



Mark your calendars to attend our 7th Annual Home Plate Gala!

SATURDAY, JANUARY 26, 2019
Minneapolis Marriott Northwest

CRESCENTCOVE.ORG/HOMEPLATEGALA



Basic Needs and Communities of Care

Relieving Pressures/Enhancing Supports

4TH ANNUAL
PEDIATRIC PALLIATIVE CARE SYMPOSIUM
OCTOBER 25-26, 2018

Thank you to the many musicians and therapists who shared their work and experiences.



Please contact Crescent Cove for more information about our Respite & Hospice Home for Kids and support being offered to families caring for a child with a shortened life expectancy.

952.426.4711 | Info@CrescentCove.org



MAKING MOMENTS COUNT FOR KIDS & FAMILIES



Relieving Pressures/ Enhancing Supports

Living with chronic medical and mental health conditions requires holistic attention and responses.

Like a teeter-totter or a mobile, there is always a tension in balancing the emotional, financial, spiritual, and daily pressures, medical care and other needs.

In this year's symposium, we will address the continuum of care necessary for families caring for a child with a life-threatening condition.

Crescent Cove's mission is to offer care and support to children and young adults with a shortened life expectancy, and their families who love them.

The Crescent Cove Respite & Hospice Home for Kids is located in Brooklyn Center, Minnesota, and is just the third of its kind in the U.S. It is a home-away-from-home, featuring vibrant and joyful spaces to live each moment as fully as possible.



Symposium Schedule

Thursday, October 25

Noon Registration, Mix & Mingle

12:30 Welcome

Todd Dalberg, DO, Jeannie Goodspeed, MD,
Katie Lindenfelser & Dr. Jim Rice

Centering Meditation
Leah Golberstein

12:45 Opening Session

Pediatric Palliative Care Overview:
Best Practices to Relieve Pressure & Enhance Support
Ted Bowman

A European Perspective: The Best of Palliative Care
Katerina Rusinova, MD

An American Perspective: Family & Hospice Perspectives
Jonathan Cottor

1:40 Table Conversations

The Best of Pediatric Palliative Care to Relieve
Pressure & Enhance Support

2:10 Naming Best Practices for Crescent Cove

Gather Table Conversations

2:25 Responses & Comments

Pediatric Clinical Training Leaders in Minnesota:
The Best of Current & Future Practices
Stacy Remke, MSW & Todd Dalberg, DO

2:45 Break

3:00 Palliative & Hospice/End-of-Life Care

Making the Connections Early & Often to Relieve Pressure
Ted Bowman & Dannell Shu

3:30 Who's On Your Team?

Widening the Circle of Care & Responsibility
Jonathan Cottor

4:00 Organizing Efficient & Nurturing Environments

The Medium is the Message
Households & Crescent Cove: Optics of Palliative Care
Dave Hecker, Teri Kwant, Mark Ostrom & Jill Wall

4:45 Table & Large Group Discussions

5:30 Reception

Friday, October 26

8:00 Mix & Mingle

8:30 Welcome to Day Two

Michele Peterson, MD & Dr. Jim Rice

Morning Meditation
Leah Golberstein

8:45 Supportive Care

From Beginning to After-Care Stories:
Siblings, Grandparents, Bereaved Parents
Elaine Allen, Tiffany DeRoma & Grant Mohwinkle

Services in the Community:
Present & Projected End-of-Life Services at Crescent Cove
Ted Bowman & Kate Rubischko

Table Conversations

What Filters Should be Used for Decisions About
What Crescent Cove Can/Should Offer?

