The 2014-2015 Haslinger Family Pediatric Palliative Care Center Report
We received a beautiful letter from one of our parents describing how much our palliative care team meant to her and her family. She addressed the letter to “The Palette of Care Team.” In that phrase, she described so well what we strive to be—a transdisciplinary collection of colors that blends together on a canvas to paint the best picture of care for all of our families. Each painting is unique, created by our patients who hold the brush. The artwork shown above is one child’s vision of “the palette of care team” in her life—11-year-old Cassidy Jackson.

About Akron Children’s Hospital

Akron Children’s Hospital is ranked among the best children’s hospitals by U.S. News & World Report, but it’s our compassionate approach to treatment that makes us truly exceptional. To ensure families have convenient access to pediatric care, we have 2 hospital campuses in northeast Ohio and 90 urgent, primary and specialty care locations.

We partner with other health systems to bring our neonatal and pediatric expertise to patients in their community hospitals, and our home care and school health nurses care for kids in their homes and schools. With nearly 915,000 patient visits in 2015, we’ve been leading the way to healthier futures for children through quality patient care, education, advocacy, community service and medical discovery since 1890.

Learn more at akronchildrens.org.

Haslinger Family Pediatric Palliative Care Center
Akron Children’s Hospital
One Perkins Square
Akron, OH 44308
330-543-3343
akronchildrens.org
Hello Friends,

As usual, 2014 and 2015 were big years for the Haslinger Family Pediatric Palliative Care Center. I’m so excited to share all the updates with you.

Our 3-year grant from the Center for Medicare and Medicaid Innovation (CMMI) was extended through the end of 2015. The Healthcare Innovation Award, received in partnership with Nationwide Children’s Hospital, gave us an opportunity to deliver care in a different way, rather than the current fee-for-service model most healthcare organizations follow. Fortunately we’ve been able to keep 3 staff members from the grant – a nurse case manager, social worker and dietitian – through funding from our Children’s Health Collaborative. We upgraded our research assistant position in 2014 and increased the hours for our child life specialist in 2015. Also in 2014, we added an attending physician, Dr. Mona Raed, one of our 2013-2014 palliative medicine fellows.

In 2015, we renewed our Advanced Certification in Palliative Care from The Joint Commission, the organization that accredits and certifies healthcare organizations and programs in the U.S. and is a standard of excellence. A site visit in April 2015 went very well, and we received certification for another 2 years. As part of the certification, we are continually identifying and tracking certain quality performance measures, which are submitted monthly to The Joint Commission.

Schwartz Center Rounds continued at Akron Children’s, a national program that provides a forum for staff to explore the emotional and psychosocial dimensions of the care we provide. Facilitated sessions are held monthly, covering a variety of issues that may cause emotional distress for providers. We have also begun to investigate adding integrative therapies, such as yoga, reiki and aromatherapy to our offerings, as we continue to expand this initiative.

We were thrilled to have several annual fundraisers that continued in 2014 and 2015. The Courage for Carina Wine Tasting with a View celebrated its 6th year in 2015, and the Pediatric Palliative Care Family Fund Committee held its third Friends and FUNds event in Hudson, Ohio, as well as guest bartender events both years. “Wish You Were Here,” a highly successful local Pink Floyd tribute band, held a second benefit concert at the Akron Civic Theater in 2015 to raise funds for our center. Meritage of Miracles is a new annual fundraiser, which was started in 2014 by long-time palliative care volunteer Michelle Sergi and her family, to benefit our program in the Mahoning Valley. Their dedication and efforts have made it a great success, with the 2015 event raising nearly $30,000.

It almost goes without saying that all of these efforts to fund our center are focused on enhancing care for the children and families we serve. In 2015, we achieved several amazing heights – serving more than 2,500 families and providing more than 2.5 million patient days of care since we began. Our census and reach continues to grow. With the opening of a new neonatal intensive care unit (NICU) in the Kay Jewelers Pavilion, we have increased our involvement with NICU patients and those identified during pregnancy through our Fetal Treatment Center.

Thank you for taking the time to read our report, and as always, thank you for your support. Please feel free to contact us if you are interested in supporting any of the programs or services you read about here. We can’t do it without you!

With gratitude,

Sarah Friebert, MD
Director, Pediatric Palliative Care
Core Values

During a strategic planning session in June 2015, our palliative care team completed an exercise to identify the 6 words that best represent our core values. Here are the core values we identified:

Collaboration
- We encourage our colleagues, families and community partners to share their trusted expertise, knowledge and resources to achieve mutual goals.
- Together we use our individual abilities to offer resources, address challenges and explore new ideas.

Empathy
- We strive to understand and share in the unique journey of each individual.
- We accept all emotions and experiences, which cultivates a safe environment and trusting relationships.

Innovation
- We continually work to be leaders in establishing transformational, pioneering services and education.
- We develop creative and original solutions to challenges as they arise.

Integrity
- As a unified team, we aim to earn and maintain the trust of the families we serve through genuine and quality care.
- We commit to act with transparency and sincerity to facilitate superior outcomes with our community partners and colleagues.

Respect
- We honor the dignity of those we serve by embracing their individual goals.
- We accept others’ fundamental humanity and encourage them to overcome challenges and redefine success.

Service
- We continually seek opportunities to provide outstanding care and compassion to those who need it most.
- Our commitment to others ignites our everyday work and motivates our action toward patient, family and community advocacy.

