

Children's Coalition Newsletter

Children's Palliative Care Coalition of Michigan



August 2017

Home-based Care for Children

"No parent should ever be forced to sacrifice hope for a child's survival merely to receive appropriate care." Devon Dabbs

When Devon Dabbs, a California film producer, learned how a family had to give up curative care to allow their child to receive hospice, it changed her path in life.

Her new direction would lead ultimately to the development of one of the most advanced and comprehensive pediatric programs in the United States.

For a parent to have to make such an intolerable decision for the child to receive palliative care was unacceptable to Devon.

She became a full time activist, lobbying state and Federal representatives for a change in law.

Together with Lori Butterworth, an administrator for a pediatric cancer nonprofit, she co-founded the Children's Hospice and Palliative Care Coalition of California to be a voice for their mission. In 2006 they had their first major legislative victory with the passing of the state's Nick Snow Children's Hospice and Palliative Care Act of 2006, requiring that children should be able to receive curative treat-

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ment concurrently with palliative care.

Four years before the Affordable Care Act's "Concurrent Care for Children Requirement" would make this the law for the rest of America, the Nick Snow Act was a significant step forward.

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Art – Lighting the Darkness

Children who create art despite overwhelming odds.

We have seen some remarkable and inspiring examples of art by children with life limiting conditions. We would welcome more.

10-year old Brodie painted with his left hand after his glioma deprived him of the use his right hand, 12-year old Julia had a friend support her hand to finish a painting, and 5-year old Charlie drew pictures that he said were to comfort his family and make his sister laugh after his death.

In this issue we showcase work by Olivia Werstein, who continued painting despite her crippling and terminal diagnosis of spinal muscular atrophy. Her mother tells her story on page 3.



Home-based Care for Children "Partners for Children"

(Continued from page 1)

For Devon this was only the start. Concurrent care for children had become part of California law, but there still needed to be a mechanism to provide it.

Through the new Children's Coalition of California, Devon continued to work on Medicaid waivers to take advantage of the mandates of the Nick Snow Act.

Concurrent Care

In requiring the California Department of Health to submit a Medicaid Home and Community-Based Service waiver, the Nick Snow Act provided the authority for the later establishment of the Partners for Children ("PFC") program. Named for a child who died from a brain tumor after "flunking" hospice care twice each time his condition improved, the Act is significant in letting seriously ill children receive hospice and palliative care without having to forgo medical treatment that might cure them or prolong their lives.

The American Academy of Pediatrics, in fact, recommends that pediatric palliative care should begin upon diagnosis of a serious life limiting or life threatening condition and continue alongside curative care or life-saving treatment.

Partners for Children Program

A pilot Pediatric Palliative Care Waiver Program was launched in 2009. Known as "Partners for Children", its success is now well proven, both for the better impact on patient care and family satisfaction, and also for the substantial cost savings.

The PFC program depends on the cooperation and participation of state and other agencies in each county. Children receive curative treatment at special care centers or hospitals. Local hospice and home health agencies provide the nurses and social workers to serve as care coordinators. So far the program is effective in 11 California counties covering more than four hundred families.

To qualify for the program, children must be younger than 21 years and have a qualifying life limiting or life threatening condition. Being a waiver program the child must also be eligible for Medicaid.

Children do not have to meet the hospice eligibility requirement of six-month life expectancy which applies to the Federal concurrent care provision. Instead a physician should be able to assert that the child is at risk of being hospitalized for 30 or more non-consecutive days during the coming year.

The waiver is based on the principle that if curative treatment is provided along with palliative care irrespective of life-expectancy projections, there can be an effective continuum of care throughout the course of the participant's medical condition.

The program is designed to meet the needs of the whole person — physical, psychological, spiritual, emotional and social. Each child is assigned a care coordinator to help the family manage their child's care based on identified needs.

Services include:

- Care coordination
- Pain and symptom management
- 24/7 on-call nursing care
- Art, music, massage and play
- Family education and training
- Support counseling
- Respite

The PFC program has been successful in building the confidence of families to provide care at home, and in reducing caregiver stress and worry related to their child's care. Studies have shown high levels of family and staff satisfaction with the PFC program among diverse families and children and a wide range of service providers.

Cost Savings and Insurance Market

The obvious limitation is the requirement that a child must be eligible for Medicaid. However, the program has been successful in inducing local commercial insurers to follow suit. The motivation to participate is prompted by the visible cost savings. A 2015 study showed:

- 50% reduction in the average number of inpatient days per month
- Average hospital length of stay reduced from 16.7 days to 6.5 days
- Net savings – after deducting program costs – of \$3,331 per enrollee per month.



