Happy Spring, and welcome to the 2nd edition of the iCAN Newsletter. After so many months of hard work, it’s hard to believe that the 2016 Summit is only a few weeks away, and we are all incredibly excited to see many of you in Barcelona. Please take some time to enjoy the content of this newsletter and the important updates from around our growing network. On a bittersweet note, Nick Frederico (our Coordinator extraordinaire) will be leaving iCAN after the Summit to begin medical school this fall. Hadleigh has written a nice farewell in this newsletter, but I wanted to share my sincere thanks and gratitude for the work Nick has done over the last year. Nick has truly been instrumental to the growth and development of this network, and it will be hard to fill the void left by his departure. While we will miss you dearly, Nick, we know that you have a bright future ahead of you, and we are honored that you have been a part of our team.
Have a wonderful summer!
Charles Thompson, iCAN Chairperson

Farewell Nick!

In just about two short months, our coordinator, Nick Frederico, will be stepping down from the iCAN Coordinator position. It’s hard to believe that he’s been working to support, maintain, and grow our network over the last year and a half! This farewell is certainly a bittersweet one: bitter because we’ll be losing an integral part of our network, but sweet because Nick is going on to do amazing things.

In celebration of Nick’s time with us, I’d like to highlight a few of his accomplishments that I’m sure many of us remember fondly. Of course, the first of these has to be our Launch and Summit in Washington, D.C last June. Nick had been working for us for only about 6 months, but already he’d put so much into iCAN and improved it so much. He’d planned the Summit so well, and it flowed more smoothly than anyone could’ve expected. Everyone had questions for Nick pretty much 24/7 throughout the week, and here our unofficial 2015 Summit motto, “Where’s Nick?” was born. The initiative, responsiveness, and work ethic displayed by Nick in planning the Summit last year (and this year!) are qualities for which we are extremely thankful.
Those of us who have been lucky enough to work with Nick in KIDS Connecticut have gotten to know him a little more. His dedication to meeting planning, securing fun and educational activities for the team, and ensuring that the members’ voices are heard have inspired all involved. As all of the KIDS CT team members can agree, Nick has done an extraordinary job developing and sustaining this team in the past year.

The final accomplishment of Nick’s that I’d like to highlight is his amazing behind-the-scenes work. Although we can see so many of his successful iCAN endeavors, there are just as many that remain unseen. The Coordinator position involves many behind-the-scenes emails, telecons, and tasks that sometimes are never even acknowledged. These things are essential to the International Children’s Advisory Network running as smoothly and effectively as it does, and we are so grateful for Nick’s work in these areas.

Nick has done so many things for iCAN that it would be impossible to highlight them all without turning this into a manuscript. While we’ll certainly miss him, we are so happy that he has earned this opportunity and will go on to do amazing things in the medical field. As we’ve been interviewing candidates for our new coordinator, we’ve all been very struck with just how far the International Children’s Advisory Network has come under Nick’s coordination and efforts. When we ask “Where’s Nick?” this fall, we know exactly where he will be: studying hard at the University of Connecticut School of Medicine! :) Thank you so much for your work with iCAN, Nick!
2016 iCAN Research & Advocacy Summit, June 27th - July 1st 2016

The iCAN Summit for the summer of 2016 will be held in Barcelona, Spain! The city of Barcelona is defined by its quirky art and architecture, imaginative food and vibrant street life. The Summit hashtag this year will be #iCANSummit2016 and our website can be found at www.icanresearch.org/summit

The expected attendance is estimated to be between 125 and 150. The venues where we will have meetings include Hospital Sant Joan de Dèu, Fundació Alicia, and CosmoCaixa Museum of Science.

Each day during the summit there will be a wide variety of scheduled events. During the first two days, events range from introductions and opening remarks to a poster presentation where each iCAN team will present a poster they have created to introduce their members and city. In the middle of the week there will be events such as interactive sessions that help teach families about how advocacy organizations tie into medical research, to a science panel where youth members will interview medical regulators. On the second to last day of the summit there will be an iCAN council meeting and some down time for families to relax and enjoy the beautiful city for a bit. On the last day of the Summit there will different workshops for both parents and for the youth as well as an award ceremony and dance for the iCAN teams!

