

A Word from Our Chair

Happy New Year to our iCAN chapters around the world. 2016 was an amazing year for iCAN as we grew the network and hosted an incredible Summit in Barcelona with our partners at Sant Joan de Deu. Now our efforts turn to the great work planned and already underway in 2017. In addition to the Summit planned for the week of July 10th at the Loew's Sapphire Falls Resort in Orlando, FL, USA, the iCAN leadership and chapters are continuing to work on important local projects, improved communication across the network, an educational platform that can be shared both inside and outside iCAN, and enhancement of the opportunities to engage external partners to ensure the voice of youth and their families are not only heard but also incorporated into projects. In January, we had the pleasure of hosting Dr. Hide Nakamura and his team from Tokyo, Japan, at the University of Connecticut School of Medicine to discuss the logistics of launching the first iCAN Chapter in Asia. As you can see in the attached picture, we were also photo-bombed by a familiar face (our dear friend and former Coordinator, soon-to-be Doctor Nick Frederico). I hope you enjoy this edition of the newsletter and share our excitement for what's to come in 2017.

Charles Thompson, iCAN Chairperson



A word from Our Coordinator



Happy New Year, iCAN! Reflecting back on 2016, it's inspiring to see the growing list of all of your accomplishments, both locally and globally. You've implemented changes within your communities, educated your peers and medical professionals around the world, influenced legislature, expanded your knowledge, and most importantly- you've used your voice to help kids across the globe!

As we hit the ground running in 2017, I'd like to continue our efforts in all areas, but with a special focus on three important themes: **Empowerment, Outreach and Advancement**. Let's find new ways to empower our youth and show the world all that we're capable of together. iCAN is growing more quickly than we ever could have imagined, and I believe that these three pieces will help us rise to the next level and have the greatest impact on the future of pediatrics worldwide.

We're rapidly approaching the 2017 iCAN Research & Advocacy Summit, which will be held July 10-14 in Orlando, Florida. Our planning team is excited to continue building a well-rounded and interactive agenda, full of fun and engaging educational workshops and events. I hope to see you all there!

Meghan Gwara, iCAN Coordinator



2017 iCAN Research & Advocacy Summit

Save the Date!

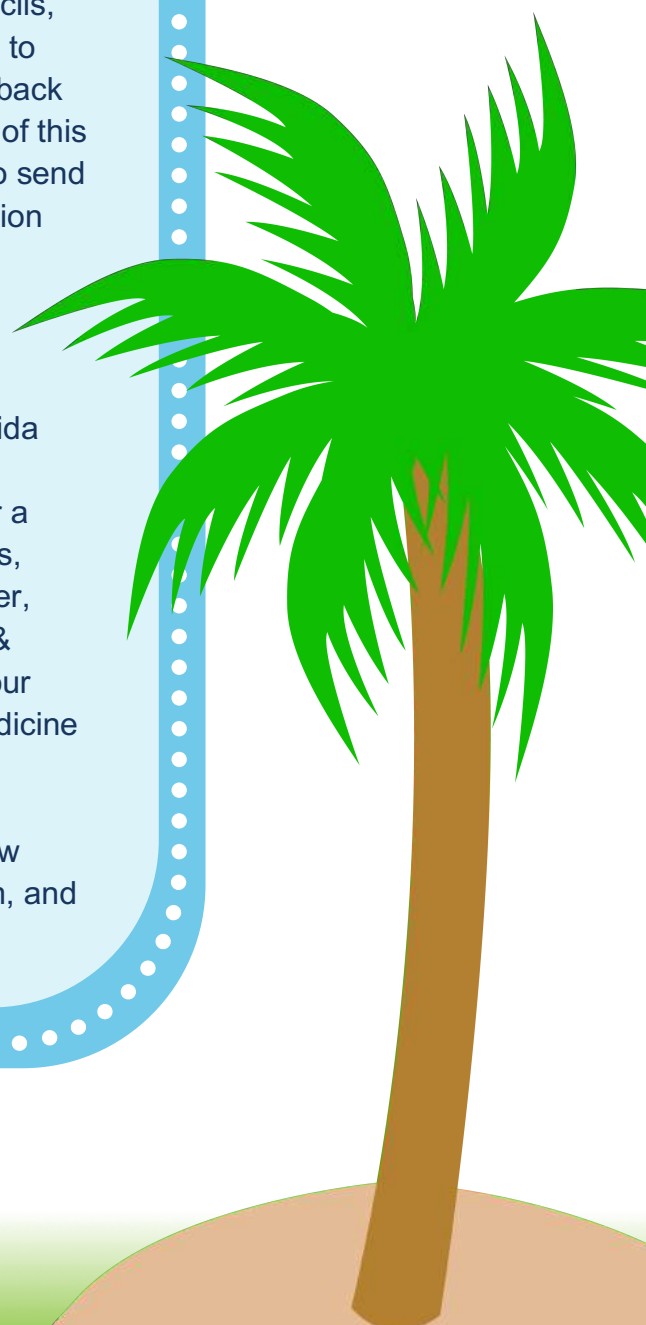
This year's Summit will be bigger than ever before, with a projected 175+ attendees, a highly-interactive agenda, and our first-ever iCAN Partner Expo! Our numerous councils, committees, Boards and partners are all working hard to build exciting hands-on workshops based on the feedback we received from you all over the past year. The goal of this year's Summit is to promote innovative thinking and to send each and every attendee home with valuable information and tangible skills to inspire you, as well as fuel the momentum of our expanding global network!