The Haslinger Family Pediatric Palliative Care Center serves children, from before birth and into adulthood, who have complex, chronic or serious medical conditions. Pediatric palliative care provides an additional layer of support for families on difficult medical journeys, in partnership with cure-directed care.
2002
Dr. Sarah Friebert founded the Haslinger Family Pediatric Palliative Care Center.

The center received an endowment commitment from the Haslinger family.

2003
The center created a pediatric palliative care fellowship program to further our commitment to education and training. To this day, it is one of a limited number in the country.

2008
The center was chosen to be one of 2 Pediatric Palliative Care Leadership Center training sites by the Center to Advance Palliative Care.

The Children’s Garden of Hope & Healing was completed.

2009
Dr. Friebert was honored with the Children’s Miracle Network “Children’s Miracle Achievement Award” for her transformational work.

Our palliative care fellowship program received accreditation from the Accreditation Council for Graduate Medical Education.

2011
Akron Children’s received a $1.2 million donation to create an endowed chair in pediatric palliative care, believed to be the first of its kind in the country.

The Emily Cooper Welty Expressive Therapy Center opened. It’s the region’s only dedicated expressive therapy facility designed for patients, families, staff and the community.

2013
The center received Advanced Certification in Palliative Care through The Joint Commission.

2014
KIDJAM! Radio™ Recording Studio opened in the Expressive Therapy Center.

2015
Hillary’s Cherished Gowns program began creating bereavement gowns for deceased infants from donated wedding dresses.

The center renewed its Advanced Certification in Palliative Care through The Joint Commission.
2014-2015 CLINICAL ACTIVITY

BIG REACH

NEW FAMILIES SERVED AND PATIENT CONSULTS

2014

254 NEW PATIENTS

297 PATIENT CONSULTS

2015

288 NEW PATIENTS

493 PATIENT CONSULTS

PATIENT GENDER

MALE

2014 - 49.2%
2015 - 54.5%

FEMALE

2014 - 49.2%
2015 - 42.4%

UNKNOWN

2014 - 1.6%
2015 - 3.1%

PATIENT AGES

UNDER AGE 1

2014 - 56.3%
2015 - 59.4%

AGE 1-10

2014 - 18.9%
2015 - 22.6%

AGE 11-15

2014 - 9.1%
2015 - 8.3%

AGE 16-20

2014 - 11.8%
2015 - 6.9%

OVER AGE 20

2014 - 3.9%
2015 - 2.8%
TOP PATIENT DIAGNOSES

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prematurity/In Utero</td>
<td>0</td>
<td>19.4%</td>
</tr>
<tr>
<td>Cardiologic</td>
<td>16.9%</td>
<td>9.7%</td>
</tr>
<tr>
<td>Hematologic/Oncologic</td>
<td>16.5%</td>
<td>12.5%</td>
</tr>
<tr>
<td>Neurologic/Neurodegenerative</td>
<td>15.7%</td>
<td>17.4%</td>
</tr>
<tr>
<td>Genetic/Chromosomal</td>
<td>14.5%</td>
<td>13.5%</td>
</tr>
<tr>
<td>Sudden/Burn</td>
<td>12.1%</td>
<td>9.4%</td>
</tr>
<tr>
<td>Complex/Chronic</td>
<td>8.5%</td>
<td>5.6%</td>
</tr>
<tr>
<td>Pulmonary</td>
<td>8.5%</td>
<td>4.2%</td>
</tr>
</tbody>
</table>
In 2014-2015, we conducted or continued work on the following studies:

- Family satisfaction with services
- Bereaved family satisfaction with services
- Difficult Conversations Simulation Study
- Critical Care Transport for End-of-Life Care of Hospice/Palliative Care Patients
- Pediatric Palliative Care and Complex Congenital Heart Disease: Improving informed decision-making at the bedside for patients, parents, siblings and caregivers
- Family Functioning within Pediatric Palliative Care
- Family Bereavement at Akron Children’s Hospital
- Softening the Impact Following Discharge from the Pediatric Intensive Care Unit
- A Retrospective Look at Home Patient-Controlled Analgesia (PCA) Use
- Palliative Care in the Fetal Treatment Center
- Process Improvement to Standardize End-of-Life Care Process at Akron Children’s Hospital
- Good Mourning: An Assessment of Quality Care
- Understanding Death and Dying in Children with Life-Limiting Illnesses and Their Siblings
- CMMI Collaborative Agreement to Support Population Health Management Initiatives
- Family-Centered Advance Care Planning for Teens Living with Cancer
- Dietitian Impact on Malnutrition in Neurologically Impaired Patients: Retrospective Review

The Haslinger Center is also engaged in many quality and performance improvement initiatives to ensure that we deliver high-quality care as safely and efficiently as possible. Examples of these projects include: tracking home visit efficiency; ensuring access to resources/support services; developing service standards for consultation, inpatient, outpatient and bereavement care; monitoring team compliance with best practices in clinical care and documentation; developing protocols for transitioning pediatric patients as they age into the adult healthcare system; tracking adherence to therapy for patients with chronic pain; tracking issues with inpatient and home PCA; and developing a protocol for critical care transport of patients desiring end-of-life care outside the hospital setting. Performance improvement measures, including psychosocial and spiritual/cultural assessment completion, post-acute care discharge follow-up, and advance care planning/goals of care documentation, are tracked and submitted monthly to The Joint Commission.

