



Mark your calendars to attend our 5th Annual **Home Plate Heading for Home Gala!**

**Saturday, January 28, 2017** at the Minneapolis Marriott Northwest.

Register on-line at [CrescentCove.org](http://CrescentCove.org)

**Thank you** to musicians and music therapist's, Hilary Fredenburg, MA, MT-BC, Sharon Alery, MA, MT-BC, Leah Golberstein 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.



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](http://CrescentCove.org)



## Caring and Critical Conversations: **The Thresholds of Living, Dying and Death**

Pediatric Palliative, Hospice and Bereavement Care



**October 14-15, 2016**

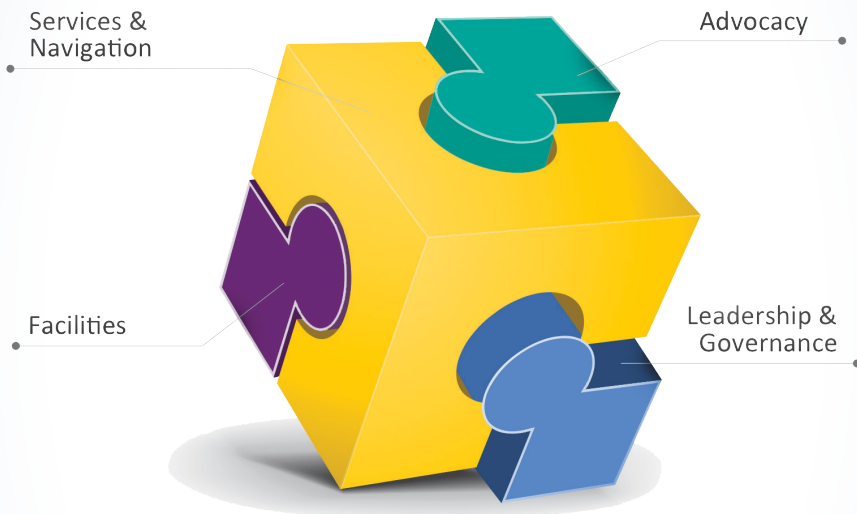
Friday, October 14, 1-6:00 pm  
Saturday, October 15, 8 am-noon

LifeSource Conference Center,  
2225 W. River Rd. N., Minneapolis, MN





*Thank you for joining us as we consider the thresholds of living, dying and death for children, adolescents and their families with special attention to the perspectives and tools for communicating about these matters with all involved.*



**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 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.

## SYMPOSIUM SCHEDULE

### Friday, October 14th

**1-1:30pm** – Welcome & Introduction

**1:30 - 2:00 pm** – Session 1  
Background and Symposium Focus

**2-2:45 pm** – Session 2  
Caring and Critical Conversations from Families

**2:45-3:30 pm** – Caring & Critical Conversations from Professionals

**3:30-3:45 pm** – Break

**3:45-4:30 pm** – Session 3  
Case Examples of Conversations

**4:30 pm** – Presentation and facilitated discussion of the results of recommended practices

**5:15-6:00 pm** – Session 4  
“Listening to Grief” – *Donna Schuurman*

**6:00 pm** – Closing remarks and brief reception in the lobby

### Saturday, October 15th

**7:30-8:00 am** – Continental Breakfast

**8:00 am** – Welcome

**8:15 am** – “When Your Patient is Dying” – Film produced by the Dougy Center

**8:45-9:30 am** – Session 5  
“Launching Support” – *Donna Schuurman*

**9:30-9:45 am** – Brief Break

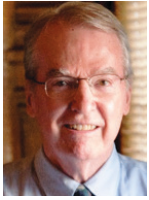
**9:45 - 10:30 am** – Session 6  
Comments on Caring & Critical Conversations from Policy Makers

**10:30-11:45 am** – Session 7  
Caring & Critical Conversations from Spiritual & Religious Clergy

Small groups – Implications of the Symposium – Mixed Member Groups

**11:45 am-12:00 pm** – Next Steps & Close of Symposium

# SPEAKER BIOGRAPHIES



**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.



**Dianne Burd** has been a social worker in healthcare for the past 24 years and a leader for the past 10 years. She received her Bachelor's Degree in Psychology from Marquette University and her Master's Degree in Social Work from the University of Minnesota. Dianne has worked in a variety of settings including mental health, home care, hospice and acute care environments. She currently manages a large interdisciplinary team at Gillette Children's Specialty Healthcare which provides specialized care to children with chronic disabilities.



