

Children's Coalition Newsletter



Children's Palliative Care Coalition of Michigan

February 2017

Children's Healthcare in a Time of Uncertainty

Medical providers may never before have faced such uncertainty in the legislative environment. The Affordable Care Act (ACA) may be repealed, Medicaid expansion ended, and the Children's Health Insurance Program (CHIP) defunded.



Insurance -- the inescapable part of US healthcare

"Repeal" and "defund" sound ominous, but change need not be for the worse. New laws might replace or even broaden benefits of the ACA. We should believe intentions are good, even if an ancient proverb suggests they could pave the way to an unfortunate destination.

The Coalition's mission to widen knowledge about pediatric palliative care now needs to include awareness of its current funding. Our first targets are local, ensuring that our state representatives, as well as the public, understand the issues.

More than 46% of Michigan children (1.9 million) are insured by Medicaid. Another 70,000 children are enrolled in CHIP. 5% are uninsured. This means that more than half the children of our state will depend on government insurance when need arises.

In Michigan, Medicaid is managed by Medicaid Health Plans under tight contracts with the Department of Health and Human Services (MDHHS). The system is efficient. The average cost of treating a child under Medicaid in Michigan is only one third the cost of treating an adult. Yet most of the funding, some 65%, comes from the Federal government. So any reduction in the Federal contribution that might come from a switch to block grants would mean a serious financial hit to the state, and almost certainly to our hospitals.

Children insured under their parents' commercial insurance policies may fare less well without supplemental state support. Such insurance may not cover home care, often the best option, nor, in the event of hospice, pay for curative care at the same time as palliative.

While the Affordable Care Act requires government funded programs (like Medicaid) to pay for concurrent care for children re-

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ceiving hospice benefit, it is not mandatory for commercial policies. Children are not born to die, at least not as children. The fear of losing hope discourages acceptance of palliative care, even though the exclusion applies only to hospice. Concurrent care is not only in the best interest of the pediatric patient, but also reduce costs overall.

Recounting the story of her son Finnegan (see page 3), his mother Terri testifies to the importance to her family of Children's Special Health Care Services, the state program enabled under the ACA.

"Finn required 24/7 care," Terri tells us. "My husband and I both had to work to keep him insured and to pay the bills. If we hadn't had the benefit of those supplementary state services to care for

Finn in our home, we could not have managed."

Replacement legislation could, with willing legislators, have comparable provisions, including concurrent care, home visits, coverage beyond 21 on parental insurance, and the prohibition of excluding pre-existing conditions. How to fund any such replacement law?

That's for those advocating change to figure out! Our task, assuming good intentions, is to ensure they are well informed. The road to Hell is paved only with *ill-informed* good intentions.

If you are a member, consider joining the Coalition Advocacy Committee led by Dr. Jane Turner. But we can all play our part by telling everyone we know about the needs of children in fragile health.

If not a member, add your voice by joining. Join online at www.childpalliative.org. Our strength is in our membership. You will find information about the Coalition on the back page of this newsletter.

"That's the first time my child has smiled!"
See "Therapy Dogs", page 2

Comments?

Members can comment on
www.childpalliative.org/memberforum.htm

Therapy Dogs

"That's the first time my child has smiled!"

These are words Joel Maier, CCLS, has heard more than once from a parent of a very ill child when he visits with Denver, the therapy dog.

"Dogs have abilities that not all humans have," says Joel, Denver's handler. "They are non-judgmental, sense what we need, and exude love."



Joel is a child life specialist, a health-care professional whose job it is to help children and families cope with the stress of hospitalization and illness. In July, 2016, he attended a Canine Assistance course in Atlanta, Georgia, to become a certified therapy dog handler, a skill that fits in well with his other responsibilities.

Denver, a two-year old Golden Retriever works in the PICU at C.S. Mott Children's Hospital, Mondays to

Fridays in two-hour shifts. He starts his rounds at 10:00, with a break from noon to 1:30. Joel will lead him to the patient. Denver decides the approach to adopt.

If the patient is sitting up, he will go right over. He is trained not to lick but will gently nudge with his nose or quietly wait to be patted. Sensing a child is in fragile health, he will approach more cautiously.

In an end-of-life situation his behavior changes. Typically, he will rest his muzzle on a parent's arm, or even take the arm gently in his mouth – a habit Joel is careful to warn the parent about beforehand.

A therapy dog's effect on a patient is clinical as well as psychological. Lana Berry serves several hospitals with 25 dogs of different breeds through Therapaws of Michigan. She reports witnessing positive

change in a patient's heart rhythm on the monitor beside the bed.

There is credible science to support this. The UCLA Medical Center in Los Angeles conducted a study of 76 heart failure patients, randomly assigned to three groups, each to be visited at the same time by a handler with a therapy dog, a human volunteer, or no visitor. Those who had the dog showed marked improvement in all monitoring metrics. Levels of the stress hormone epinephrine dropped 17% with dog visits, compared to 2% for human volunteers alone. Those with no visitor showed no improvement in the same period.

Both Joel and Lana have noted that dogs show signs of stress after long exposure. Lana limits shifts to one hour and Joel to two hours, Denver being always in familiar surroundings while Lana's dogs visit different hospitals.

