#### PEDIATRIC PALLIATIVE CARE SYMPOSIUM 2017

Mark your calendars to attend our 6th Annual Home Plate Safe at Home Gala!

**Saturday, January 27, 2018** at the Minneapolis Marriott Northwest.



Register on-line at CrescentCove.org

**Thank you** to the many musicians and therapists who shared their work and experiences; and also to LifeSource for donating the conference space and to Gillette Children's Specialty Healthcare for joint providership.







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 our home and support being offered to families caring for a child with a shortened life expectancy.

CrescentCove.org



Resiliency for All Woven Together: Care-Giving & Care-Receiving

# The Crossroads of Caring for Another & Caring for Self



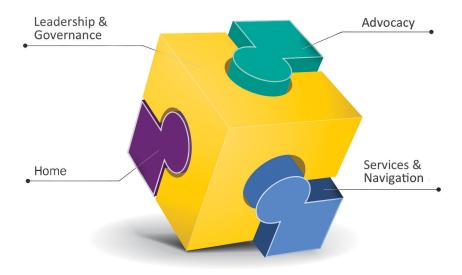
**September 28-29, 2017** 

Thursday, September 28, 1 pm-5:30 pm Friday, September 29, 8 am-Noon

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



## Thank you for joining us as we discuss The Crossroads of Caring for Another and Caring for Self.



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 opening the first residential children's hospice and respite home in the Midwest, a home with rooms for children, a family suite, living and dining spaces, spaces for creative arts, spiritual care, music therapy and hydrotherapy. While in the midst of raising funds to open 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.



## Resiliency for all:

Living with a life-limiting or life-threatening condition requires a wide circle of carers. It is not enough to support only the child with such a condition, but care extends to the siblings, parents, and whole family.

Optimizing care and hope also requires attention to the volunteers and professionals in the circles of care. If any "care-giver" is compromised in their well-being or ability to provide their best, the care of a person living with a life-limiting or life-threatening condition can be adversely affected.

In this symposium, perspectives and tools
that support, promote and extend resiliency and
hardiness for all care-givers will be presented,
demonstrated, discussed, and expanded.
Further, the intersections of care-providers will
be highlighted. Individual, family and team-care will be
addressed separately but as inextricably intertwined.
When done well, all can benefit.

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# SYMPOSIUM SCHEDULE

## Thursday, September 28th

12:30-1:00 pm - Registration

1-1:05 pm – Welcome from Crescent Cove

**1:05-1:20 pm** – An Experience of a Resource – Energy/Qigong Experiential, *Rhonda Battisto* 

1:20-1:45 pm – Toward Shared Meanings for Symposium: Resiliency, Hardiness, Self and Other Care, *Kathie Kobler and Ted Bowman* 

1:45-2:30 pm - "I've looked at Both Sides Now"
Three Parent/Professionals - How do parents sustain their own care? How do professionals sustain their own care?

Jeannie Goodspeed, Jill Wall and Natalie Wilson

**2:30 pm** – Integrative Art Therapy & Talk Therapy Conversations, *Karen Haeg and Bryan Kingsriter* 

2:50 pm – Who Tells Your Story? Integrating Narrative into Self-Care Practices, *Kathie Kobler* 

**3:30 pm** – Break, Stretching/Power of Relaxation Breathing, Candace Linares

**3:50 pm** – Honoring Meaningful Moments: Role of Ritual in the Care of Children with Serious Illness, *Kathie Kobler* 

**4:50 pm** – Open Forum and Table Conversations, *Ted Bowman and Kathie Kobler* 

5:30 pm – Please join us for a reception at Crescent Cove 4201 58th Ave. N., Brooklyn Center, MN

## Friday, September 29th

8:00 am – Welcome from Crescent Cove

8:10-8:30 am – Breakfast with Mindfulness Exercise, Denise Mattes

8:30 am - Session 1

Cultivating Resilience: Personal, Team, Hospital and Hospice ways of replenishing the well of resilience, *Scott Schwantes* 

**9:15 am** – Session 2

Erosion of Resilience: Recognition of Different Types of Distress, Grief, and Hope. Discussion of how to manage daily tasks and care for a child facing a life limiting or threatening condition, *Ted Bowman* 

**10:15 am** – Break – Music and Movement, Mark Burnett and Candace Linares

**10:35 am** – Session 3

**Resiliency in Healthcare -** perspectives from local and international healthcare leaders, *Jim Rice and Bob Bonar* 

11:00 am - Session 4 Creating a Sacred Space: Without and Within, Rabbi Lynn Liberman and Rev. Frank Bennett