BIG IDEAS

- Pediatric Palliative Care and Complex Congenital Heart Disease: Improving informed decision-making at the bedside for patients, parents, siblings and caregivers
- Family Functioning within Pediatric Palliative Care
- Family Bereavement at Akron Children’s Hospital
- Softening the Impact Following Discharge from the Pediatric Intensive Care Unit
- A Retrospective Look at Home Patient-Controlled Analgesia (PCA) Use
- Palliative Care in the Fetal Treatment Center
- Process Improvement to Standardize End-of-Life Care Process at Akron Children’s Hospital
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- Family-Centered Advance Care Planning for Teens Living with Cancer
- Dietitian Impact on Malnutrition in Neurologically Impaired Patients: Retrospective Review
When Naiima Oden was born prematurely, her mother Markita Batties expected things to go just as they had for her first child, Amirah, who was also premature and spent the first few weeks in Akron Children’s neonatal intensive care unit.

However, Naiima’s situation was much different. She spent the first 2½ months of her life at Akron Children’s and faced numerous challenges, including cerebral palsy, hearing loss and failure to thrive.

Markita was overwhelmed with caring for such a sick, fragile baby, along with her elderly mother and autistic brother.

She likened her experience during that first year and a half to being in a war zone.

“I stepped on a lot of land mines alone,” she said.

At the suggestion of one of Naiima’s therapists, who recognized that Markita needed help, she connected with the palliative care team in the Haslinger Center.

Naiima is now 7 years old. Although she has multiple special needs and requires a tracheotomy and feeding tube, her mom has learned to celebrate the small victories they’ve achieved along the way, such as when Naiima gains a pound or 2 or how she’s learned to communicate with a special device.

“Amirah is very protective of her sister and has learned a lot about medical procedures,” said Markita. “She wants to be a doctor when she grows up.”

Naiima has therapy sessions at Akron Children’s 3 times a week, with speech therapy being her favorite. She also has regular weight checks.

Although she weighs just 40 lbs., her dietitian Erin Teague has worked diligently to get her on the right formula that’s enabled her to gain weight.

Currently, social worker Denise Zehner is trying to enroll Naiima in school, which has been challenging because of her special needs and use of a wheelchair.

“Dr. Friebert has assembled an amazing team,” Markita said. “Although we know how busy they are, they make you feel like your family is the priority. I can’t say ‘thank you’ enough.”
Hillary’s Cherished Gowns

After hearing our bereavement coordinator Nancy Carst speak at an event, volunteer Karen McClain thought bringing an angel gown program to Akron Children’s Hospital would be a great idea. When a premature baby dies, finding clothing in the right size can be difficult, and grieving parents deserve something beautiful to dress their baby. Through angel gown programs, previously worn wedding gowns are sewn by volunteers into tiny-sized bereavement gowns. Karen connected with Marie Parker, a long-time palliative care volunteer, to bring the idea to fruition.

Initial progress was slow. But in February 2015, a story on the hospital’s blog highlighted a paramedic in the Mahoning Valley who asked for bereavement gowns from a national organization that provides them to hospitals upon request. That popular blog post mentioned Marie and the effort to start a local program, resulting in more than 200 emails with offers to help, sew or donate wedding gowns.

Things progressed quickly from there. Volunteers from local churches and other groups already sewing items for premature babies joined the effort. By the end of May, the group collected nearly 200 wedding gowns.

They also established an application process for gown makers to ensure they had the experience necessary to work with the precious but difficult fabrics. Once accepted, each volunteer receives a gown to sew into as many bereavement gowns as possible. Volunteers pick up the finished gowns and bring them to our center, where they are given to bereaved families. Photos of the finished gowns are sent to donors and posted on the group’s Facebook page to recognize both the donor and gown maker.

To honor Marie’s efforts in establishing the program, the group decided to name it after her daughter, Hillary, who died at 3 months of age in 1988. Currently more than 100 wedding gowns remain for the group’s 15 volunteers to turn into bereavement gowns.

If you are interested in donating or helping with the program, please visit facebook.com/hillaryscherishedgowns.
Ohio Home Choice Program

Since spring 2012, the Haslinger Center has been a transition coordination site for the Ohio Home Choice Program. This federal program is focused on getting individuals out of institutional settings to live at home. The project also focuses on redesigning the system by balancing community-based options with institutional ones. This has been a major resource for children who have been in the hospital 90 days or more and who need extra services and support to go home. To date, the Haslinger Center has served 155 families through this program, bringing in just under $2 million in available resources for families, as well as $750,000 in revenue to our center. The program continued through September 30, 2016, with possible expansion to 2020.

Grief and Bereavement Services

**Individual and Family Counseling** is available for bereaved family members as needed.

**Good Mourning Grief Support Series** helps children and their parents understand and deal with grief resulting from the death of a loved one.

**Hope for Grandparents Grief Support Series** offers support for grandparents who have experienced the pain of losing a grandchild.

**Precious Parents** is a pregnancy and infant loss support group run by parents for parents.

**Supporting Super Kids** is a support group for children ages 5-16 who have a family member coping with a chronic illness.

**Energized Toward Healing Grief Support Series** is co-facilitated by professionals and parents to provide information and support to bereaved parents.

**The Compassionate Friends, Akron Area**, is led by parent facilitators and offers friendship, understanding and hope to bereaved families.

