

SYMPOSIUM 2015

Welcome to
**Crescent Cove's 1st Annual
Pediatric Palliative Care Symposium**
*joining families, clinicians and policy makers
to advance support and care.*



Support, Care & Spirituality

October 16-17, 2015

LifeSource Conference Center
Mississippi River
2225 West River Road North
Minneapolis, Minnesota



Crescent Cove

A place of respite for kids & families

*“While we try to teach our children all about life,
our children teach us what life is all about.”*

- Angela Schwindt



**Crescent Cove’s mission is to offer
care and support to children and young adults with
a shortened life expectancy, and their families.**

Crescent Cove is working to build the first residential children’s hospice and respite home in the Midwest, a home with eight rooms for children, family suites, living and dining spaces, spaces for creative arts, spiritual care, music therapy and hydrotherapy. While in the midst of raising funds to build and operate this home, Crescent Cove is providing mini-respite experiences and support to families caring for a child with a shortened life-expectancy and also advocating to advance support available to families.

Crescent Cove has three strategic pillars:

- 1. Family Services:** Expand contact with and support and services to families caring for a child or young adult with a shortened life expectancy through connections to and referrals from pediatric palliative care clinicians.
- 2. Advocacy:** Foster a state and national conversation regarding the need for a residential home for respite and end-of-life care within the pediatric palliative care continuum and identify sustainable financial models and strategic alliances to ensure the success of these homes.
- 3. Facility:** Facilitate the design, site selection and fundraising efforts to lay the groundwork for accomplishing our goal of launching construction of the home in June of 2016, support through the building process, development of the clinical team providing state-of-the-art care and services to families.



SYMPOSIUM SCHEDULE

Friday, October 16th

1-1:30pm – Welcome & Introduction of Crescent Cove, Emcee, Dr. Jim Rice

1:30-2:30pm – Session 1

Family Panel – Four families will share their diverse experiences caring for a child who is medically fragile.

• Wilson Family • Goodspeed Family • Martindale Family • Shu Family
Moderator: Jason Albrecht, MHA, CCLS

2:30-3:30pm – Discussion

3pm-3:15pm – Break

3:15-4:15pm – Session 2

Policy: Finding Resources and relationships for supportive policy

Keynote speaker: MN State Representative Nick Zerwas

Moderator: Richard Forschler, JD

4:15-5:30pm – Panel and Discussion

Panel: Jody Chrastek, DNP, Janet Will, RN, Lynn Gruber, JD

5:30-6:30pm – Closing Remarks & Reception

Saturday, October 17th

7:30-8:15am – Continental breakfast

8:15-9:15am – Session 3

The clinical dimensions of pediatric palliative care

Keynote speaker: Hal Siden, MD

Moderator: Tamara Schafer, MBA

9:15-10am – Panel & Discussion

Panel: Scott Schwantes, MD, Naomi Goloff, MD, Susan Sencer, MD

10am-10:10am – Break

10:10-11:10am – Session 4

The importance of spirituality and emotional support in pediatric palliative care.

Keynote Speaker: Jan Aldridge, PhD

Moderator: Theresa Zimanske, Parent Advocate

11:10-11:40pm – Panel & Discussion

Panel: Ted Bowman, grief educator and trainer, Kaci Osenga, MD, Tisha Moore, chaplain

11:40-12pm – Next steps & Close

SPEAKER BIOGRAPHIES



Jason Albrecht, MHA, CCLS Jason Albrecht has over 20 years of experience working with children and families in critical care environments. His passion is working with hospitalized children, their families and health care teams to empower even the youngest patients to actively engage in their care. Jason served in the role of Pediatric Palliative Care Coordinator designing with teams of health care staff, patients and families to optimize comforting care strategies for patients with life threatening conditions. As a Child Life Specialist, he provided education and counseling to children and families receiving care for hematology/oncology, blood and marrow transplant, intensive care and HIV. In his role at the University of Minnesota Masonic Children's Hospital, he currently serves as Manager of Patient/Family Interactive Services for the new, state of the art facility built in 2011. A champion of human-centered design, he leads UMMCH's efforts to leverage point of care technologies that engage, empower and activate patients and their families in their care. "Human-centered design reveals what is truly desired. This insight leads to a well defined problem and ignites passion. It gives us a whole new canvas upon which to paint a new portrait of care."



