

# International Conference on **Hospice & Palliative Care**

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## **Walking the line: Ethical decision-making with families at the fringes**

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Over the past 100 years medical decision-making in the United States shifted from a paternalistic physician-driven process to a patient-driven autonomy-based standard. Over the past 10-years the pendulum shifted to a balanced meet-in-the-middle approach commonly defined as shared decision-making. Families who listen to all the medical options and select the recommended (standard) option are often perceived to be equal partners. Families that refuse medical recommendations or demand medically inappropriate interventions exist outside of the norm, challenge the communication and shared decision-making skills of clinicians, and may reveal our biases. In this interactive workshop participants will learn the principles of ethical reasoning used when evaluating possible medical neglect or demands for futile or medically inappropriate care. The workshop will provide participants with strategies for communicating with families perceived to be "unreasonable" or at the fringe as well as provide suggestions for reducing the moral distress inherent in these ethically challenging cases.

### Objectives:

- Differentiate when parental refusal of a recommended therapy does and does not constitute medical neglect.
- Recognize when familial requests are demands for futile or medically inappropriate care.
- Negotiate a treatment plan for families at either extreme using the principles of ethical-reasoning and shared decision-making.

### Biography

Justin N Baker is a pediatric oncologist, palliative care physician, member of the ethics committee and Phase I and end-of-life care clinical investigator at St. Jude Children's Research Hospital. He currently serves as the Chief of the Division of Quality of Life and Palliative Care at St. Jude as well as the Medical Director of the Quality of Life Service – the St. Jude palliative care team. He also serves as the Director of the Pediatric Hematology/Oncology fellowship program. His research interests include ethical considerations surrounding enrollment in Phase I clinical trials, AYA palliative oncology care, end-of-life decision making, integrating palliative care into the ongoing care of children with cancer as well as pain and symptom control in the context of pediatric oncology care. He has participated in more than 25 studies related to pediatric palliative care and has authored numerous manuscripts and book chapters on the topics ethical decision making as well as other palliative care subjects within the context of pediatric oncology.

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### Notes: