S.H.I.N.E.
Sharing • Healing • Inspiring • Nurturing • Enduring

Blank Children’s Hospital
UnityPoint Health

UnityPoint Health
Des Moines
The SHINE Program

In the past 5 years, SHINE has become a vital component of the specialty care provided at Blank Children’s Hospital and UnityPoint Health – Des Moines. It is often challenging to measure the care provided to SHINE patients and their families using traditional metrics as the true measure is our patients’ and families’ experiences. SHINE provides families with comfort, education, and the gift of time during difficult care transitions; improves pain and symptom control; plans difficult perinatal deliveries to include memory making and tangible experiences; assists with adjustment; and provides support throughout bereavement.

The joy on a mother’s face when holding her newborn with a life-limiting birth condition or the cards of appreciation highlight the care that is provided and illustrate the story of SHINE. We hope that you enjoy our 2017 year in review report. We are grateful for the ongoing support that we receive from the leaders of our organization, our staff and providers, and especially the families that we have served.

Kathy Carroll Karpowicz, BSN, RN, MA
Director of Ethics, Palliative Care, and HRPP
SHINE Throughout the Years

2012
• Pilot program for perinatal and pediatric palliative care served 19 families.
• Nurse practitioner was hired to start the program.

2013
• SHINE name unveiled January 1, 2013.
• Team received 111 consults, greatly surpassing yearly consult goal.

2014
• SHINE added a second nurse practitioner to focus on outpatient services.
• Patients and families offered in-home visits.

2015
• SHINE focused on enhancing inpatient and outpatient services.
• Consult numbers continued to grow.

2016
• Palliative Care Clinic in John Stoddard Cancer Center (Suite 410) opened in August.
• SHINE participated in a variety of educational opportunities for inpatient and outpatient providers.

2017
• Our most successful year to date – we had a 21% increase in consults this year.
• SHINE received 3.6 consults per 100 admissions to Blank Children’s Hospital. National average is 2.6/100.

The SHINE program (Sharing, Healing, Inspiring, Nurturing, Enduring) provides perinatal and pediatric palliative care services in Des Moines and the surrounding area.

**Perinatal Palliative Care** focuses on families whose unborn baby has received a complex diagnosis. The SHINE team provides an additional layer of support to these families through their pregnancy, birth, and beyond.

**Pediatric Palliative Care** focuses on children and their families living with complex chronic medical conditions.

Palliative care can be provided at any stage of a serious illness and alongside curative treatment plans. This care aims to improve the quality of life in physical, psychological, social, emotional, and spiritual ways. The SHINE team is able to offer care to patients and families in the hospital, in the Palliative Care clinic, or at their homes.

Nicole Sample  
*Administrator, Palliative Care*
SHINE Services

Symptom management

Psychological, social, emotional and spiritual support

Goal setting

Advance care planning

Birth and journey planning

Continuity across the continuum of care

Care coordination

Legacy and memory making

Bereavement follow-up
FOCUS Values

See how the SHINE Perinatal and Pediatric Palliative Care team continues to make the FOCUS values more than words on a wall.
The SHINE team **fosters unity** by seeking an understanding of the patients' and families’ knowledge of their complex chronic medical condition, support network, and goals of care, as well as collaborating with the patients’ healthcare team. The SHINE team also **fosters unity** by utilizing interdisciplinary support provided by SHINE Champions.

Stephanie Nemmers, MSN, ARNP, CPNP
*Nurse Practitioner & Team Leader, SHINE Palliative Care*
SHINE Champions

UnityPoint Health employees that offer their time & expertise to enhance program development and help provide comprehensive interdisciplinary care to palliative care patients and their families.

Eric Johnson
MDiv, MS, BCC Chaplain

Amy Couchman
MA, CCC/SLP
Speech-Language Pathologist

Abby Snoberger
RN, MSN
Pediatric Clinical Manager

Brinda Taylor Porter
RNC
Bereavement Coordinator

Kelli Powell,
MA, MT-BC, LCAT
Music Therapist

Chelsea Capper
MSAT
Art Therapist

Jolene Vos
CCLS

Casey Manser
CCLS

Laura Camerona
CCLS

Kate Granzow
CCLS

Child Life Specialists:
The SHINE team **owns the moment** by establishing and building rapport with each patient and their family as they navigate their medical journey filled with complex needs.

