

SUMMIT EDITION

A Word from Our Chair

Hello iCAN family! The 2017 Research & Advocacy Summit is almost upon us. The weather in Orlando is heating up, and Meghan and the Planning Committee are putting the final touches on the agenda. We are very excited to welcome you to the beautiful state of Florida and we are confident the Summit will be educational, informative, interactive, collaborative, and fun! Enjoy this edition of the newsletter and pack your bags for Orlando!

Charles Thompson, iCAN Chair



A Word from Our Coordinator

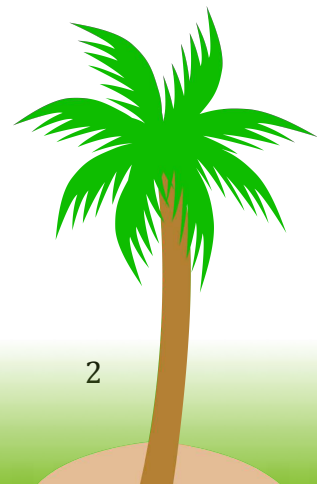


Congratulations on another successful academic year, everyone! As we transition into the summer months, many changes are in the works as we move toward a new structure and method of operations for the iCAN network. We'll soon see a formal submission system in place on our website for partners interested in engaging our network for feedback, new methods of feedback and data collection for our projects and initiatives,

further updates to our website, youth participation incentives, and a new leadership structure to help stay organized and efficient as our network rapidly grows in size! Additionally, we'll be recording our very own iCAN Educational Video Series at the 2017 Summit, and the produced videos will be shared for free on our website for partners, hospitals and the general public to use to help educate patients and families about different topics in clinical research, as well as how they can get involved to help promote patient advocacy, patient involvement, and incorporating the voices of families in the clinical research process.

For those of you who will be attending the Summit- I look forward to seeing you all next month! We've got a fantastic agenda planned for you and I can't wait for us all to be reunited once again, to see how far we've come, and to work together to figure out what is next for iCAN! Enjoy your summer, everyone!

Meghan Gwara, iCAN Coordinator



2017 iCAN Summit Updates

Registrations are officially closed for the 2017 iCAN Research & Advocacy Summit, and we've had a record of over 230 registrations in total! This number exceeds past years by almost 50, and is a reflection of the expansion of our growing network as well as a reflection of the increased support and recognition from partner organizations. Final touches are being added to our detailed agenda and will be complete over the next couple of weeks! The next page has a snapshot of events for the week.

This year, we'll be hosting an iCAN Partner Expo on the final day of the Summit. This event will consist of a series of concurrent educational sessions for youth advisers, parents, team leaders, and industry representatives to attend. These sessions will all be interactive in nature and will focus on various topics in pediatric health, medicine, research and innovation. If you're attending the Summit, keep an eye out for a session preference survey over the next couple weeks to indicate which sessions you'd like to attend based on your age and interests. These sessions will include hands-on medical skills practice, clinical research feedback opportunities, innovation challenges, and more!

Thank you to everyone who has contributed to Summit planning thus far. We're looking forward to a fun and exciting week full of impactful, educational sessions and activities that will help further iCAN's mission for years to come!



2017 iCAN Summit Agenda

Monday, July 10

10:00 AM – 12:00 PM

12:30 PM – 1:00 PM

1:00 PM – 1:30 PM

2:00 PM – 4:00 PM

6:30 PM – 10:00 PM

Registration

Introduction

Keynote Address: Raymond Rodriguez-Torres
(Chairman, Live Like Bella)

iCAN Poster Session

Welcome Celebration (Dinner, DJ, Games)

Tuesday, July 11

9:00 AM – 1:00 PM

3:00 PM – 8:30 PM

Communication, Nutrition & Pediatric Health
and Dev.: FL AAP & FL Dairy Council and
Parent/Adult Sessions

Special Event: Give Kids the World Village

Wednesday, July 12

9:00 AM – 9:30 AM

9:30 AM – 12:30 PM

3:00 PM – 10:00 PM

eYPAGnet Introduction

Council Breakout Meetings & Activities

Group Night at Universal Studios

Thursday, July 13

8:45 AM – 4:00 PM

iCAN Educational Video Series Recording
Sessions; Team Building and Educational
Activities; Parent/Adult Sessions