**Family-centered, follow-up phone calls** are made to bereaved families by palliative care volunteers and staff.

**Support for Your Journey – A Resource Guide for Grieving Families** provides information on available community resources and other services to help families through the grieving process.

**Annual Remembrance Service at the Holidays** is a non-denominational service featuring speakers, music, a candle-lighting ceremony and slide show of children who have been lost. It is a huge event, which would not be possible without hundreds of volunteers and hospital staff members.

**Funeral Assistance Program** provides up to $500 for funeral-related expenses to needy families whose children have died at Akron Children’s. This provides for the basic cost of cremation and a service, or can help defray the cost of burial or other funeral expenses. This is an ongoing need and something we feel is important to offer to families. If you’re interested in supporting or raising funds for our Funeral Assistance Program, please contact our office.

For more information about any of these programs, please visit akronchildrens.org/palliativecare or contact the Haslinger Center at 330-543-3343.
Emily Cooper Welty Expressive Therapy Center

Akron Children’s Emily Cooper Welty Expressive Therapy Center is a unique facility in northeast Ohio designed for patients, families, staff and the community to receive holistic healing through art, music, theater and dance. Here patients use the creative arts to deal with illness, cope with difficult emotions and find comfort. The center is supported by the generosity of philanthropic donors, so all services are provided free of charge. Dedicated volunteers work diligently to assist the staff with preparing and supporting groups or workshops, offering extended programs, cleaning and organizing supplies, and planning events.

In 2014 and 2015, the center experienced continued growth and expansion. Maria Golden was hired to begin offering art tracking services. Art tracking is the process in which an artist facilitates and assists those with limited speech, or mental or physical disabilities in the art-making process. Clients use traditional and adaptive art tools to make their artwork. If needed, the artist is directed by the client as to what marks, colors and tools to use in creating the painting. The artist then becomes a neutral assistant, allowing clients to have control over the process and ownership of their pieces.

The center also welcomed Jessica Cole as a contracted music therapist. This allows the center to reach more children and families through music therapy both at the hospital and home visits.

In 2014, WeatherVane Playhouse began offering monthly drama workshops. This is in addition to the various other community organizations that allow us to offer expanded programming in the creative arts.

Akron Children’s and the Summit radio station came together in 2014 to open the KIDJAM! Radio™ Recording Studio. The studio offers a unique radio-broadcast-recording experience, allowing patients, their families, caregivers and hospital staff to record personal messages of hope, healing and fun. Hospital volunteers operate the studio’s equipment and encourage children to share their stories. After each recording, the patient family receives a keepsake jump drive, which includes a copy of the Summit-produced message and a photograph taken during the recording. Recordings created in the hospital are broadcast on KIDJAM! Radio™ during the Akron Children’s hour on Saturdays from 11 a.m. to noon.

For 2014 and 2015, expressive therapy staff provided 3,448 individual patient encounters: 1,309 for art therapy, 1,755 for music therapy and 384 for art tracking. In addition, more than 12,800 people attended workshops, group sessions, performances or tours of the center. Many community organizations, musicians, actors and dancers conducted workshops and performances.

The expressive therapy team also works diligently to support hospital staff through weekly and monthly music therapy open groups and a monthly art therapy support group. Throughout 2015, the therapists of the Expressive Therapy Center offered department-focused creative therapy support groups for team building and stress management.

The center has continued to host an annual patient showcase celebration entitled “Create Heal Inspire,” which is named after a neon sign that hangs above its main entrance. This event showcases paintings, drawings, multimedia works, songs, poetry and dances, all created or performed by patients, patient family members and staff. The event ends with a special performance by Dance Unlimited, a special-needs dance class which was started in 2013 by physical therapist Kellie Lightfoot. The class is a great opportunity for kids who may be unable to participate in traditional dance classes, while also providing a different type of physical therapy.

In 2015, the center’s staff increased awareness for the benefits of creative therapies by hosting a celebration during Creative Therapies Week. An open house allowed hospital staff to experience the center’s bright and inviting space and various art mediums. During the week, the center hosted its first staff art show, which allowed hospital staff members, volunteers and medical students to submit art pieces for display.

The staff at the Expressive Therapy Center has also played a crucial role in starting the Northeast Ohio Healing Arts Alliance. This is an alliance of organizations and individuals who want to promote and integrate expressive therapies into mental health treatment. With support from the Margaret Clark Morgan Foundation, the alliance is now offering quarterly education events to broaden awareness of various mental health and expressive therapy techniques that community professionals can use with their clients and families.
“WHEN I WATCH THE CHILDREN FROM DANCE UNLIMITED PERFORM, I KNOW THAT ALL IS RIGHT WITH THE WORLD.” — BARBARA BROWN, CHAIR OF THE HASLINGER CENTER COMMUNITY LEADERSHIP TEAM
Pediatric Palliative Care Fellowship Training Program

Our Pediatric Palliative Care Fellowship Training Program is accredited through the Accreditation Council for Graduate Medical Education through 2022. Palliative care fellows trained in 2014 and 2015 include Ellie Crow, MD; Jared Rubenstein, MD; Celine Cattier, MD and Paula McPoland, MD.

Medical Education

The Haslinger Center continues to offer elective rotations for medical students from Northeast Ohio Medical University and Akron Children’s Hospital residents, as well as residents and students from institutions that do not have well-developed pediatric palliative care programs.

