

Children's Coalition Newsletter



Children's Palliative Care Coalition of Michigan

May 2017

DNR in Schools — A Bipartisan Initiative

by Dawn Krause (parent and research administrator)

When parents have a do-not-resuscitate order for their child, will all schools honor it?

The answer varies from district to district in Michigan. Some schools do, some do not, with no consistency through the state.

As reported in the February newsletter, Palliative Care Coalition members, with the help of University of Michigan Pediatric Advocacy Clinic, have been working to change this by stating that parents can get DNRs on behalf of their minor children and explicitly mentioning schools as a context in which DNR's need to be respected.

This initiative is now being drafted in the Michigan Senate by way of two bills, co-sponsored by Senator Rick Jones and Senator Rebekah Warren.



Left to right: Maureen Giacomazza, Dorian Geisler, Senator Rick Jones, Dawn Krause, Ken Pituch MD, Prof. Debra Chopp, and Russell Busch.

In our (Krause) family's case, we sent our son Willy to High Point School in the Washtenaw Intermediate School District because he needed the education plan they offered, even though they would not honor his DNR. The pros outweighed the cons.

However, after years of going through the local courts to try to have the school recognize his DNR order, we were recommended instead to work toward strengthening the current legislation.

The Michigan DNR Procedures Act is obligatory for healthcare professionals, but says nothing about schools. This creates ambiguity and uncertainty for both parents and schools.

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One allows for DNR information to be included in a student's IEP. The other amends the current DNR act to include pediatric language and provide immunity to school staff. The win-win: parents have DNR's for their kids recognized in schools and schools explicitly get immunity if they follow the DNR protocols.

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A Capitol Family

Two brothers in the legislature

The Healthy Michigan Plan is the greatest thing our governor has done.

The comment is from Senator Curtis Hertel Jr., a Democrat and the Senate Minority Whip.

"Many of my colleagues on the other side who voted for the plan were profiles in courage," the senator told us. "They risked their reelection by being tied to 'Obamacare' – the very reason some states rejected free money from the Federal government for Medicaid expansion."

Senator Hertel's comments illustrate a degree of bipartisanship in our state government that we do not often see in Washington.

The Hertels

It would be hard to find a family in Michigan more involved in state politics and public service over several generations than the Hertels.

Curtis Hertel's father, Curtis Hertel Sr., who died last year age 63, served both as a co-speaker and later as sole speaker of the House. The unusual role of co-speaker arose in the 1980's when the House was evenly divided between Democrats and Republicans. His reputation was in managing to find ways for the parties to work together.

Hertel's uncle Dennis was also a house representative, and another uncle, John, was a county commissioner.

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A Capitol Family

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Two of Curtis Hertel Sr.'s sons, Curtis Jr and Kevin, have followed their father into state government.

Senator Curtis Hertel Jr.

Senator Curtis Hertel Jr. represents the 23rd District, which includes the Lansing area. He is a Vice-Chair of the Senate Health Policy Committee on which Senator Rick Jones also sits (*see preceding DNR article*).



Kevin (left) and Curtis Hertel

Since joining the Senate in 2014, Curtis has made a notable impact with legislation that includes creating a dedicated medical organ and tissue recovery center, removing the derogatory term “crippled children” from our state’s laws, and funding programs such as indigent hospice care, Healthy Kids Dental, and Early On services. Legislation that he has sponsored this year includes bills to reduce the student debt burden and expand child care support.

A new concern is the unknown future for Michigan healthcare, particularly the impact on Medicaid if block grants are substituted.

Whatever the impact, Senator Hertel believes that the Senate should not be drawn into detailed medical decisions. As an example, he told us how the Senate Health Policy Committee, because of costs in the prison system, had spent time lately debating whether to authorize the drug Harmony under Medicaid for hepatitis patients with Level 2 or only Level 3 fibrosis of the liver.

“Medical decisions,” the senator maintains, “should be made by doctors, not by politicians.”