Friday, July 14

9:00 AM – 12:00 PM

12:30 PM – 2:00 PM

2:00 PM – 4:15 PM

4:15 PM – 5:00 PM

6:30 PM – 10:00 PM

iCAN Partner Expo Sessions

iCAN Partner Lunch; Exhibit Area Open

iCAN Partner Expo Sessions

Closing Remarks; Award Ceremony; Group
Photo

Closing Celebration (DJ, Dinner, Games,
Photo Booth)

Chapter Updates

Generation R:

The YPAG Generation R has been busy working on projects and attending events in the last few months. At the Patient as Partners Event in February 2017, presented the importance of involving young people in health research activities. In March, in Liverpool, they held a meeting reviewing an early stage study, discussing young people's views of delivering intravenous antibiotics at home for children with severe bacterial infections. They also discussed developing a child friendly research glossary. At a RAiSE meeting, Sophie Ainsworth held a focus group meeting with parents, young people, and teachers to develop resources for the information pack for schools to help young people cope with living with an invisible illness. Finally, in April, they held a research information stand at the Lupus Awareness Raising Event at Alder Hey Children's Hospital to highlight research. Generation R is making an impact by raising awareness for the benefits of youth involvement in research.

KIDS Georgia:

In March KIDS Georgia held a meeting at Children's Healthcare of Atlanta and held a career exposition with several speakers from the Marcus Autism Center and CHOA. Afterwards, they toured the helipad and the helicopter onsite. In April, they met with Georgia Tech's Healthreach BME group where there were several presented and evaluated that teach about diseases of the respiratory system. Since then, KIDS Georgia has written their script for the iCAN Educational Video Series and is working to fundraise to send more people to the Summit.

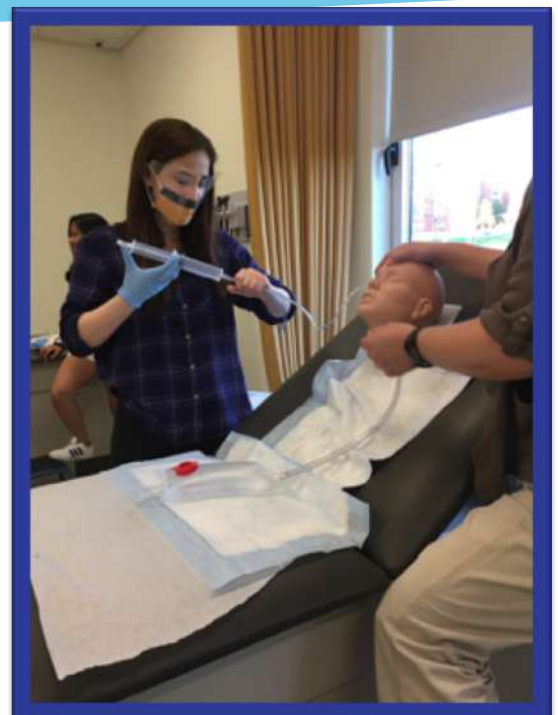


KIDS Florida:

KIDS Florida has been hard at work these past few months preparing for this year's Summit in Orlando. They are fundraising to send as many people as possible to the Summit. Further, they have worked on their script for the iCAN Educational Video Series, a welcome video, and their poster. Apart from the Summit this summer, they have been working on events for their chapter this fall.

KIDS Connecticut:

In March 2017, KIDS Connecticut visited the University of Connecticut Health Center and School of Medicine and spent time in the facility's virtual anatomy lab which included a virtual touch-screen dissection table and a simulation ultrasound. They also did a Q&A with the medical students to offer advice and to get youth members excited about pursuing careers in medicine. In April, they visited the University of Saint Joseph to do a brief tour, learn about the new Physician Assistant program, and participate in a couple of interactive learning activities. Since then, they have had a couple meetings at the CT Children's Medical Center and prepared for the Summit in July.