We host nursing and social work students, physicians and other healthcare professionals who want to learn more about pediatric palliative care. Learners participate in consultations and family meetings, and receive overall exposure to the goals, philosophies and practice of pediatric palliative care.

We also welcomed some international visitors who spent a week or more to observe and learn more about our program: a palliative care nurse and advocate from South Korea and hematology-oncology physicians from Kenya. In 2015, we became a partner and mentor to a pediatric hospice facility in India called Happy Feet Home, and will continue to provide support and education, and eventually some financial support.

EduCATIONAL ACTIVITIES

Schwartz Center Rounds

Akron Children’s became a Schwartz Center Rounds site in 2013, and has continued to offer this forum for clinical staff to explore the emotional and psychosocial dimensions of care. Hospital staff members present on a variety of topics related to specific case examples, with the focus on supporting caregivers and strengthening relationships between patients and their care providers. An interdisciplinary steering committee meets regularly to plan the curriculum.

Scholarly Publications


Presentations

**Stephanie Allen**
- National Hospice and Palliative Care Organization Annual Clinical Team Conference, Dallas, TX; October 2015  
  – *Coordination in Palliative Care for the Medically Complex Child: Palliative Care to the Rescue* (Sarah Friebert, co-presenter)
- Akron Children’s Hospital Annual Nursing Conference, Akron, OH; October 2015  
  – *Telehealth: Improving the Patient Experience*
- Pediatric Grand Rounds, Akron Children’s Hospital, Akron OH; October 2015  
  – *The Triple Aim of Health Care: From Ideal to Real* (Sarah Friebert, co-presenter)
- Akron Children’s Hospital Advanced Practice Provider Conference, Akron, OH; May 2015  
  – *Coordination of Care for the Complex Palliative Care Patient* (Sarah Friebert, co-presenter)

**M. Karen Ballard**
- The Association of Professional Chaplains Annual Conference, Louisville, KY; August 2015  
  – *Developing APC Standards of Practice for Hospice and Palliative Care Chaplains – A Peek Behind the Curtain*
- Oates Institute Spirituality in Palliative Care Conference, Louisville, KY; March 2015  
  – *Spirituality of the Child and Family Facing a Life-Threatening Illness and Care of the Team Who Serves the Child and Family* (Sarah Friebert, co-presenter)

**Sarah Friebert**
- American Academy of Pediatrics National Conference and Exhibition, Washington, DC; October 2015  
  – *Managing the Business End of Your Palliative Care Team*
- Pediatric End-of-Life Symposium, he Herman & Walter Samuelson Children’s Hospital at Sinai, Baltimore, MD; March 2015  
  – *Starting the Conversation: Communicating Across the Divide*
- American Academy of Hospice and Palliative Medicine/ Hospice and Palliative Nurses’ Association Annual Assembly, Philadelphia, PA; February 2015  
  – *Barking Up the Money Tree? Developing a Financial Case for Pediatric Palliative Care*
- Center to Advance Palliative Care National Seminar, Orlando, FL; November 2014  
  – *Overcoming Barriers to Successful Implementation of Pediatric Palliative Care*
- Dartmouth-Hitchcock Medical Center, Hanover, NH; May 2014 and Greenville Health System Children’s Hospital, Greenville, SC; November 2014  
  – *State of the Art and Science in Pediatric Palliative Care: Arrive Early and Stay Late*
  – *Pediatric Palliative Care: The Future is NOW!*
- Carpenter Lecture, Mary Baldwin College, Staunton, VA; September 2014 and DeLoache Lecture, Greenville Health System, Greenville, SC; November 2014  
  – *Keep Me Well: Coming Home to Pediatric Palliative Care*

**Cassandra Hirsh**
- American Osteopathic Association/American College of Osteopathic Pediatricians’ Pediatric Track Conference at American Osteopathic Association OMED 2014, Seattle, WA; October 2014  
  – *Stressors Associated with the Diagnosis of Complex, Chronic and/or Life-Threatening Illnesses in the Pediatric Patient*
  – *Portraits of Life, Love and Legacy through Pediatric Palliative Care Documentary*
  – *Perinatal and Neonatal Palliative Care*
- Heroes March on Grief Conference, Roanoke, WV; June 2014  
  – *How Does the Interdisciplinary Team Support Families in the Hospital and Bridge Support to the Community as Death is Approaching and During Bereavement?*
  – *Transferring Wisdom Through the Experienced Eyes of a Parent*

**Erin Teague**
- Poster presentation at the Health Care Innovation Awards National Summit, Baltimore, MD; October 2014; Ohio Society of Pediatric Nurses Conference, Shelby, OH; September 2015; and Akron Children’s Hospital Annual Nursing Conference, Akron, OH; October 2015  
  – *Nutrition Influence on Health of the Complex Patient* (Stephanie Allen and Sarah Friebert, co-presenters)
- Children’s Hospital Association, National Clinical Nutrition Manager Webinar Series, Akron, OH; May 2014  
  – *Subjective Global Nutrition Assessment: The Nutrition-Focused Physical Assessment*
- Ohio Pediatric Clinical Nutrition Manager Retreat, Columbus, OH; May 2014  
  – *Subjective Global Nutrition Assessment and Case Study*
- Annual meeting of the American Society of Parenteral and Enteral Nutrition, Savannah, GA; January 2014  
  – *Creating Interdisciplinary Teams for Children with Complex Medical and Nutritional Needs*
We are extremely grateful to our dedicated volunteers, who donate hundreds of hours to help support our patients and families in many ways such as through:

