

SPRING EDITION

A WORD FROM OUR PRESIDENT

Hello iCAN family! I'd like to introduce myself. I am Leanne West, and I am really thrilled and honored to be the first iCAN President! Aside from all of the fun things I'll get to do as your president, I have a day job too where I am the Chief Engineer of Pediatric Technologies at Georgia Tech, and the Chief Innovation Officer for the Georgia Tech Pediatric Technology Center. I get to develop all sorts of new technologies to help nurses and doctors take care of their patients. I'm pretty sure there isn't a better job out there. I love the mission and vision for iCAN, and I hope that I will be able to help iCAN grow to touch so many more lives of young people around the world.

I have been involved with iCAN since the first Summit in Washington DC, and I am so excited for the upcoming Summit in Edinburgh, Scotland! We have been working hard to make sure this is the best one yet. I can't wait to meet those of you I don't know.

I know change can be scary, but have no fear! Charlie is not leaving us – he will remain the Chair of the Executive Steering Committee. Another familiar face, Christine Woods, has volunteered to be our new Vice President. We have also brought in some other new officers to iCAN that some of you might know, including Chester Koh as Secretary and James Hury as Treasurer. And finally, I would like to welcome our new Director, Laura McMaster. Together, we are looking forward to what iCAN can become!

Leanne West, iCAN President



A WORD FROM OUR DIRECTOR

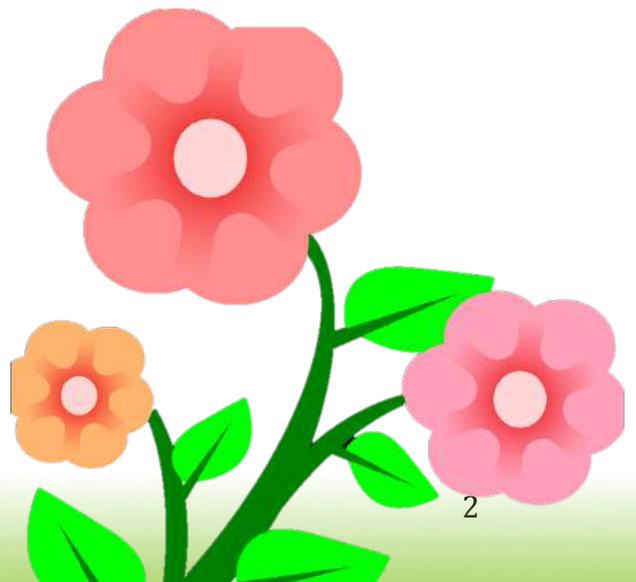


Hello iCAN youths, parents, and team leads!

I am so glad to meet you all and to have the opportunity to work with you in this dynamic organization. I write you from my homebase in Atlanta, GA where spring has certainly sprung with azaleas and dogwood blossoms everywhere we turn. In a community like ours where young people, families, and health workers join together, these signs of renewal and possibility help

us remain optimistic and forward-thinking. I decided to work for you because I wanted the chance to make the future better, using my skills and interests from years working in pediatric healthcare in both American and international settings. When I learned your network existed and had an open position, my decision to join you was clear and enthusiastic! Your former mentor and coordinator Meghan Gwara leaves large shoes to fill, and she has kindly left many notes and helpful tools behind, so that we will reach old and new targets as easily as possible. Thank you all for your welcome notes and for this chance to give new meaning and purpose to my passions for international collaboration, youth leadership opportunities, and the power of making great health decisions!

Laura McMaster, iCAN Director



SNEAK PEEK AT THE SUMMIT

Our Event Leader is Pamela Dicks, Network Manager at the Scottish Children's Research Network, living and working in Aberdeen, Scotland. She has been very thorough and enthusiastic and a pleasure to all! Big props!

One important theme: the development of medicines and healthcare to improve the outcomes of children with acute, chronic and rare conditions