Devon Dabbs – Cofounder of the Children's Hospice and Palliative Care Coalition in California, and our guest speaker.

Devon Dabbs

In 2015, Children's Coalition merged with the Coalition for Compassionate Care of California (CCCC), where Devon continues to advance the PFC program in her role as Vice President of Pediatric Programming and Education.

As a filmmaker and publicist Devon had noteworthy credits, including the Peabody Award-winning CBS documentary "*Break the Silence: Kids Against Child Abuse.*"

In her current role in advancing palliative care for children, Devon has been honored by The End-of-Life Nursing Consortium with their Award of Excellence, and by the California Association of Non-Profits for innovation in program design.

She has served on numerous boards, including California Hospice and Palliative Care Association and California Hospice Foundation boards and the National Hospice and Palliative Care Organization's Pediatric Leadership Council.

Having nursed the program from the start, Devon is uniquely qualified to share details of California's innovative "Partners for Children" program. As she will demonstrate at her conference talk on November 10, the Partners for Children provides not only better care for patients but also significant cost savings.

It is a model that other states might do well to follow.

The Anchors Programs

Expanding Pediatric Hospice and Palliative Care Across Michigan

Caring for a child with a life limiting illness can involve a family in hardships or expenses that neither insurance nor social services can compensate.

There is psychological stress for both the caregiver and the child. Taking a disabled child for repeat visits to hospital can be grueling. A single parent may have to give up his or her job to cope.

Grenisha King's family is an example. For Grenisha, a single mother with three children living in the Detroit area, life has been hard since the birth of her son Amere, born eight years ago with Brittle Bone disease. Grenisha has had to lift and carry her child for his every need, taking him to hospital for treatment more than 600 times in his short life. Having had to give up work, she struggled to survive. In 2015 she discovered Hospice of Michigan's Compass program.

Hospice care for children is still not widely available, and in any event normally requires a six-month terminal diagnosis to qualify. Yet palliative care by itself is not normally



reimbursable by state or private insurance.

Since 1995 Michigan's largest hospice, Hospice of Michigan, has offered help to families in the Grand Rapids area through their James B. Fahner Pediatric Hospice

Grenisha and Amere. program which, in conjunction with the Helen de Vos Children's Hospital, provides pediatric-trained staff offering comfort care, nursing, spiritual, emotional and grief support for children facing a terminal illness and their families.

A Pediatric Early Care Program provided non-medical palliative care for non-hospice patients, but cost limitations and the absence of insurance reimbursement were an impediment to broadening the program across the state. In 2015, the picture changed with a generous donation from Jo Elyn Nyman, a pediatric therapist and supporter of children's health.



Amere in his power chair

The donation enabled the hospice to dramatically expand its pediatric program, renamed the Compass Support Program, which is now helping families like Grishina's in more parts of the state.

We asked Grenisha for her opinion of the program.

"Wonderful!" she replied without qualification.

Her son Amere is a bright, talkative little boy, with tiny fragile legs. His diagnosis, formally known as Osteogenesis Imperfecta Type 3, is a variation of Brittle Bone disease that invariably means a shortened life span. His two older siblings, now teenagers, adore their brother, but with the demands of school the help they can give their mother is limited.

For the early years of Amere's life, Grenisha had to carry him everywhere, taking him back to hospital several times a week. At the same time, struggling with rent, Grenisha was forced to move several times.



James Fahner MD, Teri Turner RN, and Ken Pituch MD

Under the Compass program the family receive the support and comfort of regular visits from a social worker and periodic respite care. Hospital visits have ceased. More than anything, Grishina says, Amere's new power chair has changed her life. It has given Amere some relative independence, enabling him to move around without assistance.

The program social worker, Aimee Monticello, guided Grishina through the paperwork and helped her obtain approval for the cost of the chair from Children's Special Healthcare Services.

Since her involvement with the program, Grishina has moved twice. It's not easy to find single floor rental accommodation that is up to code and will allow construction of a ramp. With each move, the social worker helped the family obtain a grant for a security deposit from the Michigan Share a Smile charity. With the last move the program itself made a small additional contribution for the deposit.

The Anchors programs include a Perinatal Hospice Care program and a Center for Pediatric Research and Education. James Fahner



Elizabeth Rocha

MD is Pediatric Medical Director for the west of the state, and Ken Pituch MD is the Pediatric Medical Director for the program's expansion to the east. Teri Turner RN, who led as Statewide Director and Education Director, has recently retired.