Committee Updates

iCAN Youth Council:

The youth council has been working extensively on the new iCAN website. We have added input from our youth advisors in the form of personal testimonials, member blogs, and interactive polls. We also worked on surveys for the iCAN network and collaborated with the Scientific Advisory board in order to give a youth opinion on important healthcare topics and plan the Summit expo. In preparation for upcoming conferences, we prepared surveys such as the Genomics Survey. Aside from these projects, we also helped find publications regarding youth involvement in paediatric research and brainstorm promotions and funding ideas for iCAN. In our upcoming meetings as summer approaches, we will be preparing for Summit in July and organizing the pods and youth-led events. This upcoming year, we plan on creating a global project led by all the youth representatives on the Youth Council to continue in their respective chapters after the Summit.

iCAN Conference Committee:

In the past two months, the iCAN Conference Committee has been working to come up with fundraising ideas for sponsoring future iCAN conference attendees. We are now working closely with Meghan to set up some of the fundraising initiatives. Recently, we also started creating Summit surveys for iCAN partners so that we can have a system of collecting valuable feedback that we can use in the future.

iCAN Education Committee:

Education Committee has submit an abstract to the National Conference of AAP. One of the aims of the Education Committee is to analyze the educational resources that the different chapters of iCAN are using to train their members. To study this, we performed few months ago a survey that several teams filled in. The answers has been analyzed by the members of the committee, and with the most relevant outcomes we have written an abstract for a poster. This summary has been submitted to be assessed as a poster to be presented during the National Conference of AAP that is going to be held in Chicago (USA) between the 16th and 19th of September. The survey included 27 open ended questions about education, advocacy and innovation. 13 of the 19 iCAN Chapters responded. In summary, the educational contents used by every team are different. Standardized curricula is necessary with the aim to improve worldwide collaboration of medical care while aligning with the regulatory field as set forth by the global agencies such as FDA, Health Canada and EMA.

European YPAG Network

eYPAGnet stands for European Young Persons' Advisory Groups Network. Whereas pediatric clinical trials are developed simultaneously in different research centers (due to the low incidence of the majority of pathologies that affect children), as well as the common regulatory requirements across the European Union (EU), the need for a consolidated European group emerged.

This European network will be able to respond better to the local needs, as well as to satisfy regulatory requirement dictated by **EnprEMA** (The European Network of Paediatric Research at the European Medicines Agency) to become an accredited organization within the EU. This sub-network, as part of the umbrella organization iCAN, enables better cooperation among European chapters and the execution of new projects in a more collaborative and coordinated way.

The goals of eYPAGnet are:

- Improve the capacity of collaboration with the different stakeholders, who participate in the clinical research and development of innovative drugs.
- Gather information and experiences related to different pediatric pathologies.
- Promote the planning and development of clinical research initiatives for children in the European region.
- Consolidate capacity-building and empowerment training programs to the young patients' advocates.
- Promote and lead the creation of new chapters.
- Promote the selection of professional careers in the area of science, among youth.

Services of the network addressed to the stakeholders:

- Scientific advice by informed groups of children & youth.
- Training in clinical trial design, research governance, and drug development.
- Facilitation of meetings.
- Single point of contact for the patient's voice in the pediatric drug development.
- Networking with European research teams.


This year the **European Paediatric Medicines Regulation** celebrates the ten year anniversary of its establishment. One of the most important accomplishments that happened during this time has been an increase in the number of pediatric clinical trials. When an adult's disease exists in the non-adult population the EU law mandates the development of a **PIP** (pediatric investigation plan)

to ensure a pediatric equivalency of the same drug. At the present moment in Europe doctors prescribe between 45 and 60% medications to children that have not been developed with children in mind, therefore more research and testing is needed to ensure safety and effectiveness.

Our network is going to work very closely with the different stakeholders involved in the drug development process. This will contribute to the increase in clinical trials centered specifically on the needs of the children suffering from different diseases.