Dates: July 8-13

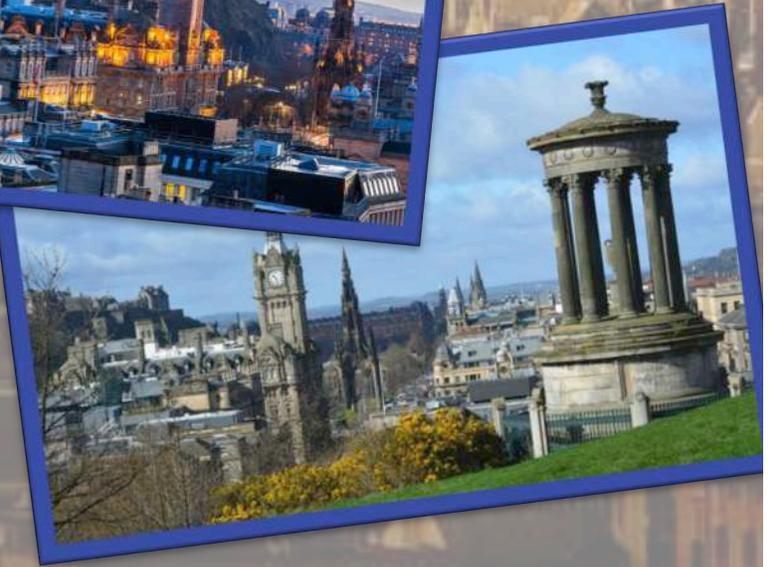
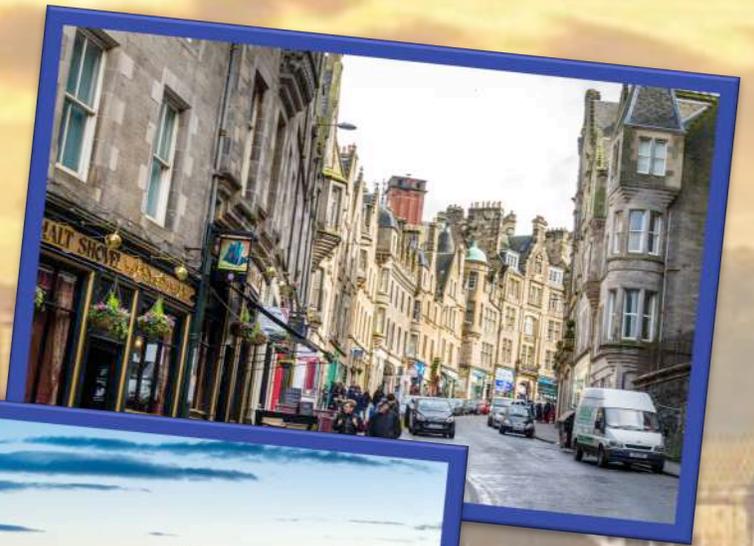
Lodging: Pollack Halls within University of Edinburgh

Educational Activities: speakers, pod learning with youth leadership, and a week-long activity to review how clinical trials work

City: Edinburgh is the capital of Scotland! Scotland is a member of the United Kingdom (UK), so has a long-standing partnership with sister countries like England, Wales, and Northern Ireland. In the capital city, Edinburgh has its own parliament, its own royal jewels, and also a famous royal residence Holyroodhouse Palace, still frequently used by the British royal family (Queen Elizabeth II, Prince Philip, William, Harry, spouses, etc). 2 large features are present in the city: Arthur's Seat can be climbed as a big hill near the city center, and of course Edinburgh Castle, which is as old as the city itself and has medieval history, and a daily tradition of firing a cannon once a day around lunchtime!



EDINBURGH





CHAPTER UPDATES

KIDS Albania

We held the 7th meeting of KIDS Albania on April 14th at the Faculty of Pharmacy, 'ALDENT' University. At the first part of meeting, we visited the laboratory of Faculty where Dr. Entela Haloci performed a several quality control tests of drugs such as: the dissolution test, tablet hardness, friability test. The KIDS saw on the microscope the internal structure of some herbal drugs as well. During the second part of the meeting the KIDS attended a very interesting lesson: 'Adolescent growth and Development' from Dr. Agim Gjikopulli, a Pediatric Endocrinologist (to open, he prepared a slide with many famous people who suffered from chronic illnesses such as: scientists, presidents, and actresses, giving faith and hope to our KIDS).

KIDS Florida

The KIDS FL team has been busy this quarter. Our team assisted the FCAAP with Storybook Village at the Children's Week event in Tallahassee. We also spread the message of Sun Safety at the Sunshine State Steak Cook-Off. We had several members attend a Bioethics lecture in February which dove deep into stem cell research and bioengineering. Our team learned about the importance of biofeedback in controlling stress and we have been invited to assist in a mental health research project over the next year. Most recently, five members attended a meeting with NORD to help establish advocacy networks in Florida.

KIDS Kansas City

KIDS KC has meets monthly. We have worked with various providers at Children's Mercy Hospital (CMH) on research projects and provided input. We have learned about the upcoming plans for the new research tower at CMH.