9:45 Group Discussion

Priorities for Services

10:15 Break

10:35 Addressing Basic Needs to Relieve Pressure

Two Breakout Sessions

- Financial Matters by Sunrise Banks
Peter Everson, Erich Mische, Mary Stoick & John Sulzbach
- Accessing Health Care by Optum
Melanie Majerus

11:35 Summary & Evaluation

12:30 Celebration of Crescent Cove Opening

**“You make this day special
just by being you. There
is no one else in the
whole world just like you.”**

- Fred Rogers



Speakers



Elaine Allen has been a registered nurse for 48 years, working with children, teens, and adults with developmental, physical and medical challenges in family homes, group homes, camps, schools, and day programs. She's taught medication administration to group home and day program staff. She also performed utilization reviews of group homes in Central Minnesota. Her volunteer connection to Crescent Cove spans the last eight years through her life experience with her granddaughter Maryah. You can read Maryah's story on the Crescent Cove website.



Ted Bowman is an educator, author and consultant who specializes in change and transition. He is an adjunct faculty member at the University of St. Thomas, teaching a graduate social work course on grief and loss. Ted was senior trainer for the Wilder Foundation and taught family education courses at the University of Minnesota. Ted has published more than 80 articles, chapters, booklets, and poems.

He received the Minnesota Council on Family Relations Distinguished Service to Families Award in 1979, the Friend of the Network Award from the Minnesota Vocational Consumer and Family Education Network in 1988, and the St. Paul Civitan Club Clergy Award in 1994.



Todd Dalberg is a pediatrician and palliative medicine physician at Gillette Children's Specialty Healthcare, specializing in neuropalliative care. His research has focused on improving integration of palliative care and oncology. Todd trained at the University of New England College of Osteopathic Medicine, and earned a Master's of Clinical Research from Oregon Health & Science University. His residency was at Connecticut Children's Medical Center and completed a fellowships at the Oregon Health & Science University and the Akron Children's Hospital.



Jonathan Cottor's son Ryan was diagnosed with Spinal Muscular Atrophy at eight months old. They were told there was an 80% chance he would not survive to his second birthday. Their family was the inspiration and founding force to bring Ryan House to fruition in Phoenix, Arizona. Living in London at Ryan's birth, they were referred to Helen House in Oxford. After returning to Arizona in 2003, Ryan House

opened its doors in March 2010. Jonathan is co-founder, first board chair, and ongoing board member of Ryan House, and a 30-year corporate marketing and sales expert. His wife of 26 years, Holly, and he are excited to transition their sons Ethan and Ryan into adulthood.



Tiffany DeRoma is a mother of four from Lakeville, Minnesota. Her daughter, Ellie, passed away at nine months old in 2010 from sepsis and functional asplenia. Her surviving children include Max, 9, who has special needs, and twins, Addy and Levi, 6. Tiffany and her husband, Dave, started non-profit Ellie's Light after Ellie died to comfort those experiencing the loss of a child and those with critically, terminally, and chronically-ill children. Before having children, Tiffany worked as a pediatric oncology and hematology RN.



Peter Everson joined Sunrise Banks in 2006 and is the branch manager of the bank's University Avenue location in St. Paul. Peter specializes in relationship banking with consumers and small businesses. He attended Saint Olaf College and is a graduate of the Graduate School of Banking in Madison, Wisconsin.



Leah Golberstein is a former academic and an artist who has extensive training in teaching mindfulness meditation; in particular, in teaching meditation to trauma sensitive populations. Leah has worked with cancer and cardiac patients, families and care givers of hospice patients, at-risk teenagers, and individuals seeking relief from anxiety. Leah has graduate degrees in both theoretical mathematics and in visual studies, and is a former faculty member of the Minneapolis College of Art & Design.



Jeannie Goodspeed is mother to three children, Greta, 12, Simon, 6, and Ivy, who died in 2014 at age 5. Ivy was a beautiful girl with complex medical challenges and disabilities. Jeannie learned so much from Ivy during her short life; lessons about patience, acceptance, living in the moment, and finding peace and fulfillment in an imperfect life. Jeannie works part-time as a pediatrician for HealthEast at the Tamarack Clinic in

Woodbury. She is also an aspiring writer and is working on a memoir to share her family's story of choosing palliative care for Ivy. Jeannie lives in St. Paul with her husband Neil and their children.



