

A Word from Our Chair

Greetings to our iCAN friends around the globe. Hopefully, the teams are each feeling the energy and momentum after participating in our 2016 Research and Advocacy Summit in Barcelona, Spain. The Summit brought together over 160 youth advisors, team leaders, parents, and scientific partners representing 15 chapters from 6 countries on 2 continents. The KIDS Barcelona team and Hospital Sant Joan de Deu were wonderful host collaborators in designing and implementing this world-class event. We are also deeply appreciative of our sponsors and partners who turned this dream into a reality. Next year's Summit will take place in Orlando, Florida, the week of July 10th, and further details will be available in the near future. The team in Barcelona and all of our wonderful attendees sure set the bar high for 2017 and beyond. I hope you enjoy this edition of the newsletter.

-Charles Thompson, iCAN Chairperson



Meet Meghan, our new Coordinator

I recently graduated from the University of Connecticut with a degree in Psychological Sciences, and I plan to apply to Physician Assistant programs in the next few years. I volunteer as a research assistant at UConn and an EMT in my town on the side. In my free time, I enjoy going to the beach, traveling, and spending time with family and friends. I was fortunate to attend the 2016 Research and Advocacy Summit in Barcelona, Spain, and I have been both humbled and inspired by all of the incredible things this organization has achieved in such a short time. Already, my experiences with iCAN have been so rewarding, and I'm looking forward to all of the amazing things we can accomplish together. Thank you everyone for giving me such a warm welcome. It's an honor to be a part of the iCAN family!

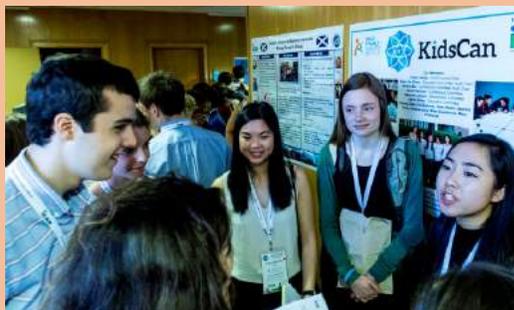
-Meghan Gwara, iCAN Coordinator



Summit Overview

2016 iCAN Research and Advocacy Summit

The 2016 iCAN Research and Advocacy Summit was an engaging five-day conference held in Barcelona, Spain that brought together over 160 youth advisors, team leaders, parents and scientific partners representing 15 iCAN chapters from 6 countries on 2 continents. iCAN partnered with Sant Joan de Déu Hospital to host this event, which held a myriad of interactive sessions, workshops and expert panels. The objective of iCAN and the Summit is to educate and empower our youth to improve pediatric health, medicine, research and innovation by sharing children's voices in an impactful way.



Among those in attendance were speakers and representatives from leading organizations such as the US Food and Drug Administration, Health Canada, European Medicines Agency, Pfizer, Premier Research, European Organization for Rare Diseases, Dravet Syndrome Foundation, Pharmaceutical Product Development, Nuffield Council on Bioethics, European Patients' Academy on Therapeutic Innovation, The Royal College of Paediatrics and Child Health, and various Children's

Hospitals from around the world. 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. A poster session gave children and young people the opportunity to present the many projects each team has worked on since iCAN's launch. 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.

This event provided our youth with an invaluable opportunity to learn from one another and network with professionals from across the globe, while allowing the scientific community to engage with children and learn about the value and the significant importance of the influence of children on research, medicine, and innovation. iCAN aims to continue to expand the network and opportunities for our youth, as well as increase the success of the Summit each year. More information and pictures from the 2016 Summit can be found at www.icanresearch.org/summit.



Thank you to the KIDS Barcelona team and Sant Joan de Déu Hospital

"Taking part in this year's ICAN Summit has been an incredible experience to acknowledge that kids can really change the way that research and medicine in pediatrics work nowadays. Plus, meeting new people from all over the world is always an enriching opportunity to learn about new cultures, different ways of thinking and, of course, make everlasting friends.

In my opinion, there wasn't a perfect day or activity that I enjoyed the most during the summit because every single one of them was extraordinary, educational and well-organized. Although, I have to say, we had a blast dancing at the opening and closing ceremony. "

-Felix JT



Daily Summaries

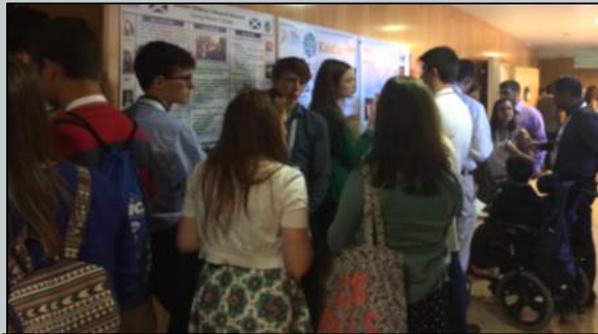
Day One

The Summit started out with introductory remarks followed by a welcome reception. We had the pleasure of listening to a presentation from Mr. Pep Torres, about how to succeed in achieving our dreams. It was very inspirational and engaging, filled with humor and some concrete examples of how children can make a difference in the world. The evening ended with a welcome reception in the ABBA Garden Hotel. This event gave everyone the chance to meet other participants and break ice. The reception was full of fun, dancing, socializing, and wonderful Spanish food, a fantastic start to the iCAN Summit.



