

I CAN Digitally Involved (iCANDI): Collaboration with the Pediatric Trials Network (PTN)

Amy Ohmer



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Spring has sprung and with that is the launch of new and exciting kid-friendly initiatives at the International Children's Research Network, Inc. (iCAN). Starting with a new approach to discussing clinical research trials, iCAN completed a collaboration with the Pediatric Trials Network (PTN) in which a 13-year old youth member, Kenneth, from the KIDS Ohio chapter shared his perspective for a lay summary. This unique project helped create a kid-friendly short video designed to educate other children (and their families) about the safety and effectiveness of pediatric medicine.

Next, iCAN participated in the latest AIMed series to spotlight

Medical Devices and pediatrics. Sharing the wisdom of 15-year-old Imaan, a member of the KIDS CT chapter, the AIMED series host, Dr. Anthony Chang, CHOC, was treated to a better understanding of what it is like to wear an insulin pump and a continuous glucose monitor as a young person. The theme of Medical Device discussion continued. During the month, iCAN's President Leanne West and Director Amy Ohmer participated in a community engagement session with MDUFA (FDA) for sharing support to create a better understanding of pediatric devices and how to help kids. This promises to be an important spotlight during the year as more understanding of pediatric medical device innovation is shared worldwide. In partnership with Boston Children's Hospital, connecting in May, KIDS Barcelona will be hosting a Hackathon. This event is designed to draw out creativity from the community to help support new pediatric medical innovation. All iCAN Chapters have been invited to serve as judges to help narrow down the finalists. We are confident this will be a terrific event. Details on our news page at www.icanresearch.org

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iCAN youth members participated globally through several surveys designed to capture feedback on clinical research trial design and helped create new iCAN Youth Member recruitment flyers. For our organization, it is vital to ensure that the kid's voice is infused everywhere, so almost everything is reviewed by kids. In completion, all of the finalized work with feedback incorporated was given the "iCAN Seal of Approval". Going forward, if you see

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the seal, you can rest assured that it was "kid reviewed - kid approved"

Additionally, iCAN summit planning (to be held July 12th - July 16th, 2021) is happily underway. Dr. Sharon Smith, CT Children's Hospital, is creating a session to help youth members understand steps to a diagnosis by doctors. The session aptly named "What Doctors Want You To Know" will be part of the weekly summit events. Furthermore, iCAN and Sing Me A Story kicked off a new and exciting musical collaboration for a global group of six lucky youth members living with rare, complicated, and chronic medical conditions. In a wonderful alignment with iCAN to support youth in providing opportunities to share children's voices, Sing Me A Story's mission is to serve deserving families in need through sharing stories of children combined with the power of music. Sing Me A Story connects professional singer-songwriters with each youth member and family to understand who the child is, what they like, such as hobbies, families, pets, vacations, or other important parts of life for the child. Once the story is shared, the singer-songwriter team sets the words to music, creating a lasting memory for a lifetime. The summit will feature the final musical creations of young people from KIDS Bari, KIDS Virtual, KIDS Albania, and KIDS Houston, and our newly created Young Adult Professionals.

Looking ahead, we invite all summit participants to send in a Chapter Poster - a culmination of work done throughout the year to support their local chapters. The Summit Poster Session is also open to other interested community members that might like to showcase their original abstracts to the iCAN Community. The Poster Session and all other open projects are available on the 'FOR KIDS' tab on the homepage. As a reminder, if any interested kids are not involved in an iCAN chapter but would like to participate, iCAN offers a Virtual Chapter to accommodate any child, anywhere in the world. There is no cost to create a chapter or for a child to participate as iCAN is supported through sponsoring partnerships. If you would like to sponsor a child, a chapter, or our summit, please contact us by email info@icanresearch.org or visit www.icanresearch.org

#iCANMakeADifference #iCAN #iCANBeDigitallyInvolved #GlobalGenes #CareAboutRARE

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