

Greater Illinois Pediatric Palliative Care
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GIPPCC strives to increase access to compassionate, quality pediatric palliative care programming and bereavement support throughout the state of Illinois.

GIPPCC is a state-wide coalition of fabulous people with a tremendous mission: to optimize the quality of life for every child living with chronic, complex, and/or life-threatening illness, their families, and the teams that care for them.

GIPPCC members include hospital systems, hospices, community organizations, individual health care providers and heroic families dedicated to supporting children and family members in their emotional journey from diagnosis through treatment and into bereavement care, if needed.

GIPPCC impacts policy, supports families, provides education, engages in research, and develops best practices guidelines to improve care and raise awareness about the unique needs of sick children.

While the death of a child is unimaginable, for over 1,500 families a year in Illinois, it is a reality. And an additional 1000 families experience a miscarriage or stillbirth each year. While the pediatric death rate is declining, the overall prevalence of children with serious illness is increasing. And sadly, infant mortality is on a raise.

Over 2,800 children in Illinois currently live with a serious illness. Another 1,200 Illinois children are newly diagnosed every year. Despite advances, 89% of parents continue to report that their child suffered greatly from one or more symptoms at the end of life. Most children continue to receive nearly all services in acute care settings, at an exorbitant cost to the health care system. Nearly half of all pediatric deaths occur in the hospital even though families consistently report the desire to be home.

Without adequate home-based pediatric services, many families end up making numerous difficult trips to the hospital hours away from home, their siblings and their community. Some children are forced to remain hospitalized because they are not able to secure adequate home-based services. Others without adequate support to stay at home, make more frequent emergency room visits and have avoidable hospitalizations. This is both tragic and expensive. Less than 1% of children who could benefit from Pediatric Palliative Care receive it. Illinois continues to rank in the bottom tier nationally for access to pediatric hospice care.

While we can not change a prognosis, we can change how we care for children and their families. Pediatric Palliative Care is family-centered care that optimizes the quality of life by anticipating, preventing and treating suffering. Palliative Care addresses physical, intellectual, emotional, social and spiritual needs throughout the continuum of the illness. Palliative care teams can help facilitate discussions regarding goals of care and assist with coordination of care across settings.

As a collaborative entity, GIPPCC undertakes several key tasks to further the growth of quality pediatric palliative care programs in Illinois, including the following: (1) organizing and leading education programs; (2) consulting and advising hospice programs, particularly smaller programs that only care for the occasional child, regarding quality care for children; (3) educating policy makers and the community regarding the need for change in the system of care for kids with advanced illnesses; (4) directing and engaging in research with the collective group; (5) improving the complex continuity of care for children with advanced illnesses; (6) operationalizing a mentorship program for nurses and physicians; and (7) striving to ensure available, consistent quality palliative care for every child in Illinois with a serious illness.



With GIPPCC support, pediatric palliative care has expanded to teams at 12 hospitals, 16 hospices and collaborates with over 70 organizations that care for seriously ill children and provide grief support in Illinois. We serve approximately 950 children in clinical care and over 1,300 families through bereavement support. Our listserv consists of over 1,300 local and national professionals. And we are honored to have the services and input from a very robust Parent Advisory Committee.

This past year, GIPPCC sponsored and/or participated in more than 11 educational events, ranging from large healthcare systems at Lurie Children’s and Advocate to individual team trainings throughout the state of Illinois, reaching diverse geographic regions of Illinois, with nearly 600 attendees, 3 parent panels and 17 presenters.

We began 2019 with an ambitious goal to work with policymakers, healthcare providers and families in developing a care delivery model for home-based pediatric palliative care. Home-based pediatric palliative services have been shown in multiple studies to keep children out of the hospital, improve the medical management of symptoms, decrease family stress and result in better childhood quality of life while maintaining budget neutrality. Pediatric Palliative Care has demonstrated an effective way to reduce costs for children serious illness by shifting costly inpatient care to more coordinated and less expensive outpatient care.

We are thrilled to report that Senate Bill 1105 unanimously passed through the Senate and approved by the Appropriations House Human Services committee. We are thankful for the Legislators and their tireless efforts to secure support from HFS/Health and Family Services

and Illinois's Medicaid managed care organizations, to develop a program to help control the cost of care while improving the health and quality of care for children and their families. Our goal is to work together to assure the state's most medically fragile children have the quality care they deserve.

With support from the Illinois Children's Healthcare Foundation (ILCHF), GIPPCC developed a model for APN/Physician Mentorship and successfully matched three mentees from low-resource areas in Illinois with experienced pediatric palliative care professionals. The mentorship included shadowing experiences, personalized home study curriculum, national and regional education program attendance and supported the development of a guided program improvement element to enhance care at the fellow's home institution. The program utilized a train-the-trainer approach by providing resources for coaching the interdisciplinary palliative team at the fellow's home institution.

The mentorship program increased access to high quality pediatric palliative care for more than 155 children in the Springfield, Peoria and Urbana areas. Interest in this program grew quickly. To reach more clinicians, GIPPCC launched weekly "virtual rounding" with nine physicians from across the state during which they discuss cases and best practices with other pediatric palliative care physicians. GIPPCC is exploring funding to expand to family services teams (social work, child life, chaplaincy). The mentorship experience has received national recognition through presentations at AAP/American Academy of Pediatrics and AAHPM/American Academy of Hospice and Palliative Medicine conferences as a successful model for growing a trained workforce in palliative care.

