

Course Announcement
OSF Seminar
on
Palliative Pediatric Care
December 3 to December 9, 2017

The Open Society Foundation's Public Health Program is pleased to invite you to apply to participate in a special seminar on **Pediatric Palliative Care** to be held **December 3 – December 8, 2017** at the Schloss Arenberg in Salzburg, Austria.

Goals

The main goals of the seminar are to provide practicing clinicians with 1) best practices in communication in childhood serious illness, including establishing goals of care and advanced care planning 2) up to date, evidence-based strategies for symptom management in children with advanced illness; 3) competence in psychosocial and spiritual care of children with serious illness and their families; 4) strategies for caring for children at end of life and their families; 5) to understand best practices in bereavement support for families of deceased children.

The conference will be held in **English ONLY**. No translation will be available. There will be small group discussions and role play which requires proficiency in English

Faculty

The course will be co-directed by Dr. Joanne Wolfe and Dr. Kathleen Foley.

Dr. Joanne Wolfe is the Chief of the Division of Pediatric Palliative Care in the Department of Psychosocial Oncology and Palliative Care at the Dana-Farber Cancer Institute (DFCI) and the Director of Palliative Care at Boston Children's Hospital (BCH), and is an Associate Professor of Pediatrics at Harvard Medical School. In addition to providing clinical pediatric palliative care, Dr. Wolfe directs a research program focusing on easing suffering and promoting wellbeing in children with serious illness and their families. She also co-directs the North American Pediatric Palliative Care Research Network. She co-developed the Pediatric Track of the Program for Palliative Care Education and Practice, a continuing medical education course offered through the Harvard Center for Palliative Care. She is also a co-investigator on the EPEC-Pediatrics Project, an on-line and face-to-face curriculum which aims to enhance primary pediatric palliative care knowledge, skills and behaviors among pediatric clinicians and subspecialists.

Dr. Kathleen Foley is a former Attending Neurologist in the Pain & Palliative Care Service at Memorial Sloan-Kettering Cancer Center in New York City and also a former Professor of Neurology, Neuroscience, and Clinical Pharmacology at Weill Medical College of Cornell

University, and previous Director of the WHO Collaborating Center for Cancer Pain Research and Education at Memorial Sloan-Kettering Cancer Center. She held the Chair of the Society of Memorial Sloan-Kettering Cancer Center in Pain Research. She was elected to the Institute of Medicine of the National Academy of Sciences for her national and international efforts in the treatment of patients with cancer pain. She is the past Director of the Project on Death in America of the Open Society Institute whose goal was to transform the culture of dying in the United States through initiatives in research, scholarship and clinical care. Dr. Foley is the past Medical Director of the International Palliative Care Initiative of the Public Health Program of the Open Society Institute working to advance palliative care globally.

Dr. Foley has focused her career on the assessment and treatment of patients with cancer pain. With her colleagues, she has developed scientific guidelines for the use of analgesic drug therapy through clinic pharmacologic studies of opioid drugs.

Dr. Foley has received numerous awards and honors for her work. She received the Distinguished Service Award and the Humanitarian Award from the American Cancer Society, the David Karnovsky Award from American Society of Clinical Oncology, and the Frank Netter Award from the American Academy of Neurology. She is a previous Rita Allen Scholar.

Dr. Foley chaired three expert committees that resulted in the publication of the three WHO monographs on Cancer Pain and Palliative Care; *“Cancer Pain Relief”* (1996), *“Cancer Pain Relief and Palliative Care”* (1990), and *“Cancer Pain and Palliative Care in Children”* (1996)

Other faculty members include Barbara Jones PhD, Dr. Stefan Friedrichsdorf, Dr. Justin Baker and Ms. Mary Callaway and their biographical sketches are included at the end of this course announcement.

Costs Covered

The cost of round trip economy fares or railroad travel, accommodation at Schloss Arenburg, visa cost, transfers, and all meals will be provided.

PLEASE NOTE insurance and per diems **ARE NOT COVERED** and are the responsibility of each participant. Applications will only be accepted from the following countries: Albania, Armenia, Bosnia Herzegovina, Bulgaria, Kazakhstan (from Astana only), Kosovo, Macedonia, Moldova, Romania, Serbia, and Ukraine. All participants must be able and committed to attend the entire course.

Who Should Apply

Physicians, psychologists, physician/nurse teams working in the care of seriously ill children including those with cancer, advanced neurological impairment, advanced heart or lung disease, critically ill newborns and those with genetic and metabolic disorders wishing to enhance skills in symptom management, management of psychological and spiritual distress and improving their communication skills. Physicians in the following disciplines are eligible to apply: pediatrics, family medicine, and general practitioners; pediatric hematology/oncology, cardiology, pulmonary, and neurological subspecialists; pediatric intensivists and neonatologists; and pediatric palliative care and hospice physicians. The ideal applicant is someone who cares

for patients on a weekly basis, teaches healthcare professionals and trainees on a regular basis, belongs to a university curriculum committee, belongs to national and international associations to advance pediatric palliative care and who wants to integrate palliative care into their clinical and teaching programs. Candidates meeting several of these criteria will be given priority.

Course Content

The course will include both interactive plenary and workshop sessions and cover the following topics:

1. Overview of Pediatric Palliative Care
2. Communication in eliciting family goals of care and advance care planning
3. The role of palliation from diagnosis to bereavement
4. Symptom management including basic and advanced pain management, and management of respiratory, gastrointestinal, neurological and psychological distress
5. Communication with the seriously ill child and adolescent
6. Psychosocial and spiritual interventions
7. Integrative therapies
8. Caring for the imminently dying child and family
9. Moral distress and ethics
10. Caring for self while caring for others
11. Bereavement Care
12. International & regional efforts to advance pediatric palliative care
13. Educational resources in Pediatric Palliative Care
14. Pediatric Palliative Care program development

Participants are asked to bring challenging cases to review in the Expert Panel sessions.