In critical situations, stress is more immediately evident. Lana sees the dog panting heavily after leaving the room. Joel reports that Denver will return to the office and go straight to sleep. If stress is still evident at the end of the day, he will call a friend with a dog to arrange a play date.

There are no formal studies of the clinical stress impact on the dog. The best evidence for relief of human stress may not be from any scientific study but the smile on a child's face.



Around the Camp Fire

Being in fragile health, even wheelchair bound, need be no bar to a camping experience for children. At North Star Reach camp in Pickney, Michigan, all can enjoy camaraderie, songs around the camp fire, and the natural world.

The camps are staffed by pediatric physicians and nurses 24 hours a day. Children who are able to can participate in all the usual camp activities, like nature hikes, canoeing, archery, swimming and crafts.

Campers sleep in cabins accommodating four families each or 16 individuals. All eat in the main hall, with meals that include a song or two! An outdoor amphitheater provides a home for the camp fire experience and performances by the campers themselves.

Summer camps are for children with specific conditions, such as cardiology, transplant, and Sickle Cell anemia. Spring and fall weekend camps are for families, providing both the camping experience for the children and respite for parental caregivers. Like the summer camps,

many are for children with a specific condition. The camp on the weekend of May 19 to 21, however, is for children in palliative care and their families.

The cost? Free of charge for children with a qualifying medical condition and their families! However, since the camp caters for children in the Great Lakes region, rather than Michigan alone, space available can be tight and it is prudent to apply early.

The founder, Doug Armstrong, is a University of Michigan transplant nurse who was instrumental in establishing the University's Michitanki transplant camp. After years of fund raising, the land in Pinckney was leased for the North Star Reach camp site, now home to Michitanki also.

In December last year, the camp became a full member of Paul Newman's SeriousFun Children's Network, joining 30 camps worldwide. The North Star Reach camp with its medical director Edward ("Skip") Walton is a member of our Coalition.

For details of the 2017 camps and how to apply, go to the camp's website, www.northstarreach.org. Campers are accepted "in order of application completion date".



Stories of our Children

The stories of our children are not eulogies but an attempt to learn what our children might teach us. Here are two boys who both died in February, 2016, one barely beyond babyhood and the other a teenager. Both lived their short lives with overwhelming challenges.

Parents interested in sharing their child's story are warmly invited to email admin@childpalliative.org

Finnegan

"His eyes were windows to his soul!"

For Finn's mother, Terri, the phrase has profound meaning. Unable to express himself through movement, words or even sound, Finn's eyes revealed his thoughts and emotions, and shone with understanding.

Finnegan Roy Daniels was born at Sparrow Hospital, Lansing, in May 2014 with obvious difficulties in breathing and swallowing. His condition was diagnosed as acid reflux and milk allergy.

He failed to thrive and seven months later his parents transferred him to C.S. Mott Children's Hospital in Ann Arbor where his condition was diagnosed as laryngeal cleft with a weakened trachea, a congenital anomaly often associated with it. When he did not improve after a tracheotomy, he went home with hospice support from the Anchors Program.

Hospice nurses were present every day in his Lansing home, including the morning he died in February, 2016.



"Despite his body failing in every way," Terri recounts, "he was always mindfully present. He would look you dead in the eyes and tell you 'I'm here'. He was like an old wise man, as if he knew so much more than we could ever comprehend. Until the moment he passed, he was blinking and smiling, letting us know that everything was going to be ok. Finnegan knew his name and always responded to it. ALWAYS. He knew he was my 'Finny' and loved to hear me sing silly songs about his name and the little boy he was."

Terri confirms how much continuing support from hospital personnel means to parents.

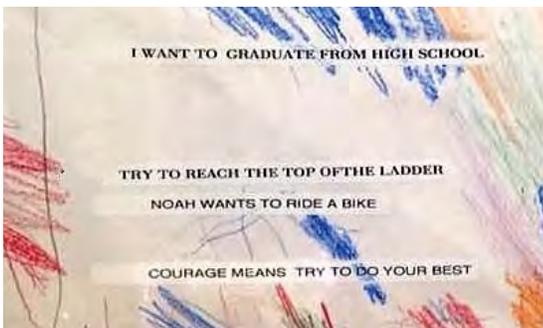
"What has been so important to the family has been the continuing outreach, including monthly phone calls from a social worker," she tells us. "His hospice doctor drove to Lansing for Finnegan's funeral, and to pay his respects to our family and our son. I will never forget his hugging me and telling me 'You did everything right.'"

(See our story on page 1 where Terri notes the dilemma of parents needing to work full time and care for a child 24/7.)

Noah

"He taught me that being joyful and present in each moment is far more important than worrying about what was to come."

Noah was diagnosed with sagittal craniosynostosis at his birth in 1997. Scans before surgery then revealed schizencephaly, a condition that can result in recurring seizures. Noah grew into his teens, severely challenged but able to talk, walk and eat and attend a school.



At age 11, Noah had an assignment to illustrate "What is courage, and what does it mean to you?". Unable to use pen or pencil, he tapped his answers on a label maker, placed them on the paper and decorated it. If not conventional art, it is nonetheless admirable.

