

# Neil Samuel Ghiso Fellowship 2009-2010

## *Project Summary:*

*Improving Pediatric Palliative Care Education for Future Health Care Providers*

Project Timeline: June 2009 – March 2010

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## **Neil Samuel Ghiso Fellowship Proposal**

*Improving Pediatric Palliative Care Education for Future Health Care Providers*

Erica Carmen Kaye

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### **Project Summary:**

Under the auspices of the Ghiso Fellowship, I created a project with three primary goals: 1) To gain a greater understanding of the definition and impact of “compassionate care” as it applies to pediatric patients, as well as an enhanced appreciation of the definition of “palliative care” from the perspective of the PACT team at Children’s Hospital; 2) To ascertain the existing level of knowledge among future health care providers regarding the goals of pediatric palliative care; 3) To create a variety of educational resources, including a comprehensive pediatric palliative care curriculum, in order to enable medical students, interns, residents, and other hospital faculty to feel more comfortable and prepared in their roles as members of the multidisciplinary team providing compassionate care to pediatric patients with chronic or terminal illnesses.

### **I. Immersion Within the Pediatric Advanced Care Team (PACT) At Children’s Hospital:**

In order to gain further understanding about the role of PACT as it functions as a multidisciplinary service at Children’s Hospital Boston, I dedicated the first four weeks of my Fellowship to full immersion within the pediatric palliative care team. I worked closely with the PACT attending, fellows, nurse practitioner, and social worker, and I learned a great deal about how to manage the care of pediatric patients on the PACT service. I spent approximately 10-12 hours a day with the PACT service during these initial four weeks, and I was exposed to a wide variety of different experiences during this time. Each day, I rounded on a panel of my PACT patients, and I also participated in a number of consults with new patients admitted to the palliative care service. I learned how to perform an intake consult with both patients and families, and I received excellent training and feedback regarding complicated issues such as how to ask difficult questions at the end of life. Following my training, I was given the opportunity to lead consults and family meetings for the PACT service, which provided me with an invaluable and extremely rewarding opportunity to experience the responsibility of guiding patients and families through the process of making difficult decisions at the end of life.

During these four weeks, I also had the privilege of making home visits to patients at the end of life, as well as visits to patients in outside rehabilitation and hospice facilities. I learned a great deal from these experiences, both emotionally and academically. Within the hospital environment, I also attended a large variety of family meetings, medical care team meetings, and ethics consult meetings, and I had the opportunity to represent PACT and the palliative care perspective at several of these gatherings. From the PACT attendings, I received valuable guidance in how to address sensitive issues, such as spirituality and controversial ethical conundrums, and I had the opportunity to practice my skills in these areas on a number of occasions. In addition, I learned a great deal about alternative therapies, and I was given the chance to participate in the provision of a variety of alternative treatments, including a variety of breathing exercises, relaxation therapies, “bubble” techniques, meditation, and guided imagery. In addition to learning on the wards, I also attended a wide variety of educational exercises, including PACT seminars and palliative grand rounds held at both Children’s Hospital and MGH.

During my initial month with PACT, I also formed meaningful relationships with several of my patients and their families, and I had the privilege to be a part of their care during this very emotional time in their lives. I also was lucky to form close relationships with the extraordinary members of the PACT service at Children's Hospital, and I learned a number of invaluable lessons from these individuals, including a greater understanding of the definition and impact of "compassionate care" geared towards pediatric patients. I also had the unique opportunity to observe first-hand how PACT functions both apart from and together with the house staff personnel at Children's Hospital, and from this experience I gained an enhanced appreciation of the specific role of PACT and how PACT perceives that its services might be best utilized by other health care providers in order to maximize compassionate care.