**11:45 am** – Summarizing the Symposium - Integrating Resiliency Practices, *Ted Bowman* 

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

- Geoff Reese



# SPEAKER BIOGRAPHIES



**Rhonda Battisto** is a Spring Forest Qigong (SFQ) Master Healer and Certified Instructor, providing healing support services, healing workshops, presentations and empowering retreats in the USA and Canada. After working as vice president in her family business for over thirty years, Rhonda worked as Executive Director of a St. Paul nonprofit block nurse program which serves senior citizens, and as Healer Coordinator for the 'Love Grows Here' Wellness Center. Rhonda has also worked closely with

International Qigong Master Chunyi Lin at his Wellness Center and many SFQ workshops, retreats and conferences. Rhonda served as Associate Director of the SFQ International Guild and co-creator of the SFQ instructor certification and community outreach programs, and has been an instructor and breakout session speaker at SFQ conferences, webinar presenter, and editor of their a student Guild Newsletter. She has completed the highest levels of study offered by Spring Forest Qigong. In the year 2011 Rhonda founded her company - Wonder Horse, LLC - to increase her reach into - and healing impact upon - the community.



**Frank Bennett, MDiv, BS** is the founder and program leader of Living Well/ Dying Well, and is a senior teaching fellow at the Center For Spirituality & Healing after years of working with individuals and their families who were living with serious and life-threatening illness. As a minister, facilitator, teacher and chaplain, he provides support, education and care for the unique emotional, mental and spiritual challenges and opportunities at the end of life. Frank's passion is to empower individuals, their providers and care partners

to live well until they die well. He draws on his experience and expertise in teaching, curriculum development, writing, organizational leadership and development to support his work.

Since 2010 Frank has been an advanced healthcare directive facilitator. In 2009 Frank was a Clinical Pastoral Education (CPE) intern in Abbott Northwestern Hospital's Spiritual Care Dept. Frank earned his Masters of Divinity in 2010 with an emphasis on pastoral care and community-based chaplaincy.



**Bob Bonar, Jr., Dr. H.A.** was appointed CEO of Children's Minnesota in December 2014. With hospitals in both Minneapolis and St. Paul, Children's Minnesota is one of the largest pediatric hospital systems in the country, and serves children throughout the upper Midwest. Throughout his career, Mr. Bonar has been focused on improving quality outcomes, establishing strategic partnerships within the community and furthering access to pediatric care for people from all backgrounds and walks of life. Prior to

Children's, Mr. Bonar served as president and CEO of Seton Family of Hospitals and CEO of Dell Children's Medical Center of Central Texas. He also held senior leadership roles at pediatric health systems in Oklahoma, Virginia and South Carolina, and served in instructional roles at several university medical centers across the country.

Mr. Bonar holds a doctorate in health administration and policy from the Medical University of South Carolina, earned master's degrees in administrative disciplines from West Virginia University and the University of Oklahoma and also holds a bachelor's degree in biology from West Virginia University.



**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.



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 the lead music therapist at U of M Masonic Children's Hospital. 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.



**Jeannie Goodspeed** is mother to three children – Greta age 11, Simon age 5 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 – she 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.



## Karen Gillespie Haeg, MA, BCMT, CIMT, CPMT

It is my honor to bear witness to the healing journey of every patient I encounter as an Adlerian Art Therapist at Crescent Cove. I find great satisfaction in providing holistic, mind/body/spirit, creative strategies to greatly reduce pain, stress, anxiety, nausea and increase comfort and coping skills for patients and their families. I integrate my skills of massage therapy, teaching acupressure, or energy healing into art therapy sessions.

My greatest joy and source of resilience is to connect patients with a wellness approach to symptom management in the hospice setting. In addition to being an art therapist, I revel in spending time with my friends and family in nature. I also love to share good food, spend time creating art, read and listen to music.

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# SPEAKER BIOGRAPHIES



**Bryan Kingsriter, LMFT** has worked as a licensed Marriage and Family Therapist for 30+ years. He is currently in a private practice group that specializes in couples therapy. For the last year he has facilitated a new support group for couples who have children with medically fragile conditions. The focus of the group is 'undoing alone-ness', from the perspective that a crucial part of maintaining psychological resilience in traumatic experiences is in the experience of others' understanding and compassion.



Kathie Kobler, MS, APN, PCNS-BC, CHPPN, FPCN is an Advanced Practice Nurse with 32 years of experience caring for infants and children with serious illness. Kathie is APN Coordinator for Center for Fetal Care at Advocate Children's Hospital. She is a published author re. perinatal/pediatric palliative care and bereavement issues, including co-author of the 2013 book, "Meaningful Moments: Ritual and Reflection when a Child Dies." Kathie has served in leadership positions in national palliative care organizations, and

is currently Co-Chair of the National Pediatric Hospice & Palliative Care Collaborative and a member of the 2017-2019 National Consensus Project Writing Committee for Community-Based Practice Guidelines for Quality Palliative Care. She is a 2014-2016 Jonas Nurse Leader Scholar, and has a PhD from the University of Illinois at Chicago. Kathie was named a 2016 Fellow in Palliative Care Nursing and received the 2017 Distinguished Career Award from the Hospice and Palliative Nurses Association.