When: July 10-14, 2017

Where: Loews Sapphire Falls Resort in Orlando, Florida

Like years before, our third-annual Summit will deliver a world-class educational experience to all iCAN leaders, delegates and partners as we engage with one another, learn about different aspects of healthcare, research & innovation, and continue to provide opportunities for our youth to share their voice in the future of pediatric medicine around the world.

For updates on iCAN and the upcoming Summit, follow @iCANResearch on Facebook, Twitter and Instagram, and use the hashtag **#iCANSummit2017!**





Conference Updates

August 17-22, 2016: iCAN had an exhibit booth at the International Pediatric Association's (IPA) 28th International Congress of Pediatrics. This event took place in Vancouver, Canada. iCAN youth delegates conducted an iCAN survey at the event that gathered information on opinions of Centralized Electronic Medical Records in healthcare. Youth delegates represented the following iCAN chapters: KidsCan (Vancouver), KIDS Florida, KIDS Georgia, and KIDS Illinois. Information from this survey is being collated, an abstract was written, and will be submitted for future conferences and publications. This was iCAN's first time ever attending this conference, which takes place once every three years. The next IPA meeting will take place in Panama in 2019.

September 22-25, 2016: iCAN had an exhibit booth at the American Academy of Pediatrics (AAP) National Conference & Exhibition (NCE). This event took place in San Francisco, California. iCAN youth delegates conducted an iCAN survey at the event that gathered information on opinions of different conditions of Genomic Testing in youth and adults. Youth delegates represented the following iCAN chapters: KIDS Florida, KIDS Michigan, KIDS Ohio and KIDS Kansas City. Information from this survey is being collated, an abstract is being written, and will be submitted for future conferences and publications.

September 26, 2016: iCAN had an exhibit booth at the OHRP (Office for Human Research Protections) forum, "Foundations of Trust: Connecting Our Community to Research." Members from KIDS Connecticut attended this event, and youth delegate Aisling Quinlan and KIDS CT Team Leader, Dr. Sharon Smith spoke about iCAN and the importance of involving the youth and family perspective in research and healthcare. The presentation was very well received by all.