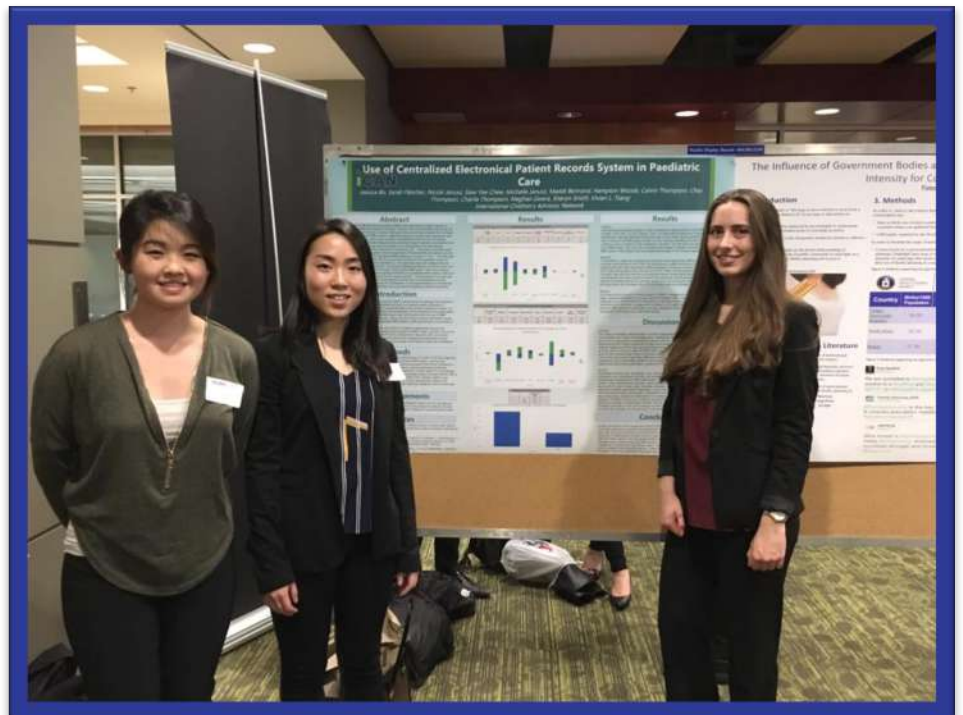


Research from KidsCan Vancouver



As summarized in the last edition of the newsletter, 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 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. In addition to the KidsCan members who contributed to this project, Hampton Woods, Maddi Bertrand, Calvin Thompson and Chaz Thompson all worked together to help collect data. The end goal of this project was to prepare a research poster that was presented at the Multidisciplinary Undergraduate Research Conference (MURC) at University of British Columbia in Vancouver on March 23rd. The team received positive feedback from several judicators at the event and were proud to represent iCAN during this valuable experience.

“Leading and presenting a research project on behalf of iCAN was a valuable experience for our members, and we believe that youth-led research initiatives should continue to be encouraged in iCAN’s mission objectives.”