## **II. Assessment of Current Status of Pediatric Palliative Care Educational Resources:**

During my initial four weeks on the PACT service, I began to assess the status of educational resources available to medical students, interns, residents, and other house staff, regarding the provision of compassionate care to pediatric patients and families. From my own perspective, I noticed a dearth of resources geared towards medical students or residents interested in learning more about pediatric palliative care, and I decided to speak to a variety of students and healthcare providers in order to verify my impression. During the second month of my Fellowship, I applied to the IRB for permission to conduct informal discussion sessions with medical students and residents, and I received approval from the IRB committee to gather information in order to identify the specific topics and areas in which medical students and residents perceive pediatric palliative care education to be lacking. I contacted the medical student educational faculty at the Integrated Clerkship at Cambridge Hospital, and I received permission to conduct an informal discussion session with a group of third-year medical students. I spent 90 minutes with this group of students, discussing their impressions of palliative care education at Harvard Medical School, and elucidating their perception of their specific gaps in knowledge regarding pediatric palliative care. They offered a number of valuable suggestions to enhance a palliative care curriculum or resource for medical students. Following this successful discussion session, I decided to expand my information base by speaking with residents at Children's Hospital. I contacted the Chief Residents at Children's Hospital, and they shared their impressions of the value of creating a pediatric palliative care curriculum and resource available to all hospital house staff. With their help, I sent an email to all of the residents at Children's Hospital in order to solicit further opinions and recommendations regarding the creation of these resources. On two occasions, I met with second-year and third-year residents in order to hear their insights into ways in which to improve pediatric palliative care education for house staff. Finally, I spoke with several attendings from the PACT service, with the goal of collecting further information about how to improve the provision of "compassionate care education" to medical students and residents. From these interactions, I became aware of several key facts: 1) No comprehensive pediatric palliative care curriculum or educational resources existed within the didactic curriculum at Harvard Medical School; 2) No pediatric palliative care curriculum was available currently to medical students or pediatric residents who rotated through the PACT service for a month's elective; 3) Both medical students and residents felt that they needed and wanted more guidance in specific areas pertaining to the end of life, particularly involving how to conduct family meetings to discuss difficult end of life issues and how to manage symptoms at the end of life; 4) Residents in particular felt that they needed easier access to specific contact information and key tips for the management of situations at the end of life.

## **III. Creation Of A Pediatric Palliative Care Curriculum and Resources:**

My goal was to create two separate pediatric palliative care resources: 1) a portable, pocket-sized, high-yield pediatric palliative care resource designed specifically for the use of medical students, interns, and residents, but which could also be relevant for reference by senior level health care providers; 2) a user-friendly, comprehensive pediatric palliative care curriculum that could be used both as an educational guide for medical students and residents rotating through the palliative care service during an elective month, as well as referenced by medical students, residents, and other health care providers working on the hospital wards.

**A. Pocket-Sized Resource:** This pediatric palliative care reference pamphlet provides helpful “tips” and guidelines, not only to explain the goals of pediatric palliative care, but also delineate the ways in which health care providers can most effectively and compassionately collaborate with PACT in order to participate in the provision of multidisciplinary palliative care. The pamphlet is constructed out of a single sheet of paper, which may be easily folded into thirds in order to create 6 columns (front and back) of high-yield information. The resource readily fits into a white-coat pocket, and it includes the following information: 1) What is pediatric palliative care; 2) Who are the members of PACT, and how to contact them; 3) Key steps for requesting a PACT consult; 4) Introducing the family to PACT (with a brief example conversation); 5) WHO pain ladder; 5) Equianalgesic conversion table; 6) Examples of how to convert between various opioid agents and how to change the route of administration; 7) Checklist of required steps to perform after the death of a child; 8) Checklist for pronouncement of death. This pamphlet will be easily reproducible and conveniently sized in the format of a pocket-sized pamphlet, and we hope to distribute the resource to interns and residents at Children’s Hospital beginning with the incoming class of interns arriving this summer. Ultimately, I hope that this concise resource will be readily accessible to future health care providers as they rotate through various wards of the hospital providing compassionate care to patients with chronic and life-threatening illnesses.

**B. Comprehensive Curriculum:** In the second stage of my project, I created a comprehensive pediatric palliative care curriculum, and I have designed this resource for dual purposes: 1) This curriculum will serve as the educational foundation for both medical students and residents who elect to spend time with the PACT service at Children’s Hospital, in order to provide them with a learning curriculum upon which to base their didactic experience; 2) This curriculum will also be available to medical students, interns, residents, attendings, and other health care providers, regardless of their interaction with the PACT service, accessible via the Children’s Hospital internet browser as well as by means of printed text versions distributed on various hospital wards. There are fifteen main chapters within this curriculum, and each section is divided into anywhere from five to twenty-five subsections which discuss specific topics. Each topic is described concisely, in no more than 1-2 pages of high-yield information, and my goal was to organize the information in a highly accessible and use-friendly manner in order to ensure that the educational process remained efficient and effective. Once the curriculum is uploaded onto the online server, a health care provider at Children’s Hospital will be able to search for key topics or words in order to find the brief educational page with the appropriate information and answers to his or her question. Similarly, a health care provider will be able to use the organized table of contents within the printed text versions of the resource available on the hospital wards in order to access more information on a variety of topics regarding the provision of pediatric palliative care.