October 10-11, 2016: KIDS Barcelona members attended “Better Medicines for Children,” and participated in a panel discussion on “How Can Children, Careers and Families Contribute to Drug Development?” Ms. Camille Gonzalvez, member of the KIDS Barcelona team, explained the different projects that iCAN and KIDS Barcelona completed over the last year, including the summary video of the best moments from the 2016 iCAN Summit. At the end of the event, an interesting discussion took place among different stakeholders (including regulators, pharma industry, patient associations, etc.) that emphasized the need to involve young expert patients in the process of developing a new medicine.

January 4-6, 2017: iCAN had an exhibit booth at the Peds2040 conference in Miami, Florida. Members from KIDS Florida represented iCAN at the exhibit booth, and took place in a two-day Young Innovators Workshop. During this workshop, kids got to identify common problems in pediatric health and develop solutions using Virtual and Augmented Reality Technology. At the end of the two-days, groups presented their projects to the rest of the group and parents. We also got to meet some very special friends at this event- Raymond Rodriguez-Torres, his daughter Rayna, and their friend Daniela Hoyos from a childhood cancer research nonprofit organization called Live Like Bella (www.livelikeybella.org), who had the opportunity to speak on stage on behalf of pediatric involvement in research. Our new friends from Live Like Bella are also working with us to pilot iCAN’s first-ever Virtual Special Interest Chapter, focused on pediatric oncology!



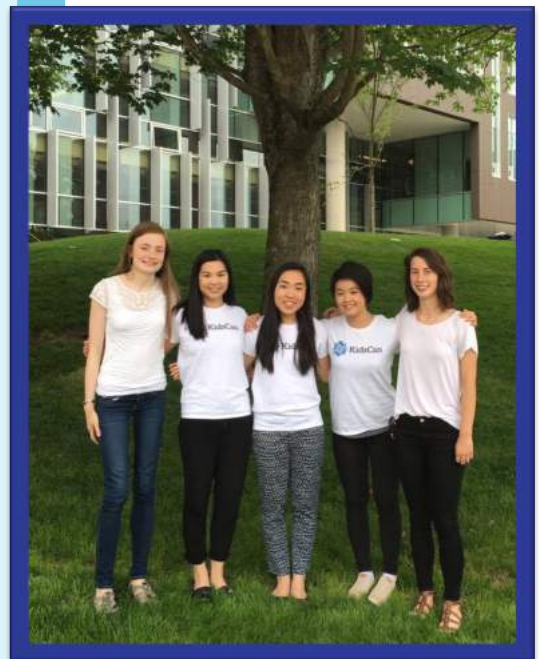


Research from KidsCan Vancouver



The Vancouver Chapter of iCAN, known locally under the name of KidsCan, conducted research on behalf of iCAN regarding the use and reputation of Centralized Medical Record Systems (EMR). The project team comprising of Jessica Bo, Siaw Yee Chew, Sarah Fletcher, Michelle Janusz, Vivian Tsang, and Nicole Janusz conducted a survey created by the iCAN Youth Council among participants of the International Pediatrics Association (IPA) 2016 Conference in Vancouver, BC. The event took place in August 2016 and was represented by iCAN group with a booth. In addition to the usual iCAN survey, KidsCan team gathered information regarding EMR systems in different countries. The IPA Conference was a great opportunity to get access to medical professionals and other representatives of the associated industry. In addition to the KidsCan members who contributed to this project, Hampton Woods, Maddi Bertrand, Calvin Thompson and Chaz Thompson all worked together to collect over 100 completed surveys at the event. After completing the survey KidsCan team analyzed the data using statistical methods and derived some interesting conclusions. At this point they are working on completing a poster that will be presented at Multidisciplinary Undergraduate Research Conference (MURC) at University of British Columbia in Vancouver, March 23 to 25. More information about this project can be found in the abstract below. If you have any interest in this topic or questions, please don't hesitate to contact the KidsCan team.