Meet a Member

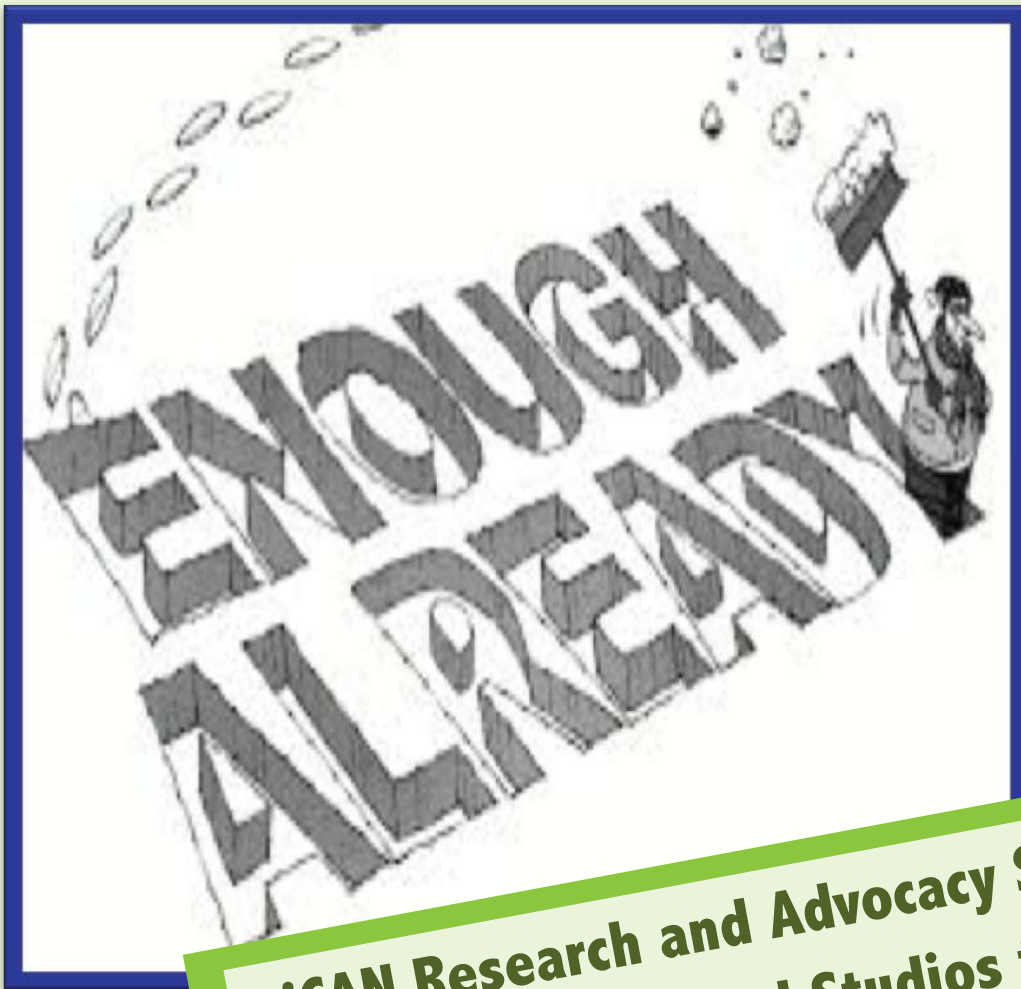
Vivian Tsang
KidsCan Vancouver, Canada

Vivian Tsang is a 21-year-old student at the University of British Columbia. She just finished her third year in Public Health and Therapeutics and will be starting a degree in medicine this coming fall. She serves as the Lead Advisor at KidsCan Vancouver and the chair of the ICAN youth Council. She also sits on iCAN's Board of Directors as the youth representative. Vivian got involved with KidsCan when she was in grade ten and is incredibly grateful for the support and opportunities iCAN has provided over the years. In her free time, she loves to talk to strangers, travel, and try out alternative restaurants.



“It is empowering to know that the voices of young people are valued and to see our efforts result in tangible contributions to improve paediatric health.”

Humour Cartoon



**iCAN Research and Advocacy Summit in
Florida at Universal Studios this July! We
will be knee deep in sand! Ooh yeah!**

From the Publisher's Desk



Welcome to the spring edition of our iCan newsletter. Traditionally at this time of year, iCAN members are preparing for the annual Summit, as this is such an important event for our organization. This year it will be held in Florida and promises to be loaded with many fun social and educational events. Perhaps the best part of each Summit is the opportunity to meet iCAN members, talk about our experiences, and have fun. I hope to see you all in Orlando, don't forget to pack your Micky Mouse ears!

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

- **Charlie Thompson:** A Word from our Chairman
- **Meghan Gwara:** A Word from our Coordinator, Florida Summit
- **Lydia ElSayegh:** Updates from Chapters, Updates from Committees
- **Begonya Nafria:** European YPAG Network
- **Michelle Janusz:** Meet a Member
- **Jubilee and Andrea Richardson:** Humor Cartoon
- **Nicole Janusz:** From the Publisher's Desk, KidsCan Research Project

I would like to re-emphasize that all iCAN members are the owners and contributors of the newsletter. The Membership Committee is very interested in hearing your feedback and suggestions on how to improve the content and format of the newsletter so that it serves the organization well and is relevant to its members. All comments are welcome and appreciated! Our next newsletter will be released after summer vacation, around the middle of September 2017. If you have any questions or comments please, don't hesitate to email us at: newspublisher@icanresearch.org

Nicole