

KIDS: Providing Children and Families a Voice in Medicine, Research, and Innovation

By Sharon Smith, MD FAAP and Charles Thompson, MD FAAP, Co-Leads, KIDS Connecticut | April 23, 2014

The active involvement of patients in health care choices, diseases, research, and innovation is an area of recent focus for many public and private entities (e.g., FDA's Patient-Focused Drug Development initiative). As an innovative method to engage children, the KIDS (Kids and Families Impacting Disease Through Science) project was launched as an advisory group of children, adolescents, and families focused on understanding, communicating about, and improving medicine, research, and innovation for children. KIDS is a unique collaboration between the [American Academy of Pediatrics \(AAP\) Section on Advances in Therapeutics and Technology](#) (SOATT), local AAP Chapters, children's hospitals, local schools, and other partners.

The objectives for the KIDS project are as follows:

- Learn, teach, and advocate for medicine, research, and innovation that improves the health and well-being of children;
- Engage in the process through projects and consultation activities with hospitals, researchers, and other partners in the public and private sectors;
- Provide input on research ideas, innovative solutions, unmet pediatric needs, and priorities;
- Contribute to the design and implementation of clinical studies for children (e.g., assent, monitoring tools, schedules, etc.);
- Serve as a critical voice for children and families in the medical, research, and innovation processes.

KIDS launched as a pilot program in Connecticut in September 2013 and will be expanding to other states in the US (e.g., Utah, New Jersey). The KIDS Connecticut Team has participated in meetings at [Connecticut Children's Medical Center](#) (Hartford,

CT) and [Yale-New Haven Children's Hospital](#), a Research Summit at [Pfizer's](#) Connecticut Laboratories, and an advisory session with Mr. David Tabatsky, author of [Write for Life](#).

In addition, the team attended the AAP's [Healthy Children Conference & Expo](#) in Chicago in March, at which they staffed an exhibit booth highlighting their work and the importance of research and innovation for children. They also conducted survey-based research by collecting more than 300 responses with a focus on participants' opinions of the importance of research in their lives and the role of children in research. Three KIDS Team Members delivered an invited Learning Zone presentation for conference attendees discussing the importance of research, the work of the KIDS Team, and the vision for future expansion. Finally, the KIDS interacted with numerous AAP leaders and staff members throughout the weekend. Overall, the KIDS involvement in the conference was a resounding success as each Team Member was articulate and passionate about their work and the importance of medicine and research. Feedback from attendees, exhibitors, and AAP leadership/staff was overwhelmingly positive. The Team will also be attending the [Pediatric Academic Societies](#) meeting in Vancouver in early May and will be collaborating with a similar children's advisory group located in that city.

In addition to a KIDS expansion in the US, SOATT is working with existing young person advisory groups and other partners to develop an international network of children advisors. The children, families, leaders, and partners are very excited about the potential opportunities for these teams and the future network to make a significant impact on the health and well-being of children worldwide.

Do you think it is important for children to be involved in shaping pediatric medical research? Have you had experience with kids getting involved in their health care? What was the outcome? Share your thoughts in the comments section.

If you are interested in participating in this project or would like more information, please contact Charlie Thompson (charles.a.thompson@pfizer.com).

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