Faculty Backgrounds

Barbara Jones, PhD

Dr. Barbara Jones is Associate Dean for Health Affairs and University Distinguished Teaching Professor at the UT Austin School of Social Work. She is Co-Director of the Institute for Collaborative Health Research and Practice. Dr. Jones is a Distinguished Scholar and Fellow of the National Academies of Practice and Vice-Chair of the Social Work Academy. Dr. Jones is the Chair of the American Cancer Society Oncology Training Peer Review Committee. She is the Past President of the Association of Pediatric Oncology Social Workers (APOSW) and recipient of the 2013 APOSW Social Worker of the Year Award. Dr. Jones was co-investigator on ExCEL in Social Work, an NCI-funded project to train oncology social workers for which she received the 2014 American Psychosocial Oncology Society (APOS) Outstanding Training and Education Award. She is a Steering Committee member of the Pediatric Palliative Care Research Network, a Project on Death in America Social Work Scholar, and recipient of the PDIA Social Work Leadership Award. Dr. Jones is Associate Editor of the Journal of Psychosocial Oncology and on the editorial board of the Journal of Adolescent and Young Adult Oncology. Her clinical experience is in pediatric and AYA oncology, pediatric palliative care, and grief and loss. Dr.

Jones conducts research on pediatric palliative care, mindfulness based interventions, adolescent and young adult (AYA) cancer survivors, and interprofessional education. Dr. Jones is a Course Director of the UT Austin Health Interprofessional Education Curriculum and a member of the Health IPE Steering Committee.

Justin Baker, MD

As a pediatric oncologist, palliative care physician, member of the ethics committee, and a patient-reported outcomes, Phase I, and end-of-life care clinical investigator at St. Jude Children's Research Hospital, *Dr. Baker* is intimately aware of the distress experienced by children with advanced cancer and the ethical and end-of-life/bereavement issues surrounding their disease progression. 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 – the largest fellowship program in the state of TN. 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 patient-reported outcomes and pain and symptom control in the context of pediatric oncology care. He has participated in >30 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. He is an expert at translating the findings of clinical trials, especially those related to patient-reported outcome data, into clinical care.

Stefan Friedrichsdorf, MD

Dr. Friedrichsdorf is an Associate Professor of Pediatrics at the University of Minnesota and medical director of the Department of Pain Medicine, Palliative Care and Integrative Medicine at Children's Hospitals and Clinics in Minnesota, Minneapolis / St. Paul (USA) - one of the largest and most comprehensive programs of its kind in the country. The department was recipient both of the "*Clinical Centers of Excellence in Pain Management Award*" by the American Pain Society and the prestigious "*ChildKind International*" pain relief certification.

Dr. Friedrichsdorf received the 2016 *Elizabeth Narcessian Award for Outstanding Educational Achievements in the Field of Pain* by the American Pain Society and the 2011 *Hastings Center Cunniff-Dixon Physician Award*. He has presented more than 600 lectures about pediatric pain medicine and palliative care in 27 countries on all six continents, and has a track record of research and publications in the field. He is the principal investigator of a US\$1.6 million National Institutes of Health (NIH) / National Cancer Institute (NCI) multisite study on the creation, implementation and evaluation of a Pediatric Palliative Care Curriculum (*EPEC-Pediatrics*), offering "Train-the-Trainer" conferences with his co-investigators (such as Joanne

Wolfe) regularly. He founded and continues to direct the annual *Pediatric Pain Master Class*, a week-long intensive interdisciplinary course for health professionals.

Mary Callaway, MME

Ms. Callaway is the past Director of the International Palliative Care Initiative (IPCI) of the Public Health Program at the Open Society Foundation. The goal of the initiative was to enhance palliative care development internationally with a specific focus on Central and Eastern Europe, the former Soviet Union, Southeast Asia, South Africa, Southern Africa, and East Africa.

From 1994 to 2003 she served as the Associate Director for the Project on Death in America of the Open Society Institute, a 45 million dollar initiative to improve end of life care in the United States. Prior to joining OSI, she was the Administrator for the Pain and Palliative Care Service at Memorial Sloan-Kettering Cancer Center in New York City for 16 years. In that position she served the Executive Director for the World Health Organization's (WHO) Collaborating Center for Cancer Pain Research and Education. She also developed educational programs for health care professionals and managed over 4 million dollars a year in research grants and philanthropic support. She organized and managed the working group for the development and dissemination of the WHO 1996 monograph "Cancer Pain Relief and Palliative Care in Children".

She is a founding member of the United States Cancer Pain Relief Committee. She was a former member of the Worldwide Palliative Care Alliance advocacy working group and the Steering Group of the International Children's Palliative Care Network. She is on the Board of Directors of the African Palliative Care Association and the International Association for Hospice and Palliative Care. She was also on the pain management working group of the African Palliative Care Association which planned and implemented three regional drug advocacy workshops to increase opioid availability.

She served on the grants committee of the Virginia Gildersleeve Foundation and has served as a technical advisor to national and international foundations interested in advancing palliative care.

With Dr. Frank Ferris, she edited the JPSM May 2008 volume on International Palliative Care.

Please Forward This Announcement

We welcome country coordinators to forward the announcement and application to hospitals, colleges, and universities.

Application, Selection Process

All applications must be received by **June 1, 2017**