
Carol with Cassie, Zayva, and Tim McCachren in 2019

Providing Family-centered, Healing Care:

A Report on Your Investment in Miracles from Maggie

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Children's
Hospital of Pittsburgh
FOUNDATION

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In these challenging times, your giving makes a difference.

Miracles from Maggie provides vital funding to families served by the Supportive Care department at UPMC Children's Hospital of Pittsburgh. **Thank you for all that you've done to contribute to the care of our patient families in Maggie's name.**


JJ's family at the Supportive Care's zoo day for bereaved families

The COVID-19 pandemic has been very difficult for the children and families we treat here at UPMC Children's Hospital. Many of our patient families are now grappling with a host of social and financial issues on top of caring for their child during these unsettling times. With charitable support, our Supportive Care team has pivoted to meet the changing needs of patient families, providing virtual appointments, conducting safe in-person visits with precautionary measures in place, and attending to the medical and non-medical needs of families. The team further very quickly modified sibling bereavement camp to a virtual "camp in a box" platform this year — which the kids and families loved and appreciated.

Thanks to philanthropy, Supportive Care remains a comprehensive patient- and family-focused service that improves patients' quality of life, while contributing to the field of palliative care in many meaningful ways. **We are grateful for your contributions to Miracles from Maggie!**

Expanding the team to reach more families than ever before.

UPMC Children's Supportive Care Program continues to grow. The team recently launched a new Pediatric Palliative Care Fellowship program. **The fellowship is a one-year clinical training program that is offered to applicants preparing for an academic and/or clinical career in pediatric hospice and palliative medicine.** This past December, the team learned that they were matched with their first choice for the fellowship! This coming July, Kaitlin (Kate) Ostrander, MD, will become the inaugural pediatric hospice and palliative medicine fellow at UPMC Children's. She joins Children's from the University of Vermont, which is one of the top pediatric training programs in the country. Dr. Ostrander did her medical school at Tufts University where she graduated in the top fifth of her class, and graduated summa cum laude from Northeastern University. The fellowship that Dr. Ostrander will hold is an important new addition to the Supportive Care team's work because medical training represents the best way to answer the long-term need for more supportive care specialists.

Supportive Care further welcomed physician-researcher Dr. Justin Yu to the team in 2020. Dr. Yu is an Assistant Professor of Pediatrics. Dr. Yu has several ongoing projects that examine important issues in pediatric palliative care. He developed a novel method to identify children with medical complexity from the National Survey of Children's Health and is collaborating with multiple researchers, within and outside of the University of Pittsburgh, to examine the impact on families caring for seriously ill children. He recently completed a longitudinal cohort study of parental caregivers of medically complex children establishing care at UPMC Children's Complex Care Clinic. He is in the process of examining how caregivers' health-related quality of life changes once enrolled in the clinic. Dr. Yu also recently completed an in-depth interview study to explore the perspectives of parental caregivers of medically complex children on what constitutes high quality care at a pediatric complex care clinic. He has had three papers accepted for publication since joining as faculty. **Through this work, Dr. Yu hopes to improve the quality of pediatric palliative care available to families and expand access to needed services for children with medical complexity.**

Dr. Justin Yu

Last November, the Supportive Care Program additionally hired a new social worker specifically dedicated to the psychological, social, and financial needs of families served through the department. The social worker partners with Carol May, RN, MSN, MBA, CHPPN, and the rest of the Supportive Care team to provide support to the family; the social worker further acts as an advocate for the child and the child's loved ones. While the social worker hired in 2019 has since moved on to another position, a new social worker, Christine Ward, MSW, was hired in November 2020. The social work position adds an additional layer of individualized attention for families and further helps to connect patients and their loves ones to important resources.

Charitable gifts enable the Supportive Care Program to continue to expand with the significant goal of providing every child and family facing life-limiting illness with the exceptional quality of life care and bereavement services they need. Thank you for ensuring that a team member is always available whenever a family needs us most.

Going above and beyond to extend bereavement care to families.

The Supportive Care Bereavement Program at UPMC Children's would not exist as it does without the support of our generous donors. Led by Carol May, Lori Malazich, LCSW, and Melanie Szigethy, our sibling bereavement coordinator, the Bereavement Program helps parents, siblings, and extended family members cope with the loss of a loved one. **Through scheduled outings, a monthly, virtual support group, mailings, and a robust summer camp program for**

siblings, the Bereavement Program touches approximately 675 bereaved families each year. This past year, despite the COVID-19 pandemic, the team was able to host several in-person events, including the Have a Heart workshop, a trip to the Pittsburgh Zoo, and a Carnegie Museum visit. They further developed a wonderful quarterly family newsletter and continue to send hand-signed holiday and occasion cards, Beads of Courage, and other memento items to families.