Centralized Electronic Medical Record systems (EMR) have the potential to provide a variety of benefits to national healthcare systems worldwide. However, their implementation has proven to be challenging and raised several concerns. Although previous work has analyzed the successes and limitations of centralized EMR systems, statistical analysis to quantify public standpoint has not yet been conducted. In order to gain a better understanding of the opinions of medical professionals and others in the field regarding their perceived support, benefits, and barriers for a centralized EMR system, a survey was conducted on the participants of the International Pediatrics Association (IPA) 2016 Conference in Vancouver, BC. The survey contained Likert Scale questions, asking participants to rate the importance of listed benefits and barriers, as well as indicate their overall support for a centralized EMR system on a scale of 1 to 5. The data was analyzed using a one-way ANOVA, with a focus on the countries with the greatest number of respondents (USA, Canada, Nigeria, and Mexico). The responses were also categorized and analyzed based on country development. The results indicated that Mexico, as well as other non-developed countries were shown to be most in favour of the EMR system. Fast record access and efficiency were rated as the most significant benefits of a centralized EMR system, while cost and implementation time were perceived as the largest barriers. These findings provide useful guidelines for consideration in the implementation of a centralized EMR system, and help in the drive towards improving national healthcare systems worldwide



Meet a Member

The story of the friendship of Jake Haygood and Hampton Woods started in 7th grade. Both shared interests in band and robotics, and the young men forged an ordinary pattern of friendship. Neither Jake, nor his family, was prepared for the condition that quickly escalated into a life-threatening condition, causing Jake to miss half of seventh grade. Hampton uniquely understood. By 7th grade, he had undergone over a dozen surgeries, including a liver transplant, and was enrolled in a first-of-its-kind clinical research study. Through his participation in this study, Hampton was asked to participate in iCAN, International Children's Advisory Network, and KIDS Georgia, and invited Jake to join.

Jake and Hampton were part of a group that represented KIDS Georgia and ICAN at the the Peds 2040 conference in Laguna Beach, California in January 2016. As conference invitees, they were asked to come up with a problem-solving idea. Through a shared frustration with previous miscommunication during hospital admissions, the boys developed a device. The boys built a working prototype, a ground-breaking viable concept. Jake and Hampton won the popular vote for their medical device, beating out 24 other startups. They were the only kid-run company to win an award, and Haygood and Woods Co. was born.

Haygood and Woods Co.'s product uses high-capacity RFID technology to store patient data on a chip. Jake and Hampton hope the availability of this data on the wristband will allow first responders and hospital personnel to read a patient's chart in an emergency, preventing loss of time, overdoses, drug interactions, reactions, and miscommunication.

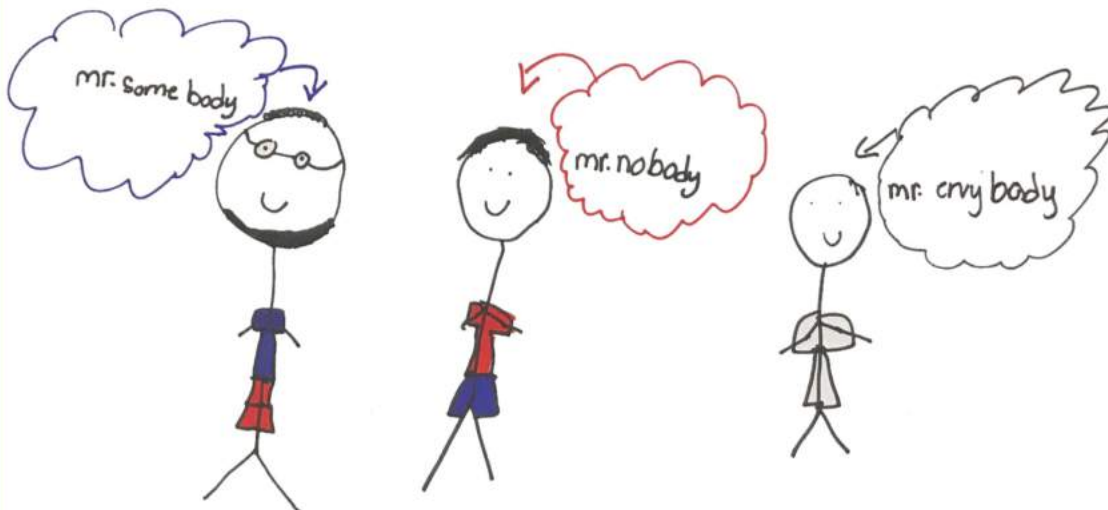
For more information, please go to www.haygoodandwoods.com