- Home visits and phone calls to patient families
- The creation of beautiful handmade cards to send to patients on their birthdays and for bereaved families on special days
- Professionally taken portraits by Flashes of Hope and Now I Lay Me Down to Sleep
- Drawings of children for bereaved families provided by Faces of Angels
- Assistance with other programs and special events, including events and workshops in the Expressive Therapy Center
- Clerical Support

Community Leadership Team

Members of the Community Leadership Team support the Haslinger Center in many ways. They serve as advocates for the center in the community; attend and support fundraisers and other activities; support the center financially as individuals and by identifying potential donors in the community, and assist in the center's holiday activities. When new members are nominated, they meet with Dr. Friebert and the group’s chair and spend a half-day shadowing the palliative care team to learn more about the program. Members attend monthly meetings with Haslinger Center staff and staff from Akron Children’s Foundation and the volunteers department.

Community Leadership Team Members

Barbara Brown, Chair  Kathi Gorman  Jeannine Marks
Shelly Brown  Vicki Kovatch  Jody Miller-Konstand
Eileen Burg  Andy Lamb  Jaynee Nance
Catherine Clark  Meg Lamb  Marie Parker
Paula Dutton  Sue Locke  Vicki Parisi

Thank You to Our Volunteers

Adrienna Adams  Cierra Clark  Jaynee Nance  Donna Smoot
Anna Ali  Lauren Cole  Madison Noble  Ginny Snyder
Olivia Avsec  Jordan Conway  Joan Oldham  Rhonda Spada
Mary Baldwin  Jennifer Culp  Nancy Kaman  Rachel Sperino
Pamela Barrett  Ann Davis  Andy Lamb  Carol Stanley
Kyle Barron  Ginny Deighton  Kelly Livesay  Deb Stinnett
Kim Barsella  Tom Deighton  Sue Locke  Catherine Swain
Isabella Bartholomew  Lauren Delsanter  Yin Luo  Bridget Swihart
Julianne Blamble  Jaquelyn DiMatteis  Mary Lyons  Linda Szeles
Becky Blankenship  Julie Dewees  Tracey Mackay  Patrick Szeles
Linda Bowlin  Julie Dews  Jeannine Marks  Mary Thompson
Jack Boyle  Paula Dutton  Hannah Marcum  Jamie Tople
Victoria Bracher  Kim Emery  Ashley Mariano  Nicole Valentino
Korie Brittain  Ed Fabian  Gary Mariano  Kevin Vazquez
Ann Britz  Laurie Fenton  Nicole Martin  Karen Vincent
Maureen Brooks  Debbie Farris  Tori Mateika  Penny White
Barbara Brown  Heather Gerrets  Shelley McDannel  Shelly White
Eileen Burg  Kathi Gorman  Sarah McIntosh  Lori Wunderle
Connie Buzek  Stephanie Gross  Emily McKenna  Melanie Yannitto
Sandra Camp  Robin Habunek  Jody Miller Konstand  Hannah Yoo
Cathy Clark  Julie Hamad  Morgan Murray  Rachel Ziemba
Meet Barbara Brown

While leafing through a magazine at her doctor’s office, Barbara Brown came across an article about Dr. Sarah Friebert, who was being recognized as one of the area’s top doctors.

“Learning about the work of Dr. Friebert and the palliative care team really resonated with me,” Barbara said.

Later that evening, she told her husband what she had read and how the Haslinger Center helps families on their journey of care. He encouraged her to contact Dr. Friebert to see how she could help.

“I looked her up and left a voicemail message explaining that while this was probably an unusual call, I was moved by her work and wanted to see if there was some way I could help,” Barbara said.

Dr. Friebert called her back and asked if she would like to learn more about the Haslinger Center. Barbara later joined the Community Leadership Team, a group of volunteers who serve as advocates for the center and help advance its mission.

Barbara has served on the Community Leadership Team for the last 7 years, currently serving a 2-year term as chair. One of her first tasks was making weekly check-in calls to families.

“I was a little overwhelmed since I don’t have a medical background, but I soon found it very rewarding to connect with the families and see how they’re doing or if there’s anything they need,” Barbara said.

It has also brought her great joy to assist with the Holiday Elves program that delivers gifts and other holiday treats to palliative care families. She enlisted her sorority sisters to help fill stockings.

“It’s wonderful to see how the families appreciate the help and how something so simple can make someone’s day,” she said.

As chair of the Community Leadership Team, Barbara leads the group in supporting the care delivered by the palliative care staff. This includes day-to-day needs such as the card ministry that provides handmade cards to acknowledge special days for bereaved families, as well as new initiatives like Hillary’s Cherished Gowns, which provides bereavement gowns for premature babies, and a global partnership with Happy Feet Home, a pediatric hospice facility in India.

Always a champion for the center, Barbara is currently trying to recruit a friend who’s an attorney to provide some needed services for the families. She continues to spread the word about the center throughout the community.

“Palliative care stills get confused with hospice,” she said. “I try to dispel myths and help others understand the important role they play in caring for the entire family.”

In some ways, her involvement with Akron Children’s has come full circle. Two years ago, she was hired as a human resources business partner at the hospital, serving as a liaison between HR and 3 different hospital divisions.

Perhaps it’s this strategic perspective that helps Barbara see the big picture when it comes to palliative care.