Jan Aldridge, PhD is a Consultant Clinical Psychologist in children's palliative care and Research Lead at Martin House Hospice for Children and Young People. She holds an Honorary post with St James University Hospital and in the Medical School at the University of Leeds. She works with children with life-shortening conditions and life-threatening illnesses and their families and with staff working in pediatric palliative care. Her experience includes lecturing, research and professional training in the UK, Bangladesh, Ireland, the US and Singapore. Currently she is part of a team delivering Master classes in England, Scotland, Wales and Ireland for the national body of children's hospices in the UK, Together for Short Lives. These events focus on the developmental and clinical needs of young adults with life-shortening conditions as they transition to adult services.



Ted Bowman is an educator, author and consultant who specializes in change and transition. He is an adjunct faculty member at the University of Saint 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. Ted 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. He was a Minnesota delegate to the 1980 White House Conference on Families. In 2008, he received the Outstanding Achievement Award from the National Association for Poetry Therapy.



Joan Jody Chrastek, DNP, CHPN, RN is a Pediatric Advance Complex Care Team Coordinator at Fairview Home Care and Hospice at the University of Minnesota Masonic Children's Hospital. She was born and brought up in India and trained as a nurse in Scotland. She has worked as a midwife and hospice nurse in the UK, India and the USA with adults and children. Jody is an adjunct faculty member of Globe University in the Nursing Department. She is the co-founder of Children's Institute for Palliative Care, offering clinical education and support. She is a board member of Hospice and Palliative Nurses Association and the Minnesota Network for Hospice and Palliative Care. Her Doctorate in Nursing Practice work focused on Pediatric palliative care. She has published and presented nationally and internationally on hospice and palliative care particularly in pediatrics.



Rich Forschler, JD has practiced as a member of the Faegre Baker Daniels government relations team since he joined the firm as a partner in 1989, and currently is the Minneapolis Government Advocacy and Consulting Group Head. Rich represents corporations, trade associations and professional associations before the Minnesota Legislature, state agencies, and local units of government, successfully leading broad coalitions of advocates on legislative issues. Rich grew up in Southeastern Minnesota and received his Bachelors of Arts from the University of Minnesota and his JD from Georgetown University Law Center. He currently resides in Minneapolis with his wife Kari.



Katie Lindenfelser, MT-BC 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. Following her training at Augsburg College, she first worked for Seasons Hospice in Chicago, IL where she provided music therapy to many children at the end of life and for their families through bereavement. She then returned to Minnesota to provide music therapy at Ridgeview Hospice and at the University of Minnesota Children's Hospital.

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. During this time, it became evident to her that it is vital to pursue the creation of a children's respite and hospice home in Minnesota.

In 2009, Katie, her husband Matt Christensen and their friends Nadine Gregerson and Jim Rice began to make this dream come true in Minnesota. They have been supported and joined by leading experts in the field and community, and are working to build Crescent Cove - to offer care and support to children and young adults with a shortened life expectancy, and their families through respite stays for the child and/or family, and by providing loving and compassionate care at the end-of-life and beyond.



Tisha Moore is a staff chaplain at the University of Minnesota Masonic Children's Hospital. She works with patients and families in two Pediatric Intensive Care units, as well as the Blood and Marrow Transplant Unit. Tisha is passionate about providing spiritual and emotional care for people across the lifespan and from all faith perspectives. She is also passionate about family-centered care and helping families stay close and connected during the often difficult circumstances of pediatric chronic illness and long hospitalizations. She also works as part of the palliative care team and has received training in integrative therapies, such as reiki, healing touch and music.



