor his DNR. We knew the pros outweighed the cons. Willy loved school. He loved the pool. He needed the therapy and the stimulation they offered there. However, we did start a lawsuit against the district to force them to honor the DNR. The suit was still in progress when Willy passed.

For Willy and kids with these regressive disorders, the "end" can be years. In the meantime, they have to live. They deserve an education. They deserve a life of their own with an educational program designed for them. This is not only a right; it is the moral thing to do. The fact that they have terminal disorders and may have a DNR should not infringe upon their right to an education. The school districts that serve our state must be consistent in their policies regarding pediatric DNR's. Their policies should not change across town or across another district's border. Just as you'd write a medical care plan that included an epi pen for a student with a deadly allergy, medical care plans for student's with DNR's should also be included in the educational setting.

When a parent or guardian reaches the agonizing decision to write a DNR for their child, no one should be able to tell them that the DNR will not be honored.

Especially in an educational setting where they have the right to have the same experiences as their peers right up until the day they pass. No child is less entitled to their rights to FAPE because of a diagnosis, prognosis, or a medical order. I ask you today to consider our story but know there are many more out there just like ours. I ask that DNR's be honored in all educational settings in our great state. I ask that the laws allow for collaboration between medical professionals, educational professionals, and families so appropriate care plans that are as individualized as the student can be put in place. Proper protocols and policies will follow so that staff is comfortable and knows what to do in case of a situation with a student. Many districts already honor DNR's and have put appropriate policies in place. Something as important as this, which really comes down to life and death, should be consistent between every educational jurisdiction in our state.

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.

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