**Mark Burnett MT-BC, NMT, NICU-MT** provides music therapy services, advocacy, and consulting in the Twin Cities, and Western Wisconsin. He maintains a private practice, and is a music therapy provider in the pain palliative and hospice program at Children's Hospitals and Clinics of Minnesota. Mark specializes in neurologic music therapy, special education, rehabilitation, child development, hospice and family wellness, and is passionate about including and involving everyone in making music. He is the author of Stay Together Play Together family music therapy programs, and over the last 25 years has performed internationally as a soloist and with a wide range of recording artists.



**Thomas C. Freeman, JD, Faegre, Baker, Daniels** With nearly a decade of experience in Minnesota politics, Tom Freeman is knowledgeable on a range of issues at the capitol including chemical regulation, public safety and judiciary issues, bonding, taxes, health care financing and data practices issues. Tom has successfully lobbied for licensing changes for the first ever Children's hospice, respite, and palliative care facility; the Mayo Clinic Destination Medical Center; allowing retail pharmacies to dispose of unused pharmaceuticals among other items. Tom previously worked as the Committee Administrator for both the House Redistricting Committee and the House Capital Investment Committee. Before that he managed the House Republican candidate campaign operations as their Field Director.



**Sen. John Hoffman**, his wife, Yvette, and their daughter, Hope, have lived in Champlin for more than 16 years. John was elected to the Minnesota Senate in 2012 and represents District 36. Sen. Hoffman serves as vice chair of the Environment and Energy Committee and is a member of the Health, Human Services and Housing Committee and E-12 Division Committee (Education Finance). His special legislative interests include; education, health and human services, energy, environment and commerce.

Prior to his election to the Minnesota Senate, Hoffman co-founded two companies dedicated to consumer credit and financial management. Additionally, John is the Marketing Director and Public Relations Director for Ally People Services, an organization committed to finding employment opportunities for adults with disabilities. He also served on several public boards, task forces, chambers, and councils. In the early 2000s, John was appointed to both state and federal Interagency Coordinating Councils. These council appointments gave John an opportunity to assist and advise leaders in education, health, defense, and services for children and families with disabilities. Sen. Hoffman is a graduate of St. Mary's University in Minnesota.



**Katie Lindenfesler, 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.

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, and they began in 2009.



**Rev. Peter E. Lund, MDiv.** is a board certified staff chaplain for Methodist Hospice Program. He was hired at the beginning of 2011, and is working full time. He is a graduate of Gustavus Adolphus College, and Andover Newton Theological School. Ordained into the United Church of Christ, he has served one parish in Anoka, then Children's Hospitals and Clinics for nearly 15 years. His wife is a teacher in the Minnetonka School district and they are blessed to be living with two children (one boy, one girl) and a golden retriever. Peter's recent interests are: increasing comfort and competence of colleagues supporting families with school age children facing death of adult; using integrative modalities, such as singing bowl, and aroma therapy; and integrating Tai Chi and other healing movement forms into his life and work.

# SPEAKER BIOGRAPHIES



**Helen Wells O'Brien, M.Ed., M. Div., BCC.** has served as a staff chaplain since 1998 for Regions Hospital and Gillette Children's Specialty Healthcare. She is a graduate of Harvard University's Graduate School of Education and United Theological Seminary of the Twin Cities.

She is an ordained minister in the Mennonite Church USA and was among the first women ordained in the Mennonite Church. Helen's specialty is coordinating chaplaincy services to pediatric patients and their families who have experienced traumatic injury, including brain injury, spinal cord injury and burn injury. Her work at Gillette focuses on providing spiritual care and support for children, teens and young adults living with complex disabilities and their families. She is currently a member and consultant for the Gillette Children's Ethics Committee and also serves as spiritual care provider for Gillette's palliative care consultative team.

Helen is the mother of two adult sons and is joyfully expecting a granddaughter in October. She loves exploring the natural world with husband John, and working in her garden at home.



**Michele Peterson, MD** is a pediatrician who currently practices at a HealthEast in Woodbury. She attended medical school and residency at the University of Minnesota. Long before entering medical school, she had the pleasure of babysitting and then becoming the Personal Care Attendant for a beautiful little girl, Jennifer Mohwinkel. Jenni was born on Halloween and was perfect in every way. Around the time she was 3 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 the age of 10. Michele supported and cared for Jenni for over 5 years, until her passing in her home. Her time with Jenni forever changed the pediatrician she would become and is the reason she believes so strongly in the mission of Crescent Cove.