Representative Kevin Hertel

Senator Hertel’s younger brother Kevin was elected in November last year as House Representative for the 18th House District which includes Detroit suburbs like St Clair Shores and Eastpoint.

Already, Kevin Hertel has sponsored several bills, including one to help stop child abuse (“Wyatt’s Law”), and another to provide wigs for kids suffering hair loss from medical treatment (“Wigs for Kids”).

Wyatt’s Law would create a registry of those convicted of child abuse to enable parents and others to check out an individual who might be involved in caring for their child.

“Wigs for Kids” states, “A health insurance policy shall provide benefits for cranial hair prosthesis for an individual who is less than 19 years of age and has cranial hair loss as a result of a medical condition or as a result of treatment for a medical condition”.

The sobriquet for the law comes from the St Clair Shores, Michigan, based charity, Wigs 4 Kids, that tries to meet the need but can cope with only a proportion of eligible children.

As Kevin Hertel explains, it is an insurance mandate which often prompts the objection that increased benefits mean increased premium. Yet while the cost of a wig, typically from \$2,000 to \$3,000, can be a heavy burden for a family, the number of affected children in Michigan is likely too low to impact an insurer’s loss ratio significantly.

Nonetheless, he fears that such objections might limit the chance of the bill being passed by the House to no more than 50:50, even with its bipartisan supporters.

The Michigan Senate

The Michigan Senate is a small world, and the ideological divide is less apparent. With different legislative initiatives, the same names pop up. For example, Rebekah Warren is a senate co-sponsor of “Wigs for Kids”. Rick Jones is a Senate co-sponsor of Wyatt’s Law. These are the same two senators sponsoring our Do-Not-Resuscitate initiative reported above.

There are, of course, divides. Both Hertel brothers believe, for example, that healthcare is a right, not a privilege, a view at odds with those who maintain it is part of a market-based economy.

Yet sometimes the divide is perceptual, rather than ideological. For example, ideologically, the Hertels share a belief that the state has a moral responsibility to provide mental healthcare. However, they focus their argument not on the moral issue, but on fiscal logic.

The state spends two billion dollars a year on its prison system. Studies by the Department of Justice find that at least 50% of prisoners are mentally ill.

“To spend \$35,000 a year to keep someone in prison today, rather than providing mental health treatment earlier, does not sound like a fiscally conservative policy,” Senator Hertel observed.

Future legislators?

Will the family tradition continue to the next generation? Although Curtis Hertel Jr. has four children, the oldest is just 12. As for Kevin Hertel, he concedes a member of his family’s next generation could follow the tradition, but that member, his first child, is not due to arrive until May.

In the meantime, the two brothers, one in the House and one in the Senate, are likely to play a more and more significant role in the Michigan legislature.



A closeknit family, the two brothers stand below their father’s portrait in the Capitol.

Children are not meant to die! (... or why we have our Coalition)

Pediatric palliative care is NOT a synonym for “hospice”, though confusion about the term has, sadly, sometimes led parents to delay commencing care for fear they might be giving up.

Pediatric Palliative Care

Much of the confusion comes from the historic association with hospice, implying a terminal prognosis, such as advanced cancer or severe congenital heart disease.

Children, even given a six-month life expectancy, almost invariably live longer. More often we may be looking at a condition where death is not inevitable, nor cure a likely outcome – some examples being severe immune deficiencies, advanced cerebral palsy, muscular dystrophy or cystic fibrosis.

Many pediatric cases involve care over years, rather than months. In this newsletter (see page 5) we tell the stories of Lila Ruetz, diagnosed with the DiGeorge Syndrome and needing constant care, and Anthony Varga who, suffering from mitochondrial disease, lived 13 years in need of care day and night.

The two stories, typical of many, should be enough to dismiss the fallacy that care is limited to the last six months of life. Palliative care enables children to live as full lives as possible, however short or long the term.

Curative treatment for the traditional hospice patient ceases on commence-

ment of palliative care. With pediatric palliative care, curative care is combined whenever feasible.

