

## Program Profile

*Erratum: Last month, we neglected to include Children's of Alabama Palliative & Supportive Care Team/University of Alabama at Birmingham in our listing of 2014 Pediatric Palliative Care Fellowship Programs. To make amends, this fabulous program is the subject of this month's Program Profile. If you know of additional training programs, please let us know!*

### Children's of Alabama Palliative & Supportive Care Team/University of Alabama at Birmingham

**Location:** Birmingham, Alabama

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**Service Delivery Model:** Our program began in 2009 in collaboration with the UAB Center for Palliative & Supportive Care. We see inpatient consults across the hospital system and in the Regional Neonatal Intensive Care Unit at UAB Women & Infant's Center. Outpatient consults are seen in primary care or other subspecialty clinics on an as needed basis; one of our physicians has an embedded palliative care clinic within our multidisciplinary muscular dystrophy clinic. We routinely partner with local hospices to coordinate care for our patients as they transition out of the hospital. In addition, we are actively involved in nursing, medical student, resident, and fellow education. In partnership with the UAB Palliative Medicine Fellowship Program, we provide a one-year training track in pediatric palliative care.

**Annual Average # of Patients Served:** In 2013, we saw over 260 consults with nearly 2000 patient/family contacts. We continue to see annual growth as hospital culture changes and our colleagues grow to appreciate the need and added benefit of our service.

**Staffing of Team:** Our team is composed of three board-certified HPM physicians (1.2 FTE split evenly). We have a full-time (1.0 FTE) nurse practitioner and a full-time (1.0 FTE) palliative care coordinator/nurse clinician. Weeknight call is covered by the physician staff and weekends are shared among the physicians and CRNP. Our interdisciplinary team is composed of Social Work, Pastoral Care, Child Life, Child Psychology, and School Teachers, shared with the health system.

**Funding sources:** Hospital support, grants, fundraising (including an annual "Caring thru Color" guided painting event).

**Research:** Active projects include communication skills training with Pediatric/Med-Peds residents, safe opioid prescribing in ENT practice, and resident quality improvement looking at palliative care consultation in the PICU.

**Memorable challenge:** Our team started with a hospital-based CRNP and physician back-up from the UAB Center for Palliative & Supportive Care. In a little over a year, we had considerable change in our staffing with the loss of two former nurse clinicians, the transition to a new CRNP, the addition of a new coordinator/nurse clinician and two additional physician faculty. During this time of transition, recognizing the clear challenge to team dynamics, we began meeting with the Director of Emotional Wellness for the health system for regular debriefing sessions. These meetings were so successful that we have continued them monthly for our entire team. Similarly, recognizing the day-to-day challenge of caring for critically and chronically ill children, one of our previous fellows began monthly debriefing sessions that we help facilitate for the pediatric residents.

**Memorable success:** In 2012, our team met Alonso, a 2 ½ year old with hemolytic uremic syndrome requiring dialysis and complicated by pancreatitis. After several complicated weeks in the hospital, his renal team consulted us to help with pain. We quickly discovered the complexity of Alonso's symptom burden (including pain, delirium, and anxiety) and the extent of his family's suffering. His parents, both physicians themselves, were struggling with the acute illness of their son, balancing care for their younger daughter, and seeing the medical system from the "other side." We found many of his clinicians uncomfortable with opioids given his age, renal failure, and critical illness. So, over the course of several months in the hospital, we were able to partner with the clinicians, educate staff on complex pain management, and work with our interdisciplinary team to support not only Alonso but his family and medical team as well. With better symptom control, Alonso began to tolerate his treatments and slowly began to improve. And we grew to love this kid who literally came back to life before our eyes. What started as a "pain consult" became an example to all of his providers of the broader scope of palliative care (not just "the death team") and the importance of working as an interdisciplinary team to manage complex patient, family, and team interactions. You can meet Alonso and hear more of his story at <http://www.youtube.com/watch?v=DGI4DXYKh9c>.