“Dr Friebert is a true visionary,” she said. “She’s able to wear both hats very well, building a highly regarded program, while connecting with her patients and their families as she guides them on a difficult journey.” – Barbara Brown

Barbara and her husband Charles live in Akron and have a 23-year-old son, Caleb. A bit of a foodie, she enjoys cooking and trying new restaurants.
Tommy’s story

From the time Tommy Domotor was a baby, his parents knew there was something special about him.

“His mom called him Angel Face because he was such a good baby,” said his aunt Rose Dobbins.

Rose became the legal guardian for Tommy, who was 13 at the time, along with his siblings Tibor and Isabella, after their mother died from aplastic anemia in 2013. Their father had died unexpectedly from a brain aneurysm in 2008.

Rose, who has 3 children of her own, Sophia, Francesca and Henry, started a new life raising 6 kids.

“Tommy was a little genius. He did so well in school and in every sport. He was good at everything he tried,” said Rose.

One day after practicing football in hot weather, Tommy began vomiting. The coach assured Rose that other players vomited too, most likely because they were not drinking enough water. When the vomiting returned during basketball season and persisted for weeks, Rose knew something was wrong, although Tommy’s blood work and CT scans of the abdomen and intestines all were normal.

Pediatrician Richard Ball of Akron Children’s Hospital Pediatrics, Green office suggested a CT scan of Tommy’s head, where they discovered a huge mass of tumors in his brain, brainstem and spine. An MRI and biopsies in January 2015 confirmed it was cancer.

Although the prognosis was grim, Tommy knew he could beat it.

When he lost the use of his right arm and right leg and all hope seemed lost, Rose brought Tommy home so he could spend his final days surrounded by family. But then the unthinkable happened. Tommy started to get better.

“The day before Easter, Tommy had an MRI that showed the tumors had shrunk, although there was no explanation,” said Rose. “We went from saying goodbye to starting radiation treatment.”

Rose was determined to help Tommy make the most of whatever time he had left. They took a trip to Seabrook Island, SC, one of his favorite places. He was confirmed and graduated with his 8th grade class at St. Michael School in Canton. He started high school at Canton Central Catholic, where he attended homecoming.

When he went back to Akron Children’s for a check-up, he proudly walked to the MRI without the use of a wheelchair. However, this time the news wasn’t good. The tumors had grown.

“It was the first time Tommy cried,” said Rose.

Sadly, Tommy lost his battle to brain cancer on Dec. 19, 2015. He was 15.

Through all the ups and downs, the Haslinger Center was there for Rose and the children. She’s also grateful for the supportive community at St. Michael.

“Although the outcome wasn’t what we wanted, everything that happened around it was perfect,” said Rose. “His doctors and nurses did everything possible to keep him comfortable. When he was in the hospital, we had an adjoining room so Tibor and Isabella could stay close by.”

She also marveled at how the team in palliative care seemed to know instinctively what they needed, and despite it all, she saw Tommy smile and laugh more in the last year than she could remember.

One day, hospital president Bill Considine stopped by to visit. His presence and concern also showed Rose they were in a very special place.

“Mr. Considine’s blood flows through the hospital,” she said. “Being at the best place possible was truly a gift. I can’t imagine going anywhere else.”
Meet KeShawn

When KeShawn Sanders Jackson was born prematurely at 23 weeks gestation, he weighed just 1 lb. 5 oz. He spent the first few months of his life at Akron Children’s neonatal intensive care unit (NICU) at St. Elizabeth Boardman Hospital before being transferred to the NICU at Children’s Akron campus.

Through every step of the way, KeShawn has defied the odds. Although he has chronic lung disease due to his extreme prematurity, he’s no longer ventilator-dependent. Now 2 ½ years old, he’s learned how to walk and loves when his mom Marquitta sings and reads to him.

Marquitta is grateful for the support she’s received from the Haslinger Family Pediatric Palliative Care Center and KeShawn’s neonatologists in the NICU. They gave her hope and helped empower her to care for KeShawn at home.

“Even when the situation seemed hopeless, Marlene (Marlene Hardy-Gomez, palliative care nurse practitioner) gave me hope,” said Marquitta. “She always made me feel better.”

The palliative care team continues to support her by making visits to their home in Warren and helping to coordinate the team of specialists that provide ongoing care. KeShawn sees a pulmonologist for his chronic lung disease and an ophthalmologist for concerns regarding his vision. Although he is walking, he tends to walk on his toes, so he will be getting braces to help improve his gait. He also receives services from the state of Ohio’s Help Me Grow program to help him overcome developmental delays because he was born so prematurely.

Another way the Haslinger Center has supported Marquitta is through the Holiday Elves program that delivers gifts and other holiday treats to families.

“They brought wonderful gifts, which really helped to make the holidays special,” said Marquitta. “Everything was really nice and very much appreciated.”

Marquitta credits her faith in God and all of the support she has received from the Haslinger Center with KeShawn’s recovery. She also knows the loving care she’s provided for her son has helped him thrive despite the odds.

The entire experience has inspired Marquitta to get her GED so she can work with special needs kids.

“I’ve learned so much from caring for KeShawn and now I know that I’d like to help other kids too,” she said.
Palliative Care Funds

The following funds support the Haslinger Family Pediatric Palliative Care Center. The funds allow donors to direct how their money is used. Your gift to any of these funds will go a long way toward enhancing the lives of children and families. If you are interested in making a donation, please use the enclosed postage-paid envelope and indicate if there is a specific fund you would like to support, or contact the Akron Children’s Hospital Foundation at 330-543-8340. Thank you!