Below, I have included the table of contents from the comprehensive pediatric palliative care curriculum that I created, in order to demonstrate the breadth of topics discussed within this resource:

I: Introduction to Pediatric Palliative Care & The Role of PACT at Children's Hospital Boston

- What Is Pediatric Palliative Care?
- How Does Pediatric Palliative Care Differ From Hospice?
- What Is The Pediatric Advanced Care Team (PACT)?
- What Does PACT Offer?
- Overall Goals For PACT Consultation
- Indications For PACT Consultation
- Contacting PACT
- Steps For Requesting PACT Consultation
- Introducing The Idea of PACT Consultation
- Introducing PACT: Special Challenges

II. Improving Communication Skills:

- Conducting a Family Conference
- Discussing Quality of Life
- Establishing End-Of-Life Goals: The Living Well Interview
- When a Family Refuses to Discuss Goals of Care: Family-Centered Interviewing Skills
- Taking a Spiritual History
- The Explanatory Model
- Responding to Emotions
- Dealing with Anger
- The Empathic Approach to Conflict Resolution
- Conflict Resolution: Principled Negotiation

III. Symptom Management: Defining & Assessing Pain

- Defining Discomfort
- Understanding Pediatric Pain Assessment
- Using Pediatric Pain Assessment Scales
- Examples of Pain Assessment Scales
- Pain Assessment in the Cognitively Impaired
- Assessing Pain in the Neonate
- Assessing the Child Who Denies Pain
- Key Tips for Pain Management
- WHO Pain Ladder

IV. Non-Opioid Pain Management:

- Step I on the Ladder: Non-Opioid Analgesics
- Dosing Non-Opioid Analgesics
- Non-Opioid Combination Products
- Available Topical Anesthetics
- Selecting Adjuvant Agents
- Using Steroids for Pain Control
- CNS Adjuvants: Anticonvulsants for Neuropathic Pain
- CNS Adjuvants: Benzodiazepines

## Miscellaneous Adjuvant Agents

### V. Pain Management: Opioids

- Step II on the Ladder: Opioids
- Common Opioids in Pediatrics
- Dose Options for Prescribing Opioids
- Opioid Pharmacokinetics
- Key Tips about Available Opioid Formulations
- Selecting the “Right” Opioid Formulation
- Choosing an Opioid Combination Product
- Commonly Used Opioid Combination Products
- Oral Opioid Dosing Intervals
- PRN Analgesia Orders
- Opioid Dose Escalation
- Controlling Breakthrough Pain
- Weaning Opioids
- Transitioning Between Opioids: Opioid Rotation & Equianalgesic Conversion Ratios
- Methadone for the Treatment of Pain
- Strategies for Initiation of Methadone
- Potential Side Effects of Methadone
- Equianalgesic Conversion for Methadone
- Patient-Controlled Analgesia
- Writing Opioid Infusion Titration Orders
- Opioid Infusions at the End of Life
- Common Opioid Side Effects
- Management of Opioid-Induced Nausea
- Management of Opioid-Induced Constipation
- Treatment of Opioid-Induced Respiratory Depression

### VI. Non-Pharmacologic Strategies for Pain Control:

- Providing Physical and Emotional Comfort
- Cognitive and Behavioral Methods
- Relaxation Techniques
- Available In-Hospital Services
- Additional Pain Resources for Children and Families

### VII. Addressing Fears of Addiction in Children with Chronic Pain:

- Addressing Parental Concerns about Opioids
- Understanding Definitions: Tolerance, Dependence, & Addiction
- Strategies for Addiction Assessment
- “Pseudoaddiction”: Diagnosis and Management

### VIII. Non-Pain Symptom Management:

- Dyspnea
- Respiratory Secretions
- Swallowing Dysfunction
- Oral Secretions at the End of Life
- Excessive Fatigue

Cancer-Related Fatigue  
Nausea and Vomiting  
Anorexia/Cachexia  
Constipation  
Diarrhea  
Spasticity  
Pruritis

IX. Management of Psychological Symptoms in Children with Advanced Illness

Grieving Children: Developmental Concepts of Death  
Responding to Children at the End of Life  
Depression  
Anxiety  
Panic Disorder  
Insomnia  
Nightmares  
Improving Quality of Life: Integrative Therapies

X. Difficult Conversations at the End of Life:

Sharing Bad News  
Discussing the Limitation of Life-Sustaining Treatments (LSTs)  
“Getting the DNR”  
Debunking Myths about CPR Survival  
LST Disagreements between Family and Health Care Providers  
Example of an LST Conversation  
Discussing Hospice  
Facilitating Hospice Referral and Transfer of Care  
Bringing a Child Home at the End of Life  
Differences Between Hospice and the Massachusetts Pediatric Palliative Care Network  
Key Issues to Address Prior to the Death of a Child  
Teaching the Family What to Expect When a Child is Dying