We realize, though, that the essential lessons learned, and the most impactful voices come from parents. Our Parent Advisory Committee is comprised of parents and caregivers representing a variety of experiences – children of different ages, different diagnoses and different decision-making choices. The parent panels at GIPPCC's educational programming provided a unique opportunity for healthcare professionals to hear powerful stories of resiliency, hope, and healing and gain a deeper understanding of how pediatric illness and death impacts families, friends, caregivers and communities. GIPPCC commends parents who bravely share their stories as their beautiful words produce more compassionate healthcare providers and caring communities.

In partnership with IDPH/Illinois Department of Public Health and ISBE/Illinois School Board of Education, GIPPCC had a unique opportunity to train nearly 1000 school nurses on pediatric palliative care and the POLST/Physician Ordered Life Sustaining Treatment. GIPPCC utilized the opportunity to partner with regional members to provide education, build awareness and promote area resources during the IDPH/ISBE School Health Days hosted at 5 locations. GIPPCC continues to offer guidance in managing medically fragile students in schools, supporting POLST, and planning for medical emergencies at school. GIPPCC is working with IDPH/ISBE to develop state-wide guidelines and education to

support school teams with the emotional and complex responsibility of caring for children with life-limiting illness.

GIPPCC partnered with coalitions in California and Pennsylvania to offer a Pediatric Palliative Care Webinar Series to raise the visibility of pediatric palliative care and to build clinicians' competencies and confidence in providing care to children. Given the success of the webinars and overwhelming positive feedback, the Coalition designed series for 2018, 2019 and 2020. This collaboration allows for more efficient use of resources and shared talents as this series focuses on commonly requested topics and highly sought-after speakers who can share their expertise with a national audience rather than replications of the same topic in multiple venues. Within this collective community, the webinar series is able to provide pediatric content in a cost effective and cohesive manner.

In addition, GIPPCC collaborated with California and Pennsylvania again for a grant from the Funeral Service Foundation (FSF), to develop guidelines and teaching materials to support funeral service professionals and the families they serve following the death of a child. The project calls upon health care providers, parents, funeral service professionals and grief specialists to offer their expertise and experience in developing tools and resources that will best help foster a healthy, healing funeral experience for families and their communities.

Childhood deaths reverberate broadly through their impact on families, schools, communities, and healthcare providers. We estimate that Chicagoland pediatric deaths impact at least 4,500 people annually. Childhood death imposes special challenges for bereaved survivors who are at risk for complicated grief, depression, anxiety, poor physical health, and increased mortality. Unfortunately, Chicago suffers from inadequate access to and delivery of bereavement support services, leaving those affected by childhood death to grieve without help

We believe that regardless of where a child dies, how they die or how old they are, every family deserves access to support. Sadly, all too many families are left to grieve on their own. The Child Loss Coalition is determined to change that. Under the auspices of GIPPCC, the coalition comprises 180 individuals from 70 organizations, working to expand the availability and quality of resources for those impacted by childhood death through education, program development, research, and collaboration. When a scoping of data on child deaths revealed that nearly 40% engage the Medical Examiner's Office, the Coalition hosted an educational session at the ME office and is working on collating specialized support packets to make available to families that interact with the ME's office.

In a primary goal to develop a central referral system, we have engaged the professional services of NowPow, a technology platform that specializes in community resource mapping. The Child Loss Coalition is currently working on developing a unique "algorithm" to help

identify best fit grief services for individuals or communities in need as well as taking into consideration key social determinants of health.

GIPPCC received additional funding from Lurie Children's, ARCC/Northwestern and NAGC/National Alliance for Grieving Children to continue this important work through rebranding the Child Loss Network with a more outward-facing community-friendly name, develop a public awareness campaign, generate a fundraising strategy, and design a website to share educational information and resources with families and professionals. Our long-term goal is to ensure that anyone affected by childhood death has access to quality bereavement support services.

The work of the Child Loss Coalition has also received national recognition with poster presentations at both the AAHPM/American Academy of Hospice and Palliative Medicine Annual Conference and AAP/American Academy of Pediatrics. GIPPCC and the Child Loss Coalition hosted their first joint conference at Lurie Children's in October 2019. The unique position of the Child Loss Coalition in relationship to GIPPCC has allowed a connection for providers and system of support for families impacted by illness from time of diagnosis through their grief journey.

GIPPCC and Child Loss Coalition members also worked together to promote the 1st Annual Butterfly Run Walk + Flutter. The goal of the event is to bring families together who are caring for children with life-limiting illness, to celebrate the memory of children who have died and honor those who serve and care for these special children. While chilly, the sunshine reflected parent's gratitude and the joy in gathering together in celebrating their children's memory. The Butterfly Walk gave us the opportunity to come together as a supportive community and to raise funds to support PPC and Bereavement Support. Over 400 participants, including families, providers and volunteers attended with an additional 50 online supporters. Before the day was over, there was already requests to do it again next year

The Greater Illinois Pediatric Palliative Care Coalition (GIPPCC) is grateful for the dedication of our staff, our partners and their deep commitment to helping families through the serious illness of their child, the end-of-life journey, and grief after their child has died. We would not be able to do the work we do, or reach as many families, without your support. As long as children continue to get sick, the need for hope and resilience remains. We hope you will join us as we pursue our goal of expanding pediatric palliative care and bereavement services to all who need it.