

Anne E. Dyson Child Advocacy Award 2007 Recipients

Project Leader Name: Joshua M. Dower, MD and Raveen Raviendran, MD
Project Title: "Literacy for End-of-Life"

"Literacy for End-of-Life" is a project targeting children and families who face terminal illness, life altering experiences including acute injuries, and fetal demise. The project will attempt to provide age-appropriate resources for individuals coping with end-of-life issues. Through books and other resources this program will give families a library of tools to attain answers to questions surrounding death and the grieving process. This will provide an opportunity to address feelings of guilt, anger and loneliness. It will also be an occasion to have a celebration of life and explain death as a natural process.

In rural areas, clinicians and institutions lack training and resources for end-of-life care. Reading opens a window for discussion of challenging psychological issues. We see reading as a form of respite care. It is an opportunity for caregivers and children to receive a break from their difficult situation and enter a world of opportunities for self-exploration and camaraderie.

Family reading time helps preserve and strengthen families and is important to the overall health of families and children with chronic conditions. Furthermore, implementing this program at WVU Children's Hospital, serving as a regional referral center, allows collateral benefits to flow into the surrounding rural communities. The long term goal will be to establish a comprehensive lending library and make the books available to children and families across the State of West Virginia.

Project Leader Name: Kitty O'Hare, MD and Manisha Shanbhag, MD
Project Title: Working Initiative for Special Health Education Services (WISHES)

WISHES is a group project of the Medicine-Pediatrics residency at the University of Pennsylvania (Penn) and Children's Hospital of Philadelphia (CHOP). Our goals are to: 1) create and administer a health care curriculum pertinent to adolescents with special health care needs (SHCN); 2) facilitate the transition of adolescents with SHCN from pediatric to adult medical providers; and 3) train Med-Peds residents as primary providers for adolescents with SHCN. In line with the goals of Healthy People 2010, WISHES seeks to remove barriers to health care for patients with disabilities.

WISHES collaborates with Widener Works and REACH, two programs for adolescents with SHCN developed by Children's Hospital of Philadelphia. The Widener School is a Philadelphia public school for children with severe disabilities. Selected seniors at Widener spend part of the week at CHOP in job readiness training. Job skills assessments are performed by specialists in physical therapy, occupational therapy, speech therapy, and neuropsychology. Over time, students are matched with job coaches and perform job trials in

various departments at CHOP. Ultimately, after successful completion of the training program, students are hired into the CHOP workforce. Students and families from Widener and other schools attend weekend support sessions conducted by the REACH group.

WISHES specifically addresses the health care needs of participants in Widener Works and REACH. Med-Peds residents review the medical record of each student, then work with the students to draft a personal health history. These durable medical summaries serve as a foundation for transition to adult providers. Further, residents try to identify adult providers for any students who have not yet transitioned to adult medicine. In 3-4 sessions, residents meet with the entire senior class at Widener to present a *Healthy Choices* curriculum. Topics include sexuality, relationships, nutrition, exercise, and substance abuse. Residents participating in WISHES report back to the Med-Peds residency program in monthly conferences. Through quarterly specialty conferences, Med-Peds residents will educate their colleagues in Pediatrics and Internal Medicine about topics related to transition and adult followup of chronic disease. In addition, Med-Peds residents are encouraged to rotate through specialty clinics addressing chronic disease, such as Penn's programs for Adult Cystic Fibrosis and Adult Congenital Heart Disease.

Funding from the Dyson Advocacy Award will be used to create and print customized health summaries for WISHES students. Also, funds will be applied toward materials used in the classroom health education sessions, including multimedia teaching tools accessible to students with a variety of sensory impairments. For example, specialized teaching materials are needed for students who are blind or with poor reading skills.

Project Leader Name: Alenka Zeman, MD, Anna Rosenquist, MD and Katharine Zuckerman, MD

Project Title: Massachusetts Pediatric Residents and Fellows Day at the State House

This project was created entirely by pediatric residents at Mass General Hospital for Children with the goal of bringing together residents and fellows from across Massachusetts to the state house in order to learn how to be child advocates. We as residents felt that there were a lot of important child health issues being debated by legislators, but we did not know how to go about making our voices heard or did not know that we could be lobbyists. Instead of just watching these issues affect the health of children we cared for in the hospital daily, we wanted to make a difference. With these ideas in mind, we created the Massachusetts Pediatric Residents and Fellows Day at the State House last year and it has been met with great success for the past two years.

Our main goal of this project is to teach residents how to promote policy and to discuss current child health issues that are actively being debated. One day a year we gather about 70-100 residents at the state house and create a day

filled with many events. The morning consists of a number of talks including, for example, speeches from: Dr. Bigby (the secretary of health and human services), Dr. Palfrey (a well known pediatrician and child advocate) and interactive workshops from Alex Calcagno and Ed Brennan (lobbyists) who role play how to be an effective lobbyist. We take time to discuss three important child health issues each year that are currently up for review by legislators. For example, this summer we discussed the new mental health care bill (H.1872) that would provide children better access to mental health facilities, the school nutrition bill (H.2168) that allow schools to provide children with healthier food options and finally discussed funding three new vaccinations: the meningococcal, rotavirus and HPV vaccine as part of the state budget. In the afternoon, we set up individual appointments for each resident to meet with his or her representative and senator so that he or she can personally discuss their support of these bills. Our goal is to have pediatric residents and fellows from across Massachusetts meet other people interested in advocacy, learn about pediatric health care issues, and personally realize that as pediatricians we have a duty to let our opinions regarding these issues be heard.

The MGH legislative advocacy group (LAG) had the idea to create this day last year and so far we have planned two very successful days at the state house. In fact, this year we doubled our participation and had almost 100 residents, fellows and faculty from all five of the Massachusetts pediatric residency programs (MGH, Children's/BMC, Baystate, Umass and Tufts) attend. Due to the amount of success that we have had, we are definitely planning on continuing this as an annual event. This one day takes about 9 months of planning to create each year, but is definitely worth the amount of work when we hear the feedback both from participants and legislators. The enthusiasm that this project has created for child advocacy really is unparalleled.