We asked the new Director of Pediatrics, Elizabeth Rocha, about plans for further expansion. A key area to reach is mid-Michigan and so the program is now in discussion with hospices in the Lansing area to find one that might provide a base.

The biggest step forward might be if our state adopts a program like "Partners for Children" program (see page 3). The Compass program, for example, could then extend its service with medical treatment to include curative and palliative care.

Final Rite of Passage

by Toulia Saratsis, parent

The mother of a dying child finds solace in a home funeral

My daughter Angelica's first metabolic crisis came when she was three days' old. Nothing was for certain as to what the outcome of her condition would hold, but the prognosis was not good. Raising a terminally ill child evokes the inevitable acceptance of preparing for a different kind of future.

The greatest advocacy I could give my child was devoted attention to her needs.

The palliative care model of decision-making highlights the child's well-being. Angelica needed to feel safe. Preparing my child for death diverted the fear of losing her. I was taking control of the dying process.

The intention to keep Angelica home until the end was set early on in her seven year life's journey.

A daily struggle to maintain Angelica's physiological equilibrium was the medical baseline. Spiritual coaching and emotional support complemented her own desire for consistency in her life.

Angelica knew that there would come a day when Mommy would not be able to take care of her. Our family is Eastern Orthodox Christian. Angelica wisely understood the significance of the separation that would come.

I took great comfort in the fact that she did not fear dying, trusting we would anticipate her needs as usual.

Planning a home funeral resonated with my cultural heritage. I found it was also in keeping with parental instinct.

Witnessing Angelica's suffering and learning to cope with 24/7 medically complex caregiving solidified my resolve to be a part of her final rite of passage.

When curative care posed a greater threat of

harm over healing, we admitted Angelica into Hospice. I talked to her about the funeral during that treasured time leading up to her death.

She knew what she was going to wear and helped with details like wanting her hot pink sequined purse in the casket. Those tender moments consoled me as we prepared the body after her last breath.

Angelica passed shortly after midnight on July 30, 2015 with a triumphant and peaceful exit.

The reverse of giving birth, human dignity clearly displays itself in those raw moments where staying present and just being determines the next step.

The preparation unfolded naturally following the instructions from our consult with a Home Funeral Guide. Sitting vigil bedside all night next to the body in her bedroom felt familiar and was a powerful experience.

It gave me time to process the magnitude of what happened, taking in the reality. It was a gift of private reflection before the upcoming activity of the funeral.

The home viewing and funeral was our chance to lavish Angelica with the attention to detail she deserved.

We welcomed friends, family and colleagues in our home to mourn the loss of our sweet angel. It was a relaxed atmosphere as mourners moved about the home and our yard with the ease of a summertime soiree. Children approaching the casket, cautiously at first, were relieved to see that Angelica appeared to be sleeping. Some slipped mementos into her purse.



Angelica with Toulia, her mother.

Sharing stories, laughter and tears of remembrance fortified us, bracing for the grief journey ahead.

That night I slept on the couch next to her casket. Being alone again one last time further validated the decision to forgo embalming.

The following day a local funeral director and his staff assisted us with transporting Angelica to St. Nicholas for the service and the cemetery for burial.

Seeing the body leave our home was the most difficult part of the day. The physical separation would soon have earthly permanence. We had kept her home until the end, just as planned.



NOTE: Parents wishing to contact the writer for advice can email info@childpalliative.org with subject heading "Toulia Saratsis"

Olivia's Story

by Cynthia Werstein RN, parent

My husband and I were blessed with two girls, Elizabeth (oldest) and Olivia (youngest). Like most families, ours never suspected that we would need, and come so much to value, our pediatric palliative care team.

At the age when most babies were starting to walk, Olivia rolled all over the house. Her legs seemed weak, but because Elizabeth had walked at 10 months, we initially hoped that she was our "later" walker. But the medical evaluation of her weakness led to the diagnosis of spinal muscular atrophy, a neuromuscular disorder identical to Lou Gehrig's disease. (Both are motor neuron diseases).

S.M.A. is a genetic disease and my husband and I had no clue that we were carriers until we had an affected child. One in 40 people are carriers! Most children with S.M.A. don't live through childhood due to complications like pneumonia. Children are, however, living longer because of interventions like feeding tubes, spinal fusions, tracheostomies, and other advances to treat the complications of the disease.

Despite Olivia's terminal diagnosis (we were told to take her home and love her — "You might get her to age 3."), we were determined to give her a childhood that was as normal as possible, focusing on the things that she could do, not on what she couldn't.



