

Our Funding Goals

We are committed to raising \$310,000 annually in support of the highest priority needs of the Paediatric Advanced Care Team (PACT). An investment in one of the key funding priorities listed below will help ensure children and families have the best quality of life possible and receive support throughout illness, at the end of life, and into bereavement.

KEY FUNDING PRIORITIES

Interdisciplinary Fellowship **\$50,000-\$75,000/year**

Fellowships ensure the next generation of health-care providers have the skills necessary to provide the best possible care for our children and their families. An interdisciplinary fellowship with PACT will build capacity and advance knowledge sharing and innovation across the hospital by enabling health-care professionals to gain expertise in palliative care.

Hospital-Wide Grief Support Coordinator **\$80,000 /year**

The Grief Support Coordinator will work to ensure consistent palliative and bereavement care practices across the hospital that respond to the unique needs of each patient and their family. When a child passes away, the Coordinator will support family and friends during their bereavement, help create lasting memories, and ensure a smooth transition to community care.

Education **\$85,000/year**

PACT will undertake a number of education initiatives to continue building capacity and empowering health-care providers, patients and families. These initiatives include an annual symposium, a four-day staff workshop, conference support, resource materials on palliative care and bereavement, and upgrades to AboutKidsHealth, the hospital's online resource for families.

Research **\$50,000 one-time, \$20,000/year**

The Team for Research with Adolescents and Children in Palliation and Grief (TRAC-PG), based in the Research Institute, is a leader in promoting excellence in paediatric palliative and bereavement care. PACT will amplify the impact of TRAC-PG's efforts by building and maintaining a patient database and providing the part-time support of a research nurse.

Community Outreach **\$50,000/year**

Support for community outreach will allow PACT to organize and host bereavement support groups for patients, parents and siblings in collaboration with experts in the community and partner organizations. This will enhance community collaboration and ensure families are well supported even if their child is no longer receiving care at the hospital.



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SickKids

Paediatric Advanced Care Team

Delivering the best possible care to children facing life-limiting illness

We are the province's primary referral centre for patients requiring paediatric palliative care.



200
patients and families are supported by PACT every year

147
new referrals were made to PACT last year

90+
percentage of patients supported by PACT who are from outside Toronto

15-20
percentage of patients and families who require more than 1 year of follow-up care

The busiest hospital-based service of its kind in Canada, the Paediatric Advanced Care Team is part of a continuum of care for children with life-limiting conditions and their families. The goal of this care is to enhance choices, relieve suffering, and ensure the best quality of life.

The Challenge

Each year, more than 100,000 children come to SickKids to receive care. While the vast majority of these children will recover from their injuries or illness, others live longer but are not cured of the many problems related to their underlying condition or the treatment required to save them. Many of these children live with unique and complex health care needs and some of them will die before reaching adulthood.

Caring for these children and their families takes a special kind of care; it requires an interdisciplinary team that can respond to the diverse psychological, practical and spiritual needs of these patients; it takes collaboration across the hospital, the community and the province to ensure patients can be treated in the location where they are most comfortable; and it requires family-friendly hospital spaces that make it easier for parents to actively participate in their child's care and be cared for themselves.

Research has shown that the lack of proper support for children and families adds considerably to the family's experience of grief and is sometimes referred to as "double loss." To better support patients and families from the time of serious diagnosis, through the

illness journey, during a child's end of life, and during a family's grieving, SickKids established the Paediatric Advanced Care Team (PACT).

Why SickKids

SickKids has long been a leader in the field of paediatric palliative care. In 1987, in recognition of the complex needs of children facing end of life, the hospital established one of the first palliative care services in Canada for medically fragile children—children who are not well enough to be cared for in the home. Since that time, the service has grown into one of the largest hospital-based paediatric palliative care services in Canada, caring for more than 200 children and grieving families a year from across Ontario.

PACT offers children and families relief from the physical, emotional, social, and spiritual suffering that comes with illness, end of life, and bereavement, ensuring child and family are intimately involved in determining priorities for care at every stage. Four part-time medical doctors, three full-time nurses and two part-time nurses make up the team. They collaborate with doctors, nurses, social workers, and volunteers across the hospital and the community to ensure children and families can access the care they need whether they are at home, the hospice, or the hospital.

Trainees from all over Canada come to SickKids to develop or improve their professional skills in this highly specialized field. The hospital is also a hive of leading-edge palliative care research, thanks to the efforts of the Team for Research with Adolescents and Children in Palliation and Grief (TRAC-PG)—a research group based in the SickKids Research Institute. TRAC-PG's work is helping to improve paediatric palliative care practices all over the world.

Vision

PACT's vision is to ensure that the best possible palliative care is provided to every patient with a potentially life-limiting disease at the right time, and in the preferred setting of the patient and family. PACT will serve as the anchor for paediatric palliative care services in Toronto, as well as the province, by providing expertise, resources and direct care to support children and families throughout the illness, end-of-life and bereavement journey.

The main pillars of this vision include:

- increased focus on family-centred care;
- early integration of palliative care in the course of illness together with standard care;
- extension of care across the trajectory of the illness (including into bereavement);
- facilitation of care in the preferred setting of the child and family;
- increased access to palliative care experts on a 24/7 basis; and
- a fully integrated care model.

Dr. Adam Rapoport, as the Medical Director for PACT, will guide the efforts to implement this new vision, which will allow SickKids to develop a new model of care to benefit patients, families and communities while also gathering necessary data and case studies to support ongoing advances in the field.

Impact

The nature of paediatrics has changed markedly in recent years. Modern paediatric medicine has produced dramatically improved survival rates for fragile patients. For example, improvements in intensive care services have led to premature infants surviving longer than ever before. Patients with formerly incurable malignancies are surviving due to early diagnosis and intensive therapeutic regimens. Similarly, children with rare genetic and metabolic conditions are also surviving with the benefit of improved care.

Although a great many children now go on to lead perfectly normal lives, those who do not need compassionate, high quality care. It is incredibly difficult to talk about children dying, and yet, this very fact underscores the need to better support paediatric palliative care patients and their families. With support, we can build a palliative and bereavement care system in Ontario that rivals the world's best. The impact of such a system will be felt by families across the city, the province and the country.

I found the entire Paediatric Advanced Care Team to be incredibly professional. They first took the time to get to know me and my family before making any suggestions. In doing that, it showed me that they understand that every case is individual and there is no cookie cutter approach to such crucial decisions. All members of the team had such an open-minded approach and tried their best to help us bridge the gap between where we were and where we wanted to be. I am forever grateful for the opportunities the Team made available to my family. With their help, our family has created unforgettable memories.

~ Tyler Cooper, bereaved father of a SickKids patient