Dave Hecker has been in the construction industry since 1994 doing both commercial and residential work. He is currently a principle at Gardner Builders, a commercial general contractor. His role includes HR, office operations and project management. Dave was Crescent Cove's construction project manager and was instrumental in helping Crescent Cove open its doors.



Teri Kwant brings a unique perspective and process to clients like Crescent Cove or Dakota County. Equal parts experience strategist and designer, Teri encourages clients to consider the emotional response that automatically happens within the built environment, helping them design desired experiences. She lectures frequently on experience design, environments and communications for the University of Minnesota School of

Design, the College of Visual Arts, and the Minneapolis College of Art & Design.

Speakers



Katie Lindenfelser is a music therapist, massage therapist, and reflexologist who has worked with children and young adults with a shortened life expectancy and their families in the hospital, hospice, and home care setting. Katie went to Melbourne, Australia to pursue a master's degree researching music therapy and pediatric palliative care. In the fall of 2008 she returned again to Australia to provide music therapy at Very Special Kids Children's Hospice. Katie is the founder of Crescent Cove and serves as its executive director.



Melanie Majerus is a product development director at UnitedHealthcare, working on the Special Needs Initiative that helps families and caregivers of children with special needs navigate a complex healthcare system. She joined the team in 2017, and is responsible for testing innovative solutions that can help UnitedHealthcare members improve the quality of life for their families. Melanie is thrilled to have found a job that aligns to her purpose in life.



Erich Mische is the executive director of Spare Key, a local Minnesota nonprofit whose mission is to provide assistance to families in crisis with critically ill or seriously injured family members through housing grant payment assistance, engaged resource referrals, and advocacy. From its founding in 1997 to 2016, Spare Key has helped over 3,000 families with nearly \$3 million in housing grants.



Grant Mohwinkel was raised in Rosemount, Minnesota and enjoys volunteering with Crescent Cove whenever possible. Grant says it is important for him to stay close with Crescent Cove and help out any way he can as it helps him feel connected to his sister Jennie, who died of Sandhoff disease in 1994 at age 10. Growing up with Jennie is the main reason why Grant believes in Crescent Cove's mission. In his free time, Grant enjoys taking walks/hikes with his fiancé, Maddy, and puppy Hobbs! He is an avid golfer and Minnesota sports enthusiast, so he spends a lot of free time frustrated.



Mark Ostrom founded Circle design to focus on an under-appreciated and overlooked aspect of wellness, that being physical space. Facilities and families do not typically have the funds to address ongoing space needs and any "extra" dollars will likely first go to support services, living expenses, or insurance. Circle design bridges the gap by bringing stellar design teams together to surround sick kids with cool space. As the ring leader, Mark's primary responsibilities are listening, dreaming and getting stuff done. Mark's project of note is the original Rainforest Café; the #1 grossing sales restaurant in the world, where no one goes for the food.



Michele Peterson is a pediatrician who currently practices at Central Pediatrics. She attended medical school and residency at the University of Minnesota. Long before entering medical school, she had the pleasure of babysitting and becoming the personal care attendant for a beautiful little girl, Jennifer Mohwinkel. Jennie was born on Halloween and was perfect in every way. Around the time she was three years old, she started to miss some of her development milestones. She eventually was diagnosed with a rare neurodegenerative disease, Sandhoff's, and subsequently died at age 10. Michele supported and cared for Jennie for over five years, until her passing in her home. Her time with Jennie forever changed the pediatrician she would become and is the reason she believes so strongly in the mission of Crescent Cove.