Kaci Osenga, MD is a board certified pediatrician with additional board certification in Hospice and Palliative Medicine. She also is the Associate Medical Director of the Pain and Palliative Care Program at Children's Hospitals and Clinics of Minnesota, Minneapolis/St. Paul.

Dr. Osenga specializes in pain and symptom management, along with other aspects of pediatric hospice and palliative care. She completed medical school and a general pediatric residency at the University of Wisconsin-Madison. In addition, Dr. Osenga successfully completed a clinical fellowship in pediatric hematology and oncology at the University of WI-Madison. Following completion of her fellowship she spent two years completing the Clinical Oncologist Research Training Program at UW-Madison where she focused on hospice and palliative care. During that time, she also dedicated her time to developing an inpatient pediatric palliative care consultation service.

Dr. Osenga currently cares for children with a variety of acute and chronic conditions, including those with palliative and hospice care needs. She offers home visits to patients who are cared for by our home based hospice and palliative care program.

She is married to David and they have one daughter age 11 years. In what spare time she has, she enjoys reading, music and spending time with her family.



Jim Rice, PhD Dr. Rice brings extensive experience in healthcare policy, governance and strategy development to Crescent Cove. He is the Director of the Leadership, Management and Governance (LMG) Project at Management Sciences for Health. Dr. Rice served as Executive Vice President at Integrated Healthcare Strategies, where his consulting work is focused on strategic governance, visioning for health care non-profit organizations, leadership development and strategic capital planning. Dr. Rice also serves as vice chairman of The Governance Institute, an organization dedicated to knowledge generation and dissemination via research and education for health system boards and leadership teams.



Tamara Schafer, MBA Health Care Relations Liaison at PHS, graduated in December 2013 with her Master's in Business Administration and a Health Care Management emphasis from Concordia University in St. Paul. In her role, Tamara communicates with our referral sources to ensure they have the resources and information necessary regarding the patients they follow that PHS provides care for. Tamara will be able to bring her increased business and leadership skills to better serve the health care professionals she interacts with, helping make the coordination of care a smooth and seamless process for the family.



Scott Schwantes, MD is board certified in pediatrics and hospice and palliative medicine. He leads the neuropalliative care consultative team at Gillette Children's Specialty Healthcare. Schwantes received his medical degree at the Medical College of Wisconsin in Milwaukee. Prior to joining Gillette, he completed a residency with the University of Minnesota's Department of Pediatrics and a year of fellowship with the Department of Pediatric Critical Care. Schwantes is board-certified by the American Board of Pediatrics. He is a member of the American Academy of Pediatrics, and he serves on the board of directors of the academy's Minnesota chapter.



Susan Sencer, MD and Chief of the Professional Staff at Children's Hospitals and Clinics of Minnesota, attended medical school at the University of Minnesota where she also completed her pediatric residency and pediatric hematology/oncology fellowship training. She joined the hematology/oncology program at Children's of Minnesota in 1991 and became medical director of that program in 2001. Her areas of interest include supportive care of children with cancer and integrative oncology. She is a "founding mother" of the Integrative Medicine program and was instrumental in helping start the Pain and Palliative Care Program. Susan is married and has three children.



Janet Will, RN, MS Janet is currently the Pediatric In-patient Program Director for Gilchrist Hospice Care in Baltimore Maryland. At this time, she is working on a project to re-envision a ten bed facility for children and families in need of end-of-life care, transitional care, and respite support. Her background includes Director of Dr. Bob's Place, Innovator at the Centers for Medicare and Medicaid, Graduate of the Metta Institute End-of-Life Practitioner Program, Faculty Member of Companioning the Dying: Opening to Living Program, and leading grief support groups for bereaved children and families. During her tenure at the Johns Hopkins Children's Center and Home Care Group her roles included: various bedside pediatric nursing positions, Pediatric Oncology Clinical Nurse Specialist, Pediatric Home Hospice Coordinator, Clinical Director of Pediatrics at Home and Pediatric Hospice Program, and Home Care Ethics Committee Co-Chair. She has presented at local and national conferences on a variety of topics related to palliative and end-of-life care for children.