SHINING STAR awards acknowledge interdisciplinary team members that **own the moment**.

Melissa Lipovac, DNP, ARNP, FNP-BC

*Nurse Practitioner, SHINE Palliative Care*
The SHINE program recognized three staff members within Blank Children’s Hospital for their outstanding contributions to the palliative care needs of patients and their families. Chelsea Capper, Kelli Rae Powell, and Casey Manser were presented with SHINING STAR awards.
The SHINE team *champions excellence* by maintaining commitment to best outcomes and highest quality in Perinatal and Pediatric Palliative Care, as well as participating in regional and national metric/data sharing opportunities.
The SHINE team shared data regionally with the Palliative Care Affinity Group within UnityPoint Health System in Iowa, Wisconsin, and Illinois.

Highlighted on subsequent slides is SHINE specific data for 2017 that includes:

• Number of families served
• Patient ages
• Demographics
• Primary diagnosis
• Consults by specialty
Patient age at time of consult ranged from 15 weeks gestation to 23 years.
Demographics

Non-English Speaking Languages

Payer Source

- Spanish
- Swahili
- Vietnamese
- Burmese
- Arabic
- Karen
- Laotian

- Medicaid
- Private
Primary Diagnoses

- Congenital: 50%
- Neurologic: 24%
- Multi-system: 12%
- Respiratory: 5%
- Heme/Onc: 3%
- GI: 4%
- Trauma: 1%
- Renal: 1%
- GI: 3%
Consults by Specialty

- Neonatal ICU: 37%
- Pediatric ICU: 23%
- Hospitalist: 19%
- Clinic: 11%
- Perinatology: 3%
- Oncology: 3%
- Pulm: 1%
- Neuro: 1%
- GI: 1%
- OB: 1%
The SHINE team also shared data nationally by participating in the *Provision of Services in Perinatal Palliative Care: A Multicenter Survey in the United States* and submitting yearly data to the National Palliative Care Registry.
Multicenter Survey on Perinatal Palliative Care

75 perinatal palliative care programs (including SHINE) from 30 states (highlighted in gray below) within the United States participated in a survey that inquired about services provided to perinatal patients and families.

**Multicenter Survey on Perinatal Palliative Care**

Below is a summary of Perinatal Palliative Care program services provided as outlined in the survey. SHINE Perinatal Palliative Care offers all of these services – specific examples provided by SHINE are noted.

<table>
<thead>
<tr>
<th>Service</th>
<th>Example</th>
</tr>
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<tbody>
<tr>
<td>Interdisciplinary team members (e.g. nurse practitioner, chaplain, child life specialist)</td>
<td>Goals of care developed (e.g. Birth and Journey Plan)</td>
</tr>
<tr>
<td>Grief and bereavement services provided (e.g. time of death, EDD, 1 month, 3 months, 1 year)</td>
<td>Information on online- and community-based support groups offered</td>
</tr>
<tr>
<td>Spiritual or religious needs addressed (e.g. Belly Blessing)</td>
<td>Participation in memory making activities (e.g. Build-A-Bear heartbeat recorders)</td>
</tr>
<tr>
<td>Cultural needs and wishes assessed</td>
<td>Ethics consultation available, if needed</td>
</tr>
</tbody>
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National Palliative Care Registry

The National Palliative Care Registry is a collaborative effort of the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center (NPCRC) that provides “actionable data that palliative care programs can use to secure and expand resources for the delivery of high-quality palliative care.” The National Palliative Care Registry has recently expanded to include national pediatric program data.

CAPC is one of the four core organizations that strengthen and advance the pediatric palliative care field. The other core organizations include the American Academy of Hospice and Palliative Medicine (AAHPM), American Academy of Pediatrics (AAP), and National Hospice and Palliative Care Organization (NHPCO).
National Palliative Care Registry

The SHINE Program submitted 2015/2016 data to be included among the 52 reporting Pediatric Palliative Care Programs in 27 states and Washington, D.C.