The National Academy of Medicine states “*Pediatric palliative care seeks to relieve symptoms associated with a serious medical condition or its treatment and to enhance the quality of life for children and their families, addressing their unique psychological, social and spiritual needs.*”

The American Academy of Pediatrics defines this further, “*the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death.*”

In Michigan, pediatric palliative care has been provided by leading children’s hospitals, like Helen DeVos, C.S. Mott and the Children’s Hospital

of Michigan, and by some of our major hospices, including Angela Hospice, the PATCH program, and Hospice of Michigan. Such care is second to none in the US. Yet its availability is not evenly distributed since our state is still largely rural with only a few concentrated urban centers.

Our Coalition

Until 2016, other states were ahead of us in creating their pediatric care coalitions, some by a decade or more. They showed what could be done — increasing availability of care across their states, lobbying to broaden Medicaid for children and lobbying both state legislators and commercial insurers for the removal of impediments to care.

At the Art for Charlie Foundation’s conference in East Lansing in 2015, representatives from the coalitions of



Anthony Varga spends Christmas at home a few weeks before his death in 2017.

five other states were invited to share their experience with caregivers here. Their reports encouraged all to move ahead. The Art for Charlie Foundation, established with the specific mission of promoting pediatric palliative care, became the sponsor of the Coalition.

In May 2016 representatives from our children’s hospitals, hospices and charities registered the Children’s Palliative Care Coalition of Michigan as a non-profit corporation and a 501(c)3 tax exempt charity.

Bereavement

Our Coalition serves primarily to coordinate and advance the needs and objectives of those who care for these children and their families. A secondary but more direct role is in creating a focus for the coordination of bereavement support.

Bereavement support is an inescapable component of the care we give. The parent/child bond starts early, even before the child is born. The death of a child is traumatic, and grief is natural. In fact, to cease to grieve could be ceasing to care. Siblings suffer too, often in ways they cannot express.

Families need the support of their circle and community, and sometimes professional help, so that they can start to look ahead and function again, even if sadness will probably always remain.

Grief is not limited to the death of a child. Parents experience anticipatory grief on receiving a potentially terminal prognosis, which may be months or even years before the death. There is

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Lila with her brother and her Aussiedoodle

Children are not meant to die!

(Continued from previous page)

also grief for a diagnosis that confirms a long term disability, whether cognitive or physical — grief for loss of expectation.

The Michigan Coalition welcomes parents with a child in palliative care, or who have lost a child. Sharing experience can help other families. Parents may find it helpful to tell their child's stories, and this can also help other families (See "Stories of our Children" on page 5).

As our Coalition grows we will be able to do more to support families.

Why we need members

We need to advocate for children and their caregivers. We need to ensure that care is not impeded by definitions of hospice, such as requiring a 6-month terminal prognosis, or excluding curative care concurrent with palliative. With

children we try not to give up hope. Children are not meant to die!

Pediatric palliative care coalitions have had a major impact on state legislation (see California's "Partners for Children" on page 6).

This makes our advocacy voice important, whether we are talking to legislators, the insurance industry or to medical institutions. As our membership grows, our voice grows stronger.

If you are reading this, you are probably a member. So how about passing it to your friends?

Members of a professional medical association pay only \$40.

Employees of a corporate member pay only \$25, as do family members.

All members receive our bi-monthly newsletter and a 50% discount on conference registration.

So pass on this newsletter, or maybe just the link to our membership page:

www.childpalliative.org/join.htm.

DNR in schools

(Continued from page 1)

So far, the only expressed concerns have been from the Catholic Coalition. Senator Warren is working with that coalition to clarify some of the language in the bill, such as specifying resuscitation efforts to be provided, requiring the consent of a child over 16, and requiring that the doctor, before signing the order, confirms the parents to be of sound mind and under no duress.

The bills should be ready to go to the Hemplouecouse in the fall after the committee hearing. So the new standards could be in effect for the fall of 2018 school year.

Our Palliative Care Coalition supports this initiative and input from members with personal experience of DNR in schools will be valuable at the Committee hearing.