When she is not working Dr. Peterson enjoys spending time with her husband, two teen-age children. She enjoys skiing, biking and traveling when she has time. To this day, she remains very close to Jenni's family as well.



*“Talk to your child and you will hear their inner voice. Walk with them through life and you will feel their heart.”*

- Geoff Reese



**Jim Rice, PhD** 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 non-profit organizations, leadership development and strategic capital planning. He also holds adjunct faculty positions with the Judge Business School at Cambridge University England and Strathmore University School of Business in Nairobi Kenya.



**Donna Schuurman, EdD., FT** is the Sr. Director of Advocacy & Training at The Dougy Center for Grieving Children & Families in Portland, Oregon, where she has served in various roles since 1986, including 25 years as Executive Director. She writes and trains internationally on bereavement issues, and authored *Never the Same: Coming to Terms with the Death of a Parent*. Dr. Schuurman served as President of the Board of Directors for the Association for Death Education & Counseling, and received their Annual Service Award in 2003 and their Clinical Practice Award in 2013. She is a member of the International Work Group on Death, Dying, and Bereavement, and a founding board member of The National Alliance for Grieving Children. She has trained the National Transportation Safety Board (NTSB) and FBI's Rapid Deployment teams, as well as medical personnel, NGO staff and caregivers following major disasters including the Oklahoma City bombing, 9/11 and Japan's 1995 Kobe earthquake and 3/11 earthquake. She serves as a national trainer for the American Foundation for Suicide Prevention (AFSP), and is a past member of the NW AFSP chapter board of directors.



**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.

# SPEAKER BIOGRAPHIES



**Rochelle Wodarz, RN, MA, CCM** has been working in different aspects of the home care industry for 15 years. She is currently a Program Director for Accra Care. Accra Care is a non-profit organization providing a variety of personalized self-directed services at home and in the community. We work with children and adults throughout the state that have a variety of disabilities, medical and behavioral needs. Prior to working at Accra, she was an Area Director and Administrator of a Pediatric Home Care Agency that provided skilled nursing for children with complex medical needs up to 24 hours per day. She has a Bachelors in Nursing, a Masters in Organizational Leadership with a concentration in Healthcare Leadership. Rochelle is certified as a Public Health Nurse and also as a Certified Case Manager.



**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.



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

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Jim Rice, PhD,  
Scott Schwantes, MD,  
Ted Bowman

Katie Lindenfelser, MT-BC  
Michele Peterson, MD

## FAMILY PROFILES

**Emily Gold:** Emily is an educator and mother of four children aged seven and under. She left her job to care for her daughter, Lizzie, full time after her life limiting diagnosis of Pallister Killian Syndrome at birth. She enjoys yoga, lake life, spending time with her children and husband, running and recently completed her first half marathon in honor of Lizzie. She is honored to advocate for palliative, respite and hospice options for families like hers.



**Elaine Allen:** Elaine has been a registered nurse for 47 years working the majority of that time in “community” nursing. In the early 1970’s she moved from Massachusetts to Minnesota and found herself in a “new” field of work....helping to get adults with developmental disabilities out of five State Institutions and helping to create group homes and communities that changed laws of acceptance for individuals. This line of work brought her into schools, work sites, groups homes around Hennepin, Ramsey County and central Minnesota and finally back into homes to help create supports for families to help keep their children in their own homes. In 2004 her then 9 year old grand daughter Maryah was diagnosed with Ewing’s Sarcoma. She was part of Maryah’s team for the 6 1/2 years that she lived with that disease. As her grandmother and an RN, she was able to hone her advocacy skills; but, most of her learning came from her directly. What she taught me was invaluable.



### **Christine and Peter O’Keefe:**

Mary Jacqueline O’Keefe, at the age of 2 was diagnosed with stage 4 Neuroblastoma and passed away one year later at the age of 3 on July 30th, 2009. This forever changed the lives of the O’Keefe family.

William, Mary’s older brother just turned 7 when Mary passed. One year and two weeks after Mary’s passing we welcomed our twins John and Katherine. They are gifts from Heaven, I believe Mary helped this happen.

We started the Mary Moon Foundation in the Fall of 2011 and all the proceeds go to Child Family Life. This tragedy has opened our eyes to what is needed in the community and it brings us great joy to be able to help other families affected by medical diagnoses that require hospitalization, multiple treatment approaches, and separation from their usual home life. This affects all aspects of the family structure when confronting a serious medical diagnosis.