At the start of each school year, we had to show her teachers and para-pros how to turn off the power to her wheelchair. Because Olivia was a speed demon in her wheelchair, we sometimes had to turn off the power and push her around as a "time-out" for speeding in the hallways, especially if other children were around. Olivia also possessed a wicked sense of humor too. Whenever an adult asked her what she wanted to do when she grew up,



Olivia Werstein

she would pretend to think for a minute and then would reply "Probably an off-road stunt unicyclist".

Olivia Werstein enjoyed painting -- and giving, possibly just as much. She painted wooden shapes as presents to give to friends, nurses and doctors. More paintings are on page 1.

Olivia LOVED creating art and despite the weakness of her body, painted wooden bird houses, wooden shapes, canvases and flower pots, usually painting them with a specific person in mind. She gave these to many people all through her lifetime. Many times she signed her art with "Live, love, laugh" on the back or bottom.

We still wonder what she might have created if her hands had worked normally. Every time she was admitted to hospital, she would ask, "Can I go to the activities center to paint?" There were late night raids more than a few times to the supply closet for paints and brushes (usually by Dad).

As Olivia grew older, it became harder to manage all of her different issues. Olivia's urologist would prescribe a medication

that would wreak havoc on her respiratory system. We felt that her pain wasn't being treated effectively. Olivia was seen by multiple different specialty doctors, but no one seemed to see her as a complete person.

We don't remember who made the initial referral to Pediatric Palliative Care Services, but it was a great call. It was such a relief to encounter a team whose focus was on symptom relief and improving the quality of her life, no matter what the length might be!

Our entire family was included because we were seen as integral to her happiness and quality of life. We were family, not just caregivers. Elizabeth's need to be a sister was now as important to Olivia's health as her medical issues. Shortly after we were referred, Dr. Kenneth Pituch sat down with Olivia and asked her what her goals were, and how his team could help her achieve them. The team approach was a huge help as it brought in multiple areas of expertise. The ultimate focus is on quality of life through symptom management.

Olivia passed away on June 23, 2015 and although we miss her



terribly, we find comfort in assisting other families dealing with child loss. Olivia's and our family's quality of life was improved significantly because of the help of the Palliative Care Services she received through the University of Michigan Mott Children's Hospital.

We believe that the Children's Palliative Care Coalition of Michigan is so important in working to ensure that more children across our state can benefit from such needed care.

Stories of Our Children

Telling the story of your child can help other parents. Every child is unique. Your child does not need to be an artist or talented in some special way.

Send an email with your phone number to stories@hildpalliative.org, and we will be in touch. Tell the story yourself, or we will work with you to tell it for you.



August 2017 Newsletter

The Children's Palliative Care Coalition of Michigan
3032 Hamlet Circle, East Lansing, MI 48823

Save the Date!

2017 Pediatric Palliative Care Conference

Friday, November 10

The Peoples Church, East Lansing, MI 48823

The conference will discuss California's comprehensive home-based care program from a Michigan perspective, and also possible future Federal legislative changes and their impact.

Devon Dabbs, co-founder of the Children's Hospice and Palliative Care Coalition in California, will outline the state's revolutionary program which provides home-based curative and palliative care without need for hospice diagnosis and at lower cost than conventional programs.

Senator Curtis Hertel Jr will talk about "Children's healthcare and the legislative future", reviewing anticipated changes in healthcare legislation and the impact on care in our state.

James Fahner MD will discuss the meaning and scope of pediatric palliative care.

Pediatric palliative care teams from our four leading children's hospitals will discuss their programs and best practices as a panel and with parents and patients. Speakers are from Children's Hospital of Michigan, Helen DeVos Children's Hospital, University of Michigan/C.S. Mott, and Beaumont Children's Hospital.

Make-a-Wish and similar charities will discuss their programs in "Charity Corner".

Work groups will focus on Education, Advocacy, Perinatal, Respite, and Bereavement, providing participants with a chance to work on ongoing projects and brainstorm initiatives.

An evening reception (appetizers and cash bar) will end the event with a networking opportunity for those able to attend.

Continuing Education certificates for social work and Nursing.

Registration

Early registration (Before October 2017) is available at low rates, particularly for members -- only \$10 for Family members, \$45 for professional members.

For more information, and/or to register, go to
<https://childpalliative.org/events.htm>

Become a Member

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

If you plan to attend the conference, consider becoming a member first to for discounted registration.

All members enjoy discounted conference registration fees, regular updates and Coalition publications. Family/parent membership is \$25. Professional or associate members employed by a corporate member or belonging to a professional medical association can also join at a discounted rate.



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:
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