Day Two

We started the second day of the Summit at the Sant Joan de Deu Hospital with introductory speeches by Dr. Charlie Thompson--the founder and Chair of iCAN, and Felix Junquera--the President of KIDS Barcelona. Following that, we held a poster session where we presented our projects to other teams and guests. We then capped off the morning with a tour of the research facilities at the hospital, which included a quick demonstration of using Virtual Reality headsets for medical procedures. In the afternoon, we learned about some innovative non-medical therapies that are used to distract or entertain young patients, such as dogs and robotic dinosaur toys. We also learned about a Lego "computer" communication tool for kids diagnosed with DIPG created by a group of youths, and an interactive respiratory rehabilitation game used at the hospital that engages kids when they perform breathing exercises. Overall, the workshops were very informative and inspirational, and showed us how people from different kinds of backgrounds can all make contributions to the medical system.



Day Three

The third day of the summit was hosted at the CosmoCaxia Science Museum in Barcelona. We began our morning hearing presentations from people involved in Clinical Research and Advocacy. The stories they told showed how impactful the work of one dedicated individual can be. We also listened to two panels, one which included Dr. Supriya Sharma from Health Canada, which was focused on health regulation and the other on clinical trials and device research. A highlight from this day was learning about the differences between Canada, the USA and Europe for drug regulation, and having the opportunity to network with leading professionals. In the afternoon, we had the chance to explore the science museum, and then we went to the FC Barcelona Stadium where we had the chance to practice our soccer skills with previous players of the soccer team.



Day Four

We had the privilege to attend the Alicia Foundation's nutrition and cooking workshop as part of iCAN where we learned about the importance of healthy eating. Then, we were split into teams to participate in a cooking challenge where we had a full range of fresh produce and lentils to produce a balanced meal. What we found especially encouraging was that various hospitals in Spain contacted the Alicia Foundation to reinvent hospital meals. They turned ordinarily boring hospital foods into gourmet dishes that also suited the strict dietary restrictions of their patients.

Fundacio Alicia: <http://www.alicia.cat/en/>



Day Five

On the last day of the Summit, we had the opportunity to attend workshop sessions based on Child and Youth Mindfulness or Bioethics. Children learned how to maintain a healthy lifestyle and acquired techniques for embracing their thoughts and emotions. Adults were exposed to ethical dilemmas and had to discern between various solutions to the problem. A highlight of this day was playing a trivia style game facilitated by the Director of the European Patients' Academy on Therapeutic Innovation (EUPATI). Although medical terminology sounds daunting, everyone was thoroughly engaged in the trivia game and had a lot of fun learning. I was impressed by EUPATI's free patient toolkit which allows patients and parents to be educated on their medical conditions, from the basics of medicine development to pharmacoepidemiology. The toolkit can be viewed here: <https://www.eupati.eu>



Meet A Member

Name: Jeremiah Kalbach
Chapter: KIDS CT

Jeremiah Kalbach is a 20 year old college student who attends a community college while working full time to pay for classes. Jeremiah joined KIDS CT after battling brain cancer (and winning!). Through the people he met during treatment he joined KIDS CT where he was the vice-president for 1 year. Jeremiah enjoys his job of working at a Panera bakery (mostly because of the food he gets to try!) and playing a variety of video games in his spare time.

"I spent so much time as a patient for my brain cancer that I would like to use the experiences I've had to help make the medical experiences of others better!"



28th International Conference of Paediatrics (IPA)

iCAN held a booth at the 28th International Congress of Paediatrics (IPA) hosted in Vancouver, British Columbia from August 17 to 22nd, 2016. It was attended by the members of KidsCan Vancouver, as well as the Chicago, Georgia, and South-West Florida Chapters. The IPA is an annual conference that allows networking between paediatric physicians, researchers, as well as various industry leaders promoting physical, mental, and social health for children. Attendees came from all around the world including Australia, South America, North America, Europe, Asia, and Africa. This gave iCAN the opportunity to gain international exposure and spread its message to regions of the world that do not have children's advisory networks in place. Several hundred people visited our booth and learned about the iCAN organization and our cause. Many expressed interest in exploring opportunities to establish new chapters in their place of origin. The Vancouver KidsCan team also conducted a survey on centralized medical record systems in order to explore the potential benefits, as well as challenges, associated with such systems. The data collected is currently being analyzed by the KidsCan Vancouver team, with the help of Meghan Gwara, and will eventually be prepared for publication. Overall, the annual IPA conference was a successful event that helped introduce iCAN to various professionals working in the field of paediatrics, and provided an opportunity to establish meaningful connections for our organization.



"Did you ever feel like you're part of something greater than yourself?"

From the Publisher's Desk



Hi, I hope everyone had a great summer and is now ready to kick off another productive year at iCAN!

This edition of the newsletter focuses mostly on the Barcelona Summit that was the main event of the year for our organization. To benefit all those who couldn't attend in person, the members of KidsCan in Vancouver prepared daily summaries of events. We also tried to include as many pictures as possible to help visualize the wonderful atmosphere of this successful event.



I would like to acknowledge the contributors to this edition of the newsletter:

- Jeremiah Kalbach: Meet a Member
- Meghan Gwara: Meet Meghan and Summit Overview
- Charlie Thompson: A Word From Our Chairman
- Nicole Janusz: Day One of Barcelona Summit and Report from IPA Conference
- Jessica Bo: Day Two of Barcelona Summit
- Sarah Fletcher: Day Three of Barcelona Summit
- Vivian Tsang: Day Four of Barcelona Summit
- Siaw Yee Chew: Day Five of Barcelona Summit
- Michelle Janusz: Day One of Barcelona Summit and From the Publisher's Desk

If you have any questions or comments please don't hesitate to contact us at:
newspublisher@icanresearch.org.

You can expect the next issue of the newsletter early in January 2017.

Thanks!