“ Friendship is born at that moment when one person says to another: What! You too? I thought I was the only one. ”

- CS Lewis



Humour Cartoon



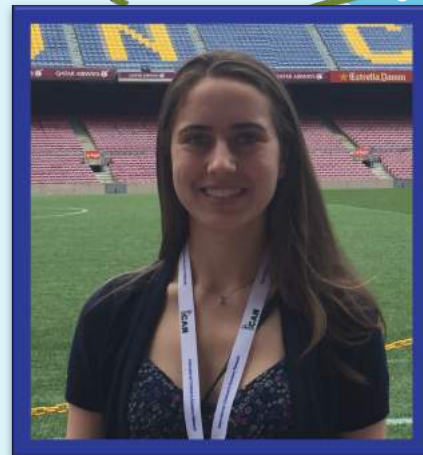
Mr. Somebody & mr. nobody went to visit
mr. everybody when they
got there, he was nowhere to be found.
They called the Police to file a
missing person report and it turns out
that he was everywhere.

by: Jubilee Richardson

From the Publisher's Desk



Hi, I took over from Michelle as the editor of the newsletter to allow her to concentrate more on her new appointment as the youth chairman of the Membership Committee as well her engineering studies at Laval University in Quebec, Canada. Congratulations Michelle! I am very humbled and proud to continue this fine work started by Michelle and the Membership Committee. I will put my best effort to provide the same quality of information in a graphically pleasing and timely fashion. I joined iCAN last year and have been very impressed with the organization, its atmosphere, and all the members. I live in Vancouver, BC and study Microbiology and Immunology at the University of British Columbia, Canada. In my free time, I enjoy volunteering in the local hospital, helping as a volunteer with new immigrants to Canada learning English in the local College, and participating in activities of our local Chapter, KidsCan Vancouver.



The highlight of this edition is the announcement from Charlie that iCAN will have a new chapter in Japan. I think that it is a wonderful news and we all welcome our new friends from Tokyo. Perhaps we will get a chance to meet some of them in the upcoming iCAN Summit in Florida next summer! I learned from Charlie and Meghan that preparation for the Summit are going well and indications are that we will have another successful event.

I hope that you enjoy this edition of the newsletter! I will list all contributors below but wanted to especially acknowledge Jubilee Richardson, a very young and talented member of the iCAN, who authored the wonderful 'humor' cartoon in our newsletter. It is not only funny and original but also very nicely drawn. Well done Jubilee! We truly have an abundance of talent in iCAN as I was so impressed with Jake and Hampton and their accomplishments in the field of medical technology. Congratulations on your success and best of luck in running your enterprise!

The next edition will be released around mid-May and we will have much more information about the Summit. I would like to acknowledge and thank all contributors to this edition of the newsletter:

- **Charlie Thompson:** A Word From our Chairman
- **Meghan Gwara:** A word from our Coordinator, Conferences Updates, Florida Summit
- **Jubilee Richardson:** Humor Cartoon
- **Lydia ElSayegh:** Meet a Member
- **Heather Marney:** coordinated team
- **Michelle Janusz:** KidsCan Research Project
- **Nicole Janusz:** From the Publisher's Desk, KidsCan Research Project

If you have any questions or comments please, don't hesitate to email me. I would love to hear your opinion and suggestions for improvements.

Email: newspublisher@icanresearch.org

Thanks!