XI. Ethical Issues at the End of Life: Making Difficult Decisions about Medical Management

Discussing Non-Oral Hydration  
Deciding Whether to Tube Feed  
Avoiding the Tube Feeding Spiral  
Controlled Sedation for Refractory Suffering  
Withdrawal of Life-Sustaining Treatments

XII. The Provision of Pediatric Palliative Care in an ICU Setting:

ICU Preadmission Checklist  
Daily ICU Care Plan Checklist  
Understanding the Options for Ventilator Withdrawal  
Supporting the Family After the Decision to Withdraw Ventilatory Support  
Strategies for Successful Ventilator Withdrawal  
Controlling Symptoms During Ventilator Withdrawal

XIII. End of Life Administrations & Bereavement Resources:

Checklist: Administrative Tasks Following Death  
Pronouncement of Death  
Completing a Death Certificate  
Bereavement Resources & Support Programs  
Bibliography for Bereaved Parents, Siblings, Family, and Friends

XIV. Pediatric Palliative Care Resources for Health Care Professionals  
Web Sites  
Professional References

XV. Patient Narratives: Stories written by children and families who received medical care at Children's Hospital, and who wished to share their experiences as patients with future health care providers.

#### **IV. Successes and Challenges:**

As I look back upon my initial hopes and goals for this Ghiso Fellowship from the perspective of a year later, I feel so honored to have had the opportunity to learn about pediatric palliative care from such an extraordinary group of individuals, and I am proud of what I have accomplished during the past year. I have achieved all of the goals and objectives that I proposed in my fellowship project, and I hope that the resources that I created will serve to benefit future medical students, residents, and health care providers in their own quests to learn more about the provision of pediatric palliative care. My experiences with the PACT service were phenomenal and invaluable, and I honestly cannot think of any suggestions for improvement regarding this component of my fellowship experience. Each member of PACT took the time to teach and provide mentorship, and I felt very supported both emotionally and intellectually throughout the duration of my time on the service.

Regarding future challenges, I am still in the process of finalizing the last edits on the pediatric palliative care curriculum, and the next step will be to organize an effective and efficient manner by which to distribute the resources. I plan to work with the chief residents in order to distribute the pocket-sized pamphlets to future interns and rising junior and senior residents, and my hope is to begin the distribution with the new class of interns arriving this June. I also hope to print and bind several text versions of the curriculum, to be placed in the Intensive Care Unit and general pediatrics wards. Additionally, Dr. Christina Ullrich and I will be working with the IT support staff in order to transfer the resources to an online format, in order to make the curriculum readily accessible by all healthcare providers affiliated with Children's Hospital. I am also in communication with Dr. Patricia O'Malley, the pediatric palliative care director at Massachusetts General Hospital, and we hope to eventually expand the reach of our project in order to provide accessibility to medical students and residents at MGH as well. Dr. Ullrich will also begin to utilize the curriculum this year as a teaching guide for medical students and residents who elect to rotate for a month with the palliative care service at Children's Hospital. As she uses the resources, she will inform me of any suggestions or recommendations for improvement, and I will continually amend and augment the educational guides with the goal of making them increasingly effective and accessible. Finally, I plan to communicate with the chief residents about the possibility of coordinating the opportunity for a representative of PACT to speak at one of the noon didactic sessions, in order to raise awareness regarding the availability of new pediatric palliative care educational resources and demonstrate the accessibility and efficient use of these resources.

## **V. Future Goals:**

The Ghiso Fellowship has provided me with a unique and meaningful opportunity to learn more about the provision of pediatric palliative care, as well as identify those areas in pediatric palliative care education might be enhanced for medical students and health care providers. I hope that the educational resources that I have created will enable future medical students and other health care providers to augment their palliative care training and will subsequently improve the provision of compassionate care to children and families. It has been a tremendous honor to serve as a Ghiso Fellow during this past year, not only because I have been passionate about the field of pediatric palliative care for many years now, but also because I hope to begin a long career in this field in the future. I hope to dedicate my career to academic pediatric oncology and palliative care, and I am particularly interested in becoming involved in research in order to improve palliative care education for medical students and other future health care providers. With the generous support of the Ghiso Foundation, I have gained invaluable exposure and experiences within my chosen field, and I have also had the unique opportunity to discover wonderful mentorships from a number of extraordinary individuals. In particular, I would like to thank my mentor, Dr. Christy Ullrich, who has provided tremendous guidance and encouragement during the past year. I would also like to thank the other members of PACT who welcomed me into their community and taught me so much: Dr. Joanne Wolfe, Dr. Tamara Vesel, Dr. Tamara Vern, Ashley Atkins, Janet Duncan, and Marsha Joselow. Finally, I would like to thank Larissa and Alex Ghiso, for making this project possible, and I would like to dedicate this project to the memory of Neil Ghiso.