The SHINE team at UnityPoint Health collaborates with Blank Children’s Hospital, UnityPoint Clinic: Pediatrics, and Blank Children’s Primary and Specialty Care Clinics as well as other surrounding hospitals and clinics.
SHINE has impacted 381 families in 44 counties across Iowa since the beginning of the program’s launch on January 1, 2013. SHINE has also supported families living in Colorado, Minnesota, Illinois, Indiana, Missouri, and Nebraska.
The SHINE team has **seized opportunities** to create partnerships within the community to provide resources to families on a variety of topics to improve care across the continuum.

- Adult care transition
- Advance care planning
- Bereavement
- Disease specific
- Equipment

- Financial
- Housing
- Memory Making
- School
- Travel
The SHINE team will continue to help each patient and their family identify their goals of care and collaborate with the patient’s health care team in order to foster unity.

The SHINE team will continue to own the moment by establishing and building rapport with each patient and their family as they navigate their medical journey.

The SHINE team will continue to champion excellence by sharing metric data locally (UnityPoint Health Palliative Care Affinity Group) and nationally (National Palliative Care Registry).

The SHINE team will continue to collaborate with healthcare teams at Blank Children’s Hospital, UnityPoint Clinic: Pediatrics, Blank Children’s Primary and Specialty Care Clinics, and other surrounding hospitals and clinics.

The SHINE team will continue to seize opportunities to create community partnerships to improve care across the continuum.
Donations

The SHINE program was given generous donations from the community in 2017.

Donations were received from:
• Annual family sponsored Turkey Trot in memory of Aaron Michael Lowe
• Annual family sponsored ISU tailgate in memory of Kaden Krausman
• Employee Giving Campaign
• Memorial gifts

These donations and philanthropic activities make it possible for SHINE to expand their program and enhance the services provided to patients and families.
Family Story

Kayra was born at 24 weeks gestation. Inpatient SHINE was consulted by the NICU team about 6 weeks after her birth. SHINE assessed mother’s knowledge of Kayra’s illness, reviewed available support, and discussed goals of care. SHINE followed Kayra throughout her stay in NICU and provided several supportive visits. Upon Kayra’s discharge, an outpatient palliative care order was placed and outpatient SHINE has been following since November 2014. Outpatient SHINE has provided care coordination, identified health care referrals, assisted with community resources, and continued to review current/future hopes/worries. Kayra has cerebral palsy, bronchopulmonary dysplasia, severe bilateral retinopathy, bilateral cochlear implants, and is G-tube dependent. Kayra is now 3 years old and enjoys attending preschool at Smouse Opportunity School.
Thank you so much for walking this journey with us. You do such an amazing job at what you do. You are thoughtful, caring, show empathy, initiate action and a great listener. We are so grateful we met you and for all you’ve done for us. - Parent

I don’t know what we would do without your team. - Physician

I don’t know how I could have done this without you. Thank you. - Parent

I’m sure you are a blessing to other grieving families like you are to mine. - Parent

Thank you for being a part of our son’s journey. It means a lot to us. You have provided us with so much hope on our journey. - Parent
As the medical world continues to rapidly advance, the need for palliative care is increasing. Improvements in medicine and technology are allowing more complex, chronic illnesses to be managed in less acute inpatient and outpatient settings. As a result, the needs of patients and families continue to increase in order to coordinate the multiple components of this care. It is humbling to be part of a team that is working diligently to do just that. Since the official start of the program in 2013, the SHINE team at UnityPoint Health has developed into an extraordinary example of patient and family-centered care. The team continues to educate other healthcare teams and providers of the multidisciplinary approach it takes to help patients with chronic and life-limiting illnesses or diseases navigate the healthcare system, addressing medical, social, psychological and spiritual issues.

For 2018, I look forward to continued growth in the program as healthcare providers from all areas start to recognize the benefits of having the SHINE team involved in the coordination of care for their patients with life-threatening chronic illnesses.

Rich Robus, MD
Medical Director, SHINE Palliative Care
Thank You For Your Support

The SHINE Program is available Monday-Friday from 8 a.m. to 4:30 p.m.

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Palliative Care Clinic
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blankchildrens.org/shine