Stacy Remke is an instructor at the University of Minnesota School of Social Work, teaching in areas of health, disabilities and aging, integrative behavioral/mental health and inter-professional collaborative practice. Her clinical experience includes 27 years as a pediatric palliative care social worker, assisting children with life-threatening and/or chronic, complex conditions and their families in-home and in community-based settings settings, as well as in the hospital. She served on the national Advisory Board for NHPCO's ChiPPS Pediatric Hospice and Palliative Care interest group. Stacy is on the board for Social Work in Hospice and Palliative Care Network and is currently engaged with advancing the practice of social work in hospice and palliative care, which are, by definition, inter-professional settings.



Jim Rice brings extensive experience in healthcare policy, governance, and strategy development to Crescent Cove. He is the managing director, governance and leadership at Gallagher Integrated where his consulting work is focused on strategic governance, visioning for health care nonprofit organizations, leadership development and strategic capital planning. He holds adjunct faculty positions with the Judge Business School at Cambridge University in England and Strathmore University School of Business in Nairobi, Kenya. Jim currently serves as the chair of the Crescent Cove Board of Directors.



Kate Rubischko joined Crescent Cove in September 2017 as its Social Worker/Family Support Coordinator. She graduated with a Clinical Social Work degree from The College of St. Catherine/University of St. Thomas. Kate has worked at Abbott Northwestern Hospital as a hospital-based social worker for over twenty years and continues to work part-time as an emergency room social worker, where she has been instrumental in establishing a fetal loss intervention program. Kate completed a nine-month clinical practicum with the Pain and Palliative Care Program at Children's Minnesota. In this role, she worked closely with children who were diagnosed with life-threatening and/or life-limiting illnesses and supported these children and their families during inpatient hospitalizations, clinic visits and through their home-based program.

Speakers



Katerina Rusinova is a senior physician specialist in the Department of Anaesthesiology and Intensive Care Medicine in General University Hospital, Prague, Czech Republic. She is a co-director of the Center for Support and Palliative Care at the 1st Medical Faculty, Charles University in Prague. In 2014 she defended her Ph.D. in Bioethics. Between 2012 and 2018, she has been a social media editor in Intensive Care Medicine,

for the official journal of the European Society of Intensive Care Medicine. She is an expert in patient-physician communication and ethical aspects of ICU care, and publishes extensively in international medical journals.



Dannell Shu is a parent advocate in pediatric palliative care and hospice and is known for fostering resilient families and care communities. An uplifting speaker, writer, consultant, and health care educator, Dannell shares powerful stories that inspire and motivate meaningful change through truth, humor and helpful insights. She is a member of the Minnesota Department of Health's Palliative Care Advisory Council,

the Pediatric Palliative Care Coalition of Minnesota. Thanks to her son Levi, Dannell is passionate about families and providers partnering together in making palliative care available early and often with access for all. Follow her blog at www.MamaShu.org.



Mary Stoick is vice president at Sunrise Banks specializing in commercial real estate and new markets tax credits transactions. Mary has over 13 years of commercial banking experience in the Twin Cities market and joined Sunrise in October 2017. She is a graduate of the University of Chicago and resides in Eagan, Minnesota.



John Sulzbach is personal financial counselor for Lutheran Social Service (LSS) on special assignment. He has spent the past 13 years meeting with people to help them solve their personal financial issues in the areas of budgeting, credit card debt, credit scoring, housing, student loans and reverse mortgages. Currently, John represents LSS at resource fairs, military/veterans programs and other community forums.



Jill Wall is a certified registered nurse of infusion (CRNI), working at Pediatric Home Service as infusion educator. She has co-authored ASPEN, INS and Society of Pediatric poster presentations, provided collaboration in development of NHIA "Home Based Pediatric Patient CVAD Care," and was one of four authors in the JAVA article, "Central Vascular Access Device Guidelines for the Pediatric Home-Based

Patient: Driving Best Practices." Jill graduated with a BSN in nursing from Viterbo College in LaCrosse, Wisconsin and joined the PHS infusion team in 2007. Additionally, Jill has the blessing and unique perspective as a parent of a medically-fragile daughter.

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