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Commentary

International Children's Advisory Network: A Multifaceted Approach to Patient Engagement in Pediatric Clinical Research

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ABSTRACT

Pediatric youth advisory groups were created to provide insight and guidance to the clinical research community. Such efforts have become a priority and parallel the demand for patient-centered health care. While steps are being made to integrate the patient voice into research, there remains a lack of pediatric-specific engagement in the development of pharmaceuticals and in clinical research. For example, a significant number of children are still treated with medications that are not approved for use in this age group, due to a lack of clinical trials involving younger children and neonates. The American Academy of Pediatrics noted that physicians are faced with an ethical dilemma, as they must frequently either not treat children with potentially beneficial medications or treat them with medications based on adult studies or anecdotal empirical experience in children. By improving the approach to pediatric study design, indications for pediatric-specific therapies can be developed. We describe a structured organization with empowered youth and parents who are beginning to play a key role in the research process that suggests ways to improve pediatric research and for innovative medical products to be more "child friendly" and usable. We will also describe how investigators can engage the International Children's Advisory Network to obtain valuable youth perspectives on many aspects of clinical research and health care advocacy. (*Clin Ther*. 2017;∎:∎∎∎–∎∎∎) © 2017 Elsevier HS Journals, Inc. All rights reserved.

Key words: pediatric research, young persons' advisory groups, patient and public involvement, patient engagement, patient advocacy.

INTRODUCTION

Pediatric youth advisory groups were created to provide insight and guidance to the clinical research community. Such efforts have become a priority and parallel the demand for patient centered health care. While steps are being made to integrate the patient voice in research, there remains a lack of pediatric specific engagement in the development of pharmaceuticals and in clinical research. For example, a significant number of children are still treated with medications that are not approved for use in this age group, due to a lack of clinical trials involving younger children and neonates.[1] The American Academy of Pediatrics (AAP) noted that physicians are faced with an ethical dilemma, as they "must frequently either not treat children with potentially beneficial medications or treat them with medications based on adult studies or anecdotal empirical experience in children."[2] By improving the approach to pediatric study design, indications for pediatric-specific therapies can be developed. The International Children's Advisory Network (iCAN) addresses these focus areas through a multifaceted approach.

iCAN is a worldwide consortium of youth and family advisory groups collaborating to provide a voice for children in pediatric clinical research, medicine, and innovation.[3] Having access to a structured engagement system provides young patients and their families a platform on which they can share their voice in a meaningful way. This novel organization offers medical

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and research professionals the opportunity to collect feedback from youth advisory groups and their families about all aspects of pediatric clinical research. Engaging patients and caregivers in the clinical research process not only provides valuable insight, but may allow researchers to improve their clinical studies through increased enrollment, better participant retention, and ultimately generate more significant outcomes.

At the center of iCAN's mission are four integral components: Education, Innovation, Advocacy, and Youth and Family Engagement. Together, these four pieces allow the iCAN network to collectively provide valuable and insightful feedback that may have a significant impact on the future of pediatric clinical research and medicine. Individual iCAN chapters or teams interact with local universities and researchers on a regular basis. Most local chapters meet monthly and review and discuss submitted materials, listen and interact with investigators in person, or connect online to provide feedback and advice.

iCAN Research and Advocacy Summit

iCAN officially commenced in 2015 at the iCAN Launch and Research Summit. This event took place in Washington, DC, and united 130 of iCAN's inaugural youth advisors, parents, politicians, pharmaceutical organizations, and other stakeholders. For the very first time, young people from across the globe had the opportunity to come together and interact face to face with researchers, industry, regulatory, and government leaders to learn from one another and advocate for pediatric clinical research and health care. This successful event marked the beginning of this new international organization, and inspired youth advisory groups to build on their local and global agendas so children could have a voice in pediatric medicine.[4]

In June 2016, the second-annual iCAN Research and Advocacy Summit took place in Barcelona, Spain. The size of the Summit increased to 160 attendees, and focused on rare diseases, innovation, and pediatric health and well-being. At this event, "children and families had the opportunity to engage with world leaders in science, while learning about different innovative treatments, personal health, regulation, the clinical research design and process, and patient advocacy."[4] A poster session gave youth the opportunity to present the many projects that each local team had worked on since iCAN's launch. Projects included revising a multitude of assent forms and clinical trial subject information sheets, a visit to a motion analysis laboratory to provide feedback, and working with Child Life Specialists to develop new strategies. The Summit also included other educational and cultural activities, such as tours of the Sagrada Familia de Gaudi, FC Barcelona's Camp Nou, CosmoCaixa Museum of Science, and Fundació Alícia, a research center focused on healthy lifestyles.[4]

iCAN saw a tremendous growth this year, resulting in a 50% increase in attendance at the 2017 iCAN Research and Advocacy Summit in Orlando, Florida. Approximately 250 youth advisors, families, and stakeholders came together to once again learn about pediatric research, medicine, and innovation. The recent heartbreaking loss of a beloved youth advisor sparked a wave of strength and inspiration throughout the network to ensure that we do our part to decrease future cancer deaths. The event commenced with a keynote address from Raymond Rodriguez-Torres, Chair and Founder of the childhood cancer foundation, Live Like Bella. Mr. Rodriguez-Torres' message resonated deeply with attendees, as he shared the story of his late daughter's unwavering optimism and commitment to leading a happy and fulfilling life, despite being faced with a very rare and aggressive form of childhood cancer. He has dedicated his life to making childhood cancer a curable disease, founding Live Like Bella, and raising awareness and funding for pediatric cancer research. This set the tone for the rest of the week, as attendees participated in more than 30 hours of programming. Specific sessions included a nutrition workshop; an advocacy activity during which caregivers wrote letters to policy makers; a workshop teaching basic medical skills; and presentations on research ethics, STEM (science, technology, engineering or mathematics) careers, injury prevention, patient safety in drug development, pharmacogenomics, and the role of regulatory agencies. Attendees also visited the Give Kids the World Village, a resort where "children with life-threatening illnesses and their families are treated to week long, cost-free vacations."[5] There, attendees received an informative tour of the facility and participated in a community service activity making celebration props for guests at the resort. The 5-day Summit ended with a keynote address by Florida Senator Marco Rubio, who discussed ways children and families can best advocate for pediatric clinical research, specifically for childhood cancer.