The Haslinger Family Pediatric Palliative Care Center Fund was created in 2002 with a generous $4 million commitment in support of the center’s operations.

The Palliative Care General Fund provides financial support for the immediate needs of the center, such as equipment and supplies for patient use, educational needs, or other expenses related to operations.

The Cushwa Family Pediatric Palliative Care Fund was established by Mr. and Mrs. William Cushwa to support program staff who provide unreimbursed care, such as our psychologist, dietitian, child life specialist and massage therapist.

The Pediatric Palliative Care (PPC) Family Fund assists families coping with the extreme financial stress of caring for children who have complex, chronic or serious medical conditions. The fund helps families with groceries and nutritional needs, transportation assistance, burial expenses and household expenses, primarily for families who do not meet the financial requirements of other assistance programs. Special items or experiences can also be funded for siblings.

Sarah Elizabeth Friebert, MD Leadership Chair in Pediatric Palliative Care Fund supports the director of the Haslinger Center and was started by a gift from the Sutkowski Foundation. This is the first pediatric palliative care endowed chair position in the country.

The Pediatric Palliative Care Fellowship Fund supports programs and activities to enhance the education of pediatric palliative care fellows trained at Akron Children’s Hospital.

The Courage for Carina Gift Card Fund was established in honor of Carina Britz, a palliative care patient who died in 2009. Funds are used to purchase gift cards for patients to buy items such as groceries, clothing, gasoline and other necessities.

Lauren Ellen Gartner, Forever in Our Hearts, Expressive Therapy Fund supports our Expressive Therapy Center, where patients and family members can participate in music, art, dance, photography and other forms of creative expression.

The Austin Michael Davis Memorial Endowment Fund was created by donations received in memory of Austin Michael Davis who died in 1992 at age 2½ from hemolytic uremic syndrome. It funds parent and family support services.

The Stan and Roberta Marks Fund for Music Therapy supports staffing, supplies, instruments, programming, education and other needs of the music therapy program.

The Colin James Carr Fund supports community bereavement services and programs at Akron Children’s Hospital. It was established in 2001 by Adam and Valerie Carr in memory of their son.

The Andre Sobel River of Life Fund assists caregivers by relieving financial burdens when other resources have been exhausted or are unavailable, particularly for housing, utilities, groceries, transportation, medical and burial expenses.

The Manny Rodriguez Patient Safety Education Fund supports education and training of staff and families related to patient safety, as well as the importance of pediatric palliative care for patient families.
Beloved daughter’s spirit lives on through Courage for Carina Gift Card Fund

With her chubby cheeks and dark brown curls, Carina Ruth Ann Britz brought joy to everyone who loved her. Although she passed away at just 21 months old, Carina’s spirit continues to brighten the lives of other families who are facing their own child’s serious illness.

Somewhere between the 20th and 25th week of her mother's pregnancy, Carina developed a condition known as hydranencephaly. The 2 main arteries to her brain failed to carry adequate blood supply to the cortex, preventing this portion of the brain from developing. Most babies with hydranencephaly do not live more than a few days to a month after birth.

Five days after Carina was born on June 25, 2007, her parents Ann and Joe took her home. With the help of the palliative care team in the Haslinger Center, they made sure she had a life filled with hope, peace and comfort.

“We can’t say enough about Akron Children’s Hospital,” said Ann. “The staff there is amazing.”

Joe and Ann wanted to find some way to give back to the hospital for the excellent care their daughter received.

“Initially, we thought we would fund some big piece of medical equipment,” said Ann. “We soon learned what's really needed is support for basic needs, especially during prolonged hospital stays.”

In 2009, shortly after Carina’s passing on March 31, Ann and Joe started the Courage for Carina Gift Card Fund to benefit patient families of the Haslinger Center.

The funds raised through an annual wine tasting event are used to purchase gift cards for groceries, gasoline and other necessities, which are given to families in need.

“We were fortunate to have good insurance and a great support system,” said Ann. “Not everyone is as fortunate.”

In 2009, Ann, Joe and their family and friends held a 5K to raise money for the fund, but decided that a wine tasting event would have broader appeal.

The following year, they held the first annual Wine Tasting with a View at Skyview Lodge in Brunswick, Ohio. Along with proceeds from the wine tasting, funds are raised through a silent auction of items donated by local businesses.

Since 2010, the Wine Tasting with a View event has raised $138,000, drawing a sell-out crowd of about 220-250 patrons each year.

Ann and Joe also invite a handful of families from the Haslinger Center to attend as guests of honor and share their stories, so other attendees can see first-hand how they’re helping others.

“We have an awesome team of friends and family members who help coordinate this event,” said Ann. “It would not be possible without their support, the staff at Skyview Lodge and the generosity of local businesses, especially those in the Strongsville and Brunswick communities, that have continued to support this event.”

For more information, visit courageforcarina.org.
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January 1, 2014 through December 31, 2015

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In 2015, Don Sitts Auto Sales in Cuyahoga Falls worked with members of the Pediatric Palliative Care (PPC) Family Fund committee to provide a vehicle for palliative care team members to use on home visits. Removable decals feature the Akron Children’s logo and Pal, the PPC Family Fund mascot.