Samuel's family at a bereavement group outing


A Camp Wakchazi family enjoying camp fun at home (left) in memory of their brother (pictured right)

As indicated, the very popular bereaved siblings summer camp program, Camp Wakchazi, was very quickly shifted to a virtual format this year. With the support provided by donors, Melanie and the team were able to pack camp boxes for all participating children. In total, the boxes contained over 900 pieces and parts, including snack items, art supplies, a journal for reflection, yoga and exercise activities, books, and even a camp lantern that kids were encouraged to use at night to relax and enjoy memories of their sibling.

While not ideal, the virtual Camp Wakchazi experience proved to be great fun for children and parents, alike. **One mother shared, "This helped our summer in quarantine to be much more fun and exciting and we feel very supported by staff! It was also wonderful to see [my child] think of her sister and remember her in a fun way." Another parent stated, "It is obvious a lot of time, effort, thought, and love went into the boxes for our kids! Great job!"** The flexible funding provided by compassionate Supportive Care donors enabled the Bereavement team to quickly and seamlessly transition to a virtual platform for this year's camp. We remain grateful to our donors for ensuring that families are supported and cared for on their grief journey.

A physician's perspective.

Thanks to charitable contributions received of generous partners like Miracles from Maggie, Supportive Care patients and their families continue to find healing in our care. This is Keaton's story, as told by chief of Supportive Care, Scott Maurer, MD:

Keaton was born nine years ago with a rare genetic condition that causes fluid to build up in the brain. Normally, you can put a shunt in the brain to bypass the blockage, but Keaton had multiple *complications with this procedure. About five years ago, he was in the OR having his shunt revised yet again when his heart stopped and the surgical team had to try to revive him.*

They were successful, but the result was that his already damaged brain was even more damaged. That's when we met his mom. She was very young, inexperienced with medical decisions, and often was disagreeing with Keaton's father and his family because their goals were different than what she thought was best for Keaton.

Eventually, she made a decision to send him home on hospice after being told by the neurosurgeon that he would likely die in a couple of weeks.

He didn't die.

In fact, after a year he was discharged from hospice because he was growing but remained very debilitated by his neurologic condition. His mother began to see her mission as providing him the best possible life she could. Over time, she came to see our team as her lifeline. She called frequently whenever Keaton had an illness or if she had a question. Sometimes she'd call for reassurance. For a good deal of time—probably 18 months—we were able to keep Keaton at home. She was happy, he was happy.

Then he started getting recurrent pneumonias. He came to the hospital and required intubation. He got better, but every six weeks or so he came right back with the same issue. Sometimes he'd be intubated for three or four weeks at a time. This went on for about six months until, with our help, Keaton's mom decided to have him re-enrolled on hospice. It was a hard decision. She wasn't ready for him to die, but she couldn't keep putting him through the ICU admissions and intubations.

So home on hospice he went with the expectation that he would get another pneumonia in a few weeks and not survive.

He didn't die.

In fact, Keaton went the next 15 months without another hospitalization. And again, he came off hospice. During this time, he and his mother were able to show love to each other in their own special way. She began to refer to Carol and I as her "primary care providers." She called often and came to trust us with all aspects of Keaton's care. We did whatever we could to maximize his time at home, prevent hospitalizations, and everyone was happy. In the meantime, she matured into an amazing mother. She always put him first. It was an amazing transformation.

Over the last two to three years, Keaton's been in and out of the hospital, but rarely was it for anything severe until this past September, when he had what seemed like a mild illness. He recovered from it, but he stopped tolerating his g-tube feeds. Typically, when he was sick, his intestines would just stop working, but they always woke back up. This time they didn't. We tried for weeks to get them *working again, but to no avail. Eventually, his mom made a decision to put him on IV nutrition and see how he did.*

In November, Keaton's intestines gave out for good. He came to the hospital with a ruptured colon. A decision to have major surgery or keep him comfortable had to be made. His mother refused to make any decision until she could see Carol and me. She told the ICU we were like, "her mom and dad," and she needed us.

So we were there with her. We gently told her this was Keaton's time, and that surgery would not help him. She knew it already, but she just needed to hear it from us. And so we decided not to do surgery, and expected him to die within a day or two. But he didn't die…at least not right away. He lived for a couple more weeks, and then he declined for the last time. His mother said, "Please just keep him comfortable." And so we did.

Keaton died on November 27, 2021 with his mom, his grandma, his stepdad, Carol, and me at his bedside. I'm grateful to share that thanks to the support provided through donations, we were able to help Keaton's mom cover his burial costs.

With the generous contributions received of families like yours, our team was there for Keaton and his mom along every step of their journey. And even when Keaton's time came, we were there for the family then, too, providing direct financial assistance to help alleviate some small bit of the burden placed on this grieving mother's shoulders.

Our gratitude for your generosity.

We can never thank you enough for your part in improving the lives of children like Keaton, and their families. Every day, regardless of the circumstances, our Supportive Care physicians, nurses, and staff remain committed to providing every family with the healing care they need. Community partners like *Miracles from Maggie* make this work possible. **Your philanthropy in Maggie's name continues to make a difference.**