Anyone interested, please call me (Dawn Krause) at 734-904-5663 or email drkrause@umich.edu.

Spiritual Advisers in Hospice and the special needs of the Muslim patient

The role of the spiritual adviser in a hospice or a hospital is not always well defined, and, in an increasingly secular age, it may be changing.

We asked a member of the Lansing area clergy who had worked previously in hospice what his role had been.

"I was there for those who needed me," he answered. "Some did. Some didn't."

He considered his role as more than merely ministering to patients of his own belief system. In some cases, he would act as a spiritual broker, locating someone from another sect or religion according to the patient's faith. Other times, his role might be more that of a social worker.

"So you, as a spiritual adviser cannot help people of every faith?" we asked.

"I certainly try and I will always listen", he answered. "But sometimes a faith has its own demands and practices

and it would be wrong for me even to try to accommodate them."

"Faiths such as?"

"Well, Islam, for example. It's tenets are demanding."

The Muslim Patient

So what about Muslims? We asked an Imam how important religious counseling was to a Muslim patient.

"Very," he told us. "Muslim patients may be more in need of a spiritual leader like an Imam or Shaykh (Islamic Scholar) than other spiritual or psychological support."

"More than a qualified therapist?"

"More than a doctor," he replied. "A Muslim spiritual leader is seen as an authority figure by most Muslims and his words mean more to many Muslims than the words of a doctor, nurse or social worker. Muslim patients are looking for answers in religion as much as in

medical science."

"What kind of answers?"

"Answers to the choices they should make. We should also remember that the needs of a Muslim patient include dress codes, interaction with the opposite gender, five daily prayers, washing and purification for prayers, fasting needs in the month of Ramadan, alternative medications, and dietary requirements."

"Sounds like a tall order," we commented.

The Imam shook his head. "These needs may be unfamiliar to healthcare providers in the west. But the patient comes first. Such care is essential if the best interests of the patient are to be served."



Stories of Our Children

Lila Ruetz -

"She knows more than people think."

We may never know what 7-year old Lila thinks. She has only 50 percent hearing, can distinguish little more than light and dark, and depends on oxygen through a breathing tube to live.

She cannot tell us in words what gives her joy, sorrow or pain, or what she fears and what she loves. Yet her eyes reflect how she feels the pains and pleasures in her life.

Lila Ruetz was born in Toledo, Ohio. With an impaired heart and severe breathing difficulties, she was diagnosed with DiGeorge Syndrome (sometimes known as CATCH22, an acronym for the multiple symptoms arising from partial deletion of chromosome 22).

Her condition required a series of operations before she could leave hospital three months after her birth.

Two months later, renewed concerns led to her return to hospital. A routine

heart catheterization may have prompted the seizures that caused brain damage. When no more could be done, Lila came home for the second time.

"She cried and cried for several days," Dawn, her mother, reports.

This made clear the urgency and importance of pediatric palliative care.

"It has helped Lila and helped us all to make our lives livable," says Dawn.

Both working people, Lila's parents would be unable to manage without home care under Medicaid expansion, which is 16 hours a day in two eight hour shifts during the week.



Lila with her mother Dawn

Although Lila cannot communicate in any conventional way, she enjoys the pleasures of life, like being walked in her stroller or splashing in the pool in summer. Her eyes light up for music – not so much Beethoven, perhaps, but certainly songs of Shirley Temple and country music with a strong beat.

Her staunch champion is her older brother. 9-year old Landon reportedly stood up in his class at school when the teacher, discussing a story they had read, remarked how people think the handicapped may not be so smart.

"Well that's not true," Landon protested. "My sister is handicapped but knows a lot more than people think."

Anthony Varga -

"He talked with hugs."

Anthony Varga could not talk, but he could hear and understand, testifying to a degree of inner cognition we can only guess at.

Coming from an American-Hungarian family, he was bilingual, understanding two languages. He enjoyed music, ranging from lullabies to opera. He was empathetic to others. To a sign of love or sorrow, he would respond in the only way he could – by hugs or kisses.