Hal Siden, MD, MHS, FRCPC, DABP As Medical Director at Canuck Place, Dr. Siden directs the physician team and collaborates in implementing research and education programs. His clinical interests are pediatric palliative care, pediatric pain management and general pediatrics. He has Fellowship and advanced training in biochemical diseases, developmental pediatrics, palliative medicine, pain management and pediatric hypnosis. Dr. Siden is a Clinical Associate Professor in the Department of Pediatrics at the University of British Columbia (UBC). He has a cross appointment in the Division of Palliative Medicine, Department of Family Practice at UBC. He is also a physician on the Pain Service at British Columbia's Children's Hospital. He founded the Telehealth Program at Children's & Women's Health Centre of BC, which uses advanced telecommunications for long-distance clinics and education around the province.



Bob Tift, Ed.D. began his service as President of Crescent Cove in July of 2014. Prior to joining Crescent Cove, he served for 22 years in private school administration as the Principal and later as President of Benilde-St. Margaret's School in St. Louis Park. Bob's educational career began in public education where he served as a special education teacher and administrator working with children with severe mental and physical disabilities. Bob's commitment to our mission was fostered witnessing his great niece Maryah's five-year battle with bone cancer. Maryah and her family are passionate about the need for a home that would provide respite and end of life support for the children with life threatening illnesses. Bob is active in many local activities such as the Twin West Chamber of Commerce, Minnesota Independent School Forum, Southwest Light Rail Advisory Committee, Elmwood Neighborhood Association, Catholic Charities and Rotary. Having raised four sons with his wife Anna, he has also been involved in many organizations serving youth such as Children First, Little League, Open Arms for Children, Aim Higher Foundation, and other youth sports organizations.



MN State Representative Nick Zerwas is a lifelong resident of Elk River. His father, Tom Zerwas, was the Police Chief in Elk River from 1980-2003. Nick was born with a congenital heart defect, and his parents were told he would not live past 7 years old. He has had a total of 10 open heart surgeries, the last surgery was 7 years ago. While he has been told 6 different times that he had less than 6 months left to live, through the power of prayers and the advancements in medicine he is now feeling great!

Nick graduated from Hamline University in 2003, with a degree in Biology and Forensic Science. He worked as a latent print examiner for the Anoka County Crime Lab, and for Target Corporation's private forensic lab. While working for Target he earned his MBA. He served on the Elk River City Council for 6 years. His priorities on the council have been to improve efficiency, downsize government, and lower our city property tax.

Nick is currently serving in his second term in the MN House. He serves on the Health and Human Service Finance Committee, Health and Human Service Policy Committee, and the Public Safety and Civil Law Committee.



Theresa Zimanske wife, mother and *be the change advocate*, gives voice to the patient family perspective as a partner to the healthcare community. She represents the human experience as she advocates for patients and their families made vulnerable by illness, disease or injury. Her son, Michael Zimanske at age 13, passed away from a rare life limiting disease. Yet, his legacy of hope and love continues.



Lyn Gruber, JD gained a Doctor of Jurisprudence law degree from Hamline University School of Law. She currently leads her own consulting firm – Summit Solutions Unlimited – where she and associates specialize in health care management, communications, government relations, and strategic planning.