At age 15 the seizures began.

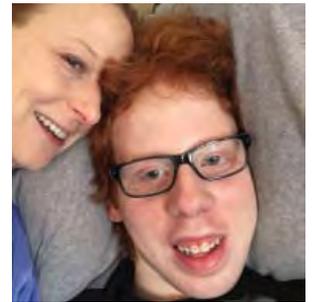
Noah declined rapidly to become non-mobile, non-verbal and totally dependent upon wheelchair, gastric feeding tube, and implanted catheter. There was comfort, his mother Heidi reports, in the way the teams at C.S. Mott, led by doctors like Terrance Murphy and Sucheta Joshi, worked together to ensure that Noah could live a life at home as normal as was possible.

Admitted for an infection, he died at the hospital in February, 2016.

"Joy and Laughter, Love and Light." These are the words we use to describe Noah and the way he lived his life. Despite all of the challenges hurled at him, he danced and smiled his way around them, over them, or through them with joy and laughter, love and light. He didn't understand the word "stranger", and every person he encountered was met with a fist bump, nose touch, or gentle hand hold.

His last four years, with the onset of epilepsy, were the most grueling years of our journey. Dr. Murphy's palliative care team, along with the medical team, worked hard to ease his struggles. They brought dignity and comfort into his last year without giving false hope. They were unobtrusive, inserting themselves into our hearts and minds, bringing calm and peace into the chaotic and terrifying world of end-of-life decisions.

I will forever be grateful for their presence in our lives."



Heidi Strasser, Noah's mother

Do Not Resuscitate (DNR) orders — Heidi's note:

I worked with the team to put a DNR into place for Noah in December 2015. They warned me that his school may not want to honor it, and I was ready for a battle.

There was no battle! They accepted it and worked out a plan. But I know this is a battle for some parents. If you want more information, please let me know.

See the report on the DNR legislative initiative on page 4. Members can contact Heidi through the member forum. Alternatively, The Coalition will forward emails.



About the Coalition

www.childpalliative.org



The Coalition was formed in the summer of 2016 by the leading children's hospitals and hospices of Michigan and by professionals specializing in pediatric palliative care. Primary objectives are advocacy and ensuring that resources are shared and available across the state.

Startup and the early months have been funded by the Art for Charlie Foundation.

Established as a professional association, the Coalition also welcomes all who support the cause, even if not involved in pediatric palliative care.

As a 501(c)3 charity, contributions by non-professionals may be tax deductible.

For membership information, see the website or contact info@childpalliative.org, or call 517-763-4413

Our Logo



"The inspiration for the logo came from three key words in the Children's Palliative Care Coalition of Michigan name—Care, Coalition and Michigan. I wanted the logo to reflect care and commitment to children which was the inspiration for the heart. The coalition is represented by the joining of the blue and green sections that make up the heart shape. For the reference to the state of Michigan I challenged myself to incorporate the image of the "mitten" through a fluid line that joins the blue and green sections. The colors were inspired by the natural blues of our state's waters and green of our land. I also wanted the color palette to be professional, friendly and approachable."

Daniel Henne



A graduate of the University of Michigan with a BFA in design, Daniel has been a Creative Director and Marketing Strategist for advertising agencies in the Midwest most of his career. His work has appeared internationally for clients in high tech, building products, financial, hospitality and health care industries.

Advocacy Can Work!

"Do-Not-Resuscitate" initiative moves forward

Under the Michigan "Do-Not-Resuscitate" Procedure Act, DNR orders are mandatory for health professionals. However, schools may have trained staff who are not "health professionals" defined under the Act, and a school may regard itself as liable because of its independent responsibility for the welfare of its students.

At our November conference, U of M law students Dorian Geisler and Russell Busch explained their initiative to make DNR orders mandatory for schools. Our Advocacy Committee endorsed the proposal, rating it high both for impact and feasibility.

Recently Dorian and Russell obtained an introduction to Michigan Senator Rick Jones and arranged a meeting including Maureen Giacomazza RN and Ken Pituch MD. Senator Jones indicated he is prepared to co-sponsor a bill, and passed the proposal to the state's Legislative Services Bureau to draft appropriate wording. Coalition testimony will be invaluable at the next committee stage.

As Maureen noted, "We look forward to legislative support to do the right thing for these children while allaying the fears of school personnel." (See also a parent's experience on page 3.)

2017 Conference

"Early Palliative Care - When to Start"

NOVEMBER 10 — SAVE THE DATE!

Friday, November 10, The Peoples Church, East Lansing
 Registration and program detail will be on the website shortly.

Members enjoy a 50% discount.

Pre-registration allows a further 25% discount.

Become a Member

Medical professionals gain from shared expertise and advocacy. All members enjoy discounted conference registration fees, regular updates and Coalition publications. Members of other recognized professional associations, can join for a nominal \$40.

To join, go online to www.childpalliative.org/member.htm.

If you received this newsletter in the mail, just detach and return the address panel at the top. We will mail an application form with a schedule of dues. (Or add email or phone for contact.)