Born with serious neurological issues stemming from mitochondrial disease, Anthony grew into his teen years, wheelchair bound, unable to talk, and dependent on a feeding tube.

For his mother, Krisztina, caring for him, though an act of love, was a hard struggle that finally required her to stop work.

"I am a single mom who had to take an unpaid leave of absence to care for

my son," Krisztina tells us, adding, "We were not lucky enough for the state to approve nursing care for my son and respite care never showed up."

The family is an example of those who fall through the cracks of healthcare. Initially unable to qualify for Medicaid because income was too high, cover was denied later, the mother was told, because Anthony's height had reached five feet. Community Health accepted an appeal for home visits for respite care, but it was some months later that the designated agency turned up – on the day of Anthony's death.

Reimbursement for home care under their insurance was restricted to 150 days. Krisztina's mother, living with the family, was a major support but she died a year before Anthony.

Yet Krisztina is thankful for much.

"I remain passionate about the need



Anthony (right) with grandmother, brother and sister.

for better care for children with terminal illnesses," she says. "I could not have managed to get through all this without the wonderful team at UofM. Their encouragement and support and love for my son will always be with me."

Anthony's life profoundly impacted the family, and his twelve-year old sister Tiffany struggles with the trauma of grief. She will need the compassionate understanding of her community, and counsellors.

Want to receive free print copies of this newsletter?

- * And get 50% off conference registration fees?
- * And advance the cause of pediatric palliative care?
- * And keep up to date and network with colleagues?
- * And see your voice make an impact on Michigan healthcare?

It can cost as little as \$25 a month to be a full member of the Children's Palliative Care Coalition!

\$25 for employees or members of institutions belonging to the Coalition.

\$25 for family members.

To join, click on: www.childpalliative.org/join.htm

"Partners for Children"

California's Waiver Program

Any program providing better care for children at less cost is of interest.

California's Partners for Children is a Medicaid waiver program that does exactly this.

The core service of the program, Care Coordination, allows the sick child to receive medically necessary care at home and in the community. The saving is in home care as an alternative to hospitalization. It expands coverage and represents a break from the traditional constraints of hospice.

Instead of requiring a terminal prognosis of six months or less, the sick child must be diagnosed with a condition which, in theory at least, will require 30 non-consecutive days of hospitalization during the course of the year.

Benefits are clearly defined. The program allows "eligible children and their families to receive palliative care services during the course of the child's illness, while concurrently pursuing any curative treatment available for the child's life limiting or life threatening medical condition".

The legislation that made this possible, the Nick Snow Children's Hospice and Palliative Care Act of 2006, was the result of the direct initiative of California's Children's Hospice & Palliative Care Coalition. The enabling waiver took effect in 2008.

It is a great example of what a pediatric palliative care coalition can achieve.

Devon Dabbs from the California coalition will be describing the program in detail at our November conference.



2017 Conference

"Early Palliative Care - When to Start"

Friday, November 10,
The Peoples Church, East Lansing
Register early and SAVE!
www.childpalliative.org/events.htm

Stories of Our Children

(See page 5)

We welcome stories and pictures.

Parent members who would like the stories of their children told should email:
stories@childpalliative.org, or
phone 517-763-4413



About the Coalition
www.childpalliative.org



The Coalition is a 501(3)c charity, and welcomes all who support the cause.

Primary objectives are advocating for patients and providers, and ensuring resources are available across the state.

The Coalition was formed in the summer of 2016 by the leading practitioners, children's hospitals and hospices of Michigan, and funded initially by the Art for Charlie Foundation.

For more information:
info@childpalliative.org / 517-763-4413

Become a Member

Join online at
www.childpalliative.org/join.htm

All members, including employees of corporate members, enjoy discounted conference registration fees, regular updates and Coalition publications.

Employees of corporate members can join as individuals at a nominal rate. Members of professional medical associations can also join at discounted rates.

Membership dues are normally tax deductible.