KIDS Georgia

Over the past quarter KIDS Georgia has had a couple amazing opportunities. In February, KIDS Georgia members held a meeting all about concussions and concussion treatment. We had six fascinating speakers, including one of our own youth advisors, Jake Haygood, sharing his personal experience with concussions, and one of our own adult advisors, Dr. Linda Kelly, sharing about her efforts to unify how doctors evaluate concussions. In March, KIDS Georgia had a booth sponsored by Georgia CTSA at the Atlanta Science Festival Expo -Atlanta's biggest interactive science event reaching thousands of children. KIDS Georgia's booth exhibited Hampton Woods and Jake Haygood's RFID wristband that facilitates communication of medical records. We also featured and facilitated a kid-friendly STEM activity creating binary code bracelets. It was a new and fun experience that helped us reach out to a large amount of people. We look forward to our next meeting closing out the school year with Georgia Tech's BME HealthReach students.





COMMITTEE UPDATES

Education Committee

The Education Committee is continuing to create a list of educational resources to be shared with all iCAN chapters. Our team is assembling articles that highlight the need for and support the benefit of patient involvement in research, particularly in paediatric patients and other similar topics. We are also gathering informational videos about clinical research, diseases, patient advocacy, innovation, and more that could be used to help orientate new youth advisors to what iCAN's goals are. Keep an eye out for this project on the website in the future!

Conference Committee

The Conference Committee has been working on writing and producing a video tutorial on teaching new members of iCAN different ways that they can give an elevator pitch at a conference. The idea behind the project was conceived by our members last year in order to address the gap of experience felt by newer and younger members who are presenting on behalf of iCAN for the first time. We brainstormed the content and style of the script as a team, then individual sections were later divided up and written by our committee members. Filming will be taking place soon with the Kansas City chapter, so we are excited to see the results and move on the editing phase!

Youth Council

For the past few months, ICAN's Youth Council has been busy at work. Aside from discussing our respective activities in our local chapters and providing input for any ICAN-related projects, we have also been using the remaining time to work on a Transitions Project. We started off by doing literature review on the topic of pediatric transitions and then reached out to various stakeholders to ask for their opinion on the topic. By having a representative from each ICAN chapter, we were able to sample many different frontline clinicians and healthcare workers as well as policy writers and administrators. The Youth Council developed two interview guides and each chapter met up with key stakeholders from their local hospital and academic centers. The interviews are currently being transcribed and the responses are quite enlightening! The second interview guide was developed for youth and we are currently planning to run two sessions at this year's ICAN Summit to get input from youth with chronic or rare diseases who have gone through or are anticipating transition between pediatric and adult healthcare providers. If you would like to participate, please look out for an invitation from the Youth Council sometime in late May. Through everyone's enthusiastic participation and comments, we have also noticed that there is very little literature on the formation and maintenance of youth pediatric research advisory group models around the world. Some of the Youth Council members are excited to be exploring this as a possible project in the future!

MEET A MEMBER

Lydia El-Sayegh **KIDS Georgia, USA**

Lydia is a 17-year-old high school student who will graduate this May and will attend Georgia Institute of Technology beginning next semester to study biomedical engineering. She has served as president of KIDS Georgia for the 2017-18 academic year and has been a member of the iCAN Youth Council and Membership Committee since September 2016. In her spare time, Lydia enjoys reading, gardening, and learning languages. One of her goals is to build a hospital in an impoverished area in the Middle East. She appreciates the unique opportunities she has had through iCAN to learn, research, and advocate in the area of pediatric medicine, and she will carry these experiences forward as she pursues her future goals.



HUMOUR CARTOON



FROM THE PUBLISHER'S DESK



Hi Everyone,

Welcome to the Spring edition of the newsletter. Spring is a special time not only because winter is finally over (we certainly appreciate this up here in Canada) but it's also during this time of year that the excitement surrounding the upcoming summit is starting to kick in. This year it will be held in Edinburgh, Scotland! Organization efforts are already underway, and it promises to be another successful event. It'll provide another great opportunity for iCAN members to get together as a team, reconnect, and participate in a variety of exciting and educational events.

I hope that you enjoy this edition of the newsletter, and I look forward to seeing everyone in Edinburgh!

I would like to acknowledge everyone who contributed to this edition of the newsletter:

- **Leanne West:** A Word from our President
- **Laura McMaster:** A Word from our Director, Sneak Peek at the Summit
- **Lydia El-Sayegh and Hearther Marney:** Chapter Updates, Committee Updates,
- **Michelle Janusz and Lydia El-Sayegh:** Meet a Member
- **Nicole Janusz:** From the Publisher's Desk, Humour Cartoon

I would like to re-emphasize the fact that all iCAN members are owners and contributors to 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 better serves everyone. All comments are welcome and appreciated! Our next newsletter will be released in June! If you have any questions or comments please, don't hesitate to email us at: newspublisher@icanresearch.org

Nicole Janusz, Editor of the iCAN Newsletter