**Rabbi Lynn C. Liberman, BCC** works as a Hospice Chaplain with HealthEast, Jewish Community Chaplain through Jewish Family Service of St Paul, Per Diem Chaplain to Regions Hospital and Gillette and is honored to provide Spiritual Care to Crescent Cove families.



**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. 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.



**Michele Peterson, MD** 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 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.



**Candace Linares** is privileged to work with Crescent Cove providing in home Massage and Healing Touch services for children and parents/caregivers. She enjoys helping kids and parents relax during a body work/Healing Touch session. She also works as a pediatric MT at Children's hospitals and clinics of MN. She is certified in both pediatric and infant massage.

Candace earned a BA degree in Dance/Choreography from the University of Minnesota. She has had the joy of teaching children Ballet classes and dancing with Sacred dance Arts. She lives in Minneapolis with her husband Miguel, two active boys, Liam in high school and George in preschool! The kids especially enjoy playing with their two cats, Petunia and Smokey.



**Denise Mattes, RYT** has had the great privilege of working with families for over 30 years. She served as a parent educator and children's teacher in Robbinsdale School District's Early Childhood and Family Education program and was named a finalist for Teacher of the Year. A curriculum author and community speaker, she presented a parenting and child development segment on KARE 11's morning program monthly

for over 3 years. A certified Infant Massage Instructor, Denise teaches parents massage techniques to help ease babies' common maladies such as indigestion, teething pain, and nasal congestion. A registered Yoga Teacher, she guides parents and children through breath work, yoga sequences, and meditation for relaxation, strength, and stress-relief. Denise is passionate about enhancing the lives of families through education, touch, movement, and meditation.



**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.

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# SPEAKER BIOGRAPHIES



**Scott Schwantes, MD** is currently the Associate Medical Director of Pediatrics at Gillette Children's Specialty Healthcare in St. Paul, Minnesota. He is board certified in Hospice and Palliative Medicine as well as in Pediatrics. Dr. Schwantes received his Bachelor of Science in Physics & Astronomy and Mathematics from the University of Wisconsin and then went on to complete his Doctor of Medicine from the Medical College

of Wisconsin. His postdoctoral training included a residency in pediatrics, a fellowship in pediatric critical care as well as training in medical acupuncture and business leadership. Dr. Schwantes has been a member of the American Academy of Hospice and Palliative Medicine since 2010, and most recently was named a Fellow of the Academy. He is currently co-chair of the Pediatric Palliative Care Coalition of Minnesota, a member of the Pediatric Palliative Care Research Network, and on the Board of Directors for the Minnesota Chapter of the American Academy of Pediatrics. In 2017, he was appointed as the first Medical Director of Crescent Cove, a community pediatric respite and hospice home. In addition to his physician responsibilities, Dr. Schwantes is an assistant professor and fellowship supervisor at the University of Minnesota. He has published a myriad of articles and texts on pediatric pain and palliative care and is renowned in his field.



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". She is also involved with

"EMS: Train the Trainer", collaboration with local EMS, to educate infusion care of complex pediatric patients. 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.



**Natalie Wilson** has for the past 12 years, spent much of her time in the Neonatal Intensive Care as a RN and NICU ground/flight transport nurse, working for the Twin Cities leading Children's hospitals. With the birth of her second son, she found herself on the other side of the looking glass. At 20 weeks, Liam was diagnosed with a Hypoplastic Left Heart and her family walked a tough road of advocacy for the last 18 weeks of his pregnancy. It was important to the Wilson's that

their little Liam live a life full of love, no matter how short. He arrived in April 2012 and their family of 4 was together for the next 49.5 hours. Then the grief settled in. The unbelievable heartache pushed Natalie to further advocate for perinatal hospice. She became Resolve Through Sharing Certified, and in 2015, Natalie was awarded the Champion for Children for her innovative care of a dying patient and in 2016 was inducted into the International Nurses Association as a World Leader RN for perinatal hospice. Her resiliency has sustained her through the last 5 years and enabled her to integrate her grief into a life she never could have imagined.

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

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Karla Vaughan Office Manager

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Director of Engagement

**Deb Bryan** 

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Helen O' Brien, Chaplain – Gillette Children's Specialty Healthcare

Jill Wall, RN – Pediatric Home Service

Michele Peterson, MD – Central Pediatrics

Katie Lindenfelser, MT-BC – Crescent Cove

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Natalie Wilson, RN

Jeannie Goodspeed, MD – HealthEast

Ted Bowman - *Grief*Educator and Counselor

#### International

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Anita Oliva

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

Katie Lindenfelser, MT-BC

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