Thank you again for joining us on behalf of our Crescent Cove Board of Directors and Clinical Advisory Committee Members including:

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Scott Schwantes, MD,
Jody Chrustek, DNP,

Ted Bowman
Bob Tift, PhD,
Katie Lindenfelser, MT-BC

FAMILY PROFILES

The Goodspeed family: Jeannie and Neil Goodspeed are parents to three children: Greta age 9, Simon age 3, and Ivy forever 5. Ivy was born with complex disabilities and medical problems - she lived a short but beautiful life. During Ivy's life, Jeannie and Neil were able to access respite care, and experience the rejuvenation this provided for their family. This couple also chose to pursue palliative care for Ivy when the end of her life drew near. Jeannie and Neil are forever grateful that they were able to create a peaceful end-of-life experience for Ivy and the whole family - a time when Ivy was comfortable, celebrated and completely surrounded in love. Jeannie is also a pediatrician, giving her additional perspective as a member of the medical community.



The Martindale family: Julie Martindale and her husband, Mark, live in Elk River, MN. They have 11 children between the ages of 6 and 24 and share their home with 2 dogs, a pot belly pig, four chickens, two bunnies, some finches and a beautiful little foster baby, Adam. After losing their son, Evan, in 2006, the Martindales have chosen to adopt children with medically complex conditions. Isaac, age 6, was born healthy but soon contracted a herpes infection that caused catastrophic brain damage. He is a beautiful, amazing and inspiring little guy who changes the world one smile at a time. Isaac has a team of exceptional doctors, nurses and support organizations that have

allowed him to reach his potential and live life filled with joy among the struggles he faces each day. He has recently entered hospice care through Fairview Hospice and is followed by the palliative care team of Children's Minnesota. In her spare time, Julie enjoys serving on the Ethics Committee and promoting the Patient and Family Centered care philosophy to medical professionals as a volunteer at Children's Hospital.



The Shu family includes Dad - Peter, Mom - Dannell, older brother Levi and younger brother Leo from Minneapolis. In December 2009 Levi was born with severe brain damage. As first time parents they were unexpectedly thrust into a world of medical complexities. Levi was expected to depart from this life as fast as he entered it. Five-and-a-half years later the Shu's are still running a 24/7 ICU at home to support Levi's complex needs. Levi also receives all of his therapies and public education at home. He is a happy, alert, peaceful child whose sweet spirit has transformed many hearts. In her spare time Dannell enjoys advocating for pediatric palliative care through speaking, writing, and as a member of PPCCMN and PACCT.



The Wilson family: Dad - Alan, Mom - Natalie, Big Brother - Gavin and Little Brother - Liam. In December 2011 at Liam's 20 week ultrasound, the Wilson family learned Liam would have a short life. As a NICU RN mom and a loving father, Liam's parents sought information and guidance on how to make the most of their family time together. Their ventures led them to perinatal hospice. The love and support provided by the staff that facilitated perinatal hospice allowed this family of four to make a lifetime of memories together in a short time. Perinatal hospice gave the gift of allowing this family to relish in their time together without fear or worry. Perinatal

hospice supported the family in giving Liam a life of love and a peaceful, dignified death. They share their story to enlighten others that although we do not get to choose when we die, we can choose to make the lifetime we have as wonderful, loving and peaceful as possible. Natalie is certified in Perinatal Loss Care and is a March of Dimes NICU RN of the Year for Bereavement Care.



Mark your calendars

to Give from your Heart to Crescent Cove on **Give to the Max Day**, November 12th & to attend our 4th annual Home Plate 'Where the Heart is' on Saturday, January 30th, 2016.

Register on-line at CrescentCove.org



Thank you

to musicians and music therapist's, Hilary Fredenburg, MA, MT-BC and Mark Burnett, MT-BC for providing music during the symposium; and also to LifeSource for donating the conference space and to Gillette Children's Specialty Healthcare for joint providership.

LifeSource
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 **Gillette Children's**
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Thank you to Kim Berning at Berning Design and to Perception Ink for media relations support.

**Thank you for participating at this symposium
and for advancing the support available to children,
young adults and their families.**

*Please contact Crescent Cove for more information about
mini-respite experiences and support being offered to
families caring for a child with a shortened life expectancy.*

CrescentCove.org



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