Aside form the summit events, there are three optional fun-filled special attractions. Two of our three choices are a guided tour of the Sagrada Familia church as well as a museum tour and a football match where iCAN will play with amateur players from the Barcelona team at the Barcelona Football Club stadium. We hope to see you there!

All of the amazing things to come could not have been possible without support from the Summit sponsors of iCAN: Pfizer, Janssen, inVentiv Health, Premier Research, Nestlé Nutrition, BIO: Biotechnology Industry Organization, KinderPharm, and PPD.

Sneak Peek at Barcelona
Kansas City

Kids KC has been busy over the last few months. One project we have worked on recently has been the assent process with a medical technology company. The teens and parents participated in an assent simulation on iPads and engaged in discussions at the end. They provided input on a variety of issues including graphics, phrasing, and readability. Additional members plan to contribute to a presentation on this project for the summit. We have also had The Children’s Mercy Hospital Community Health Director present and do an interactive project with us. This project looked at evaluating a variety of topics that relate to community health and whether or not it was important to the community, could and impact be measured, and whether the hospital could have any impact on it. It was a great discussion and great idea generator on the variety of ways community and health are impacted.

We have 2 members who just recently joined in the Greater Plains Collaborative Patient Advisory Council. This group has a monthly phone conversation, and the teens and adults engage with researchers and professionals within the hospitals on ways to increase patient engagement. We will be participating in the planning and hope to attend portions of their conference in October here in Kansas City. A few different diagnosis-specific groups within our hospital have asked how our board feels about certain diagnosis or medical apps, we created a formula for evaluating apps. This allows us to have a standard in which each app is reviewed. We look at ease of use, age group targeted, and whether the app fulfilled its description and expectations. This information is then shared with the individual who has requested it.

Michigan

Greetings from the Mitten State! We are the Teen Advisory Council (TAC) for the University of Michigan C.S. Mott Children’s Hospital located in Ann Arbor, Michigan. During 2015, we joined ICAN and became KIDS Michigan. Each month, our team of amazing teenagers aged 12 – 19 meet at Patient and Family Centered Care (PFCC) room to host a fun ‘Teen Game Night’ with tons of food, laughter and fun, for in-patients at the hospital. After our game night, we then meet as a council to work on projects that help to provide a young patient perspective on various products, plans and procedures from nurses, doctors and staff within the hospital. We hope to engage and empower teens by improving communication between teens and their healthcare providers through educating staff, faculty and students about the needs of teen patients.
Meet A Member

Name: Marta Carnero  
Chapter: KIDS BCN (Barcelona, Spain)

Marta is 17 years old and is always excited about medical research. Moreover, she is helping children that need assistance by doing an informed consent tailored for them. She got involved in KIDS BCN when her school, Col·legi Montserrat, offered her the opportunity and she accepted it gratefully. She’s really happy to be a part of KIDS BCN because she is learning a lot of things related to medicine, which is what she loves, and has also met nice people in her group. In her free time she enjoys music and traveling abroad, apart from meeting new people. “I can not describe with words the happiness I feel by doing this awesome and gratifying project that gives me the chance to actively contribute to the improvement of our modern society.”

Besides our work within the TAC, we also take our projects out to the community in an effort to collaborate and gather support for improving pediatric care. To spotlight Rare Disease Month, during February 2016, our TAC members worked with schools and community groups to obtain donations for the Wacky Sock Drive which included fun, bright and cheerful socks that could be given to all pediatric patients within the hospital. Exceeding our expectations, the TAC was able to provide over 700 pairs of socks for not only pediatric patients, but their siblings as well. To make the morning even more fun, on the day that we handed out socks, we also had a Wacky Donut Party, so patients could have a special time.

During April, 2016, our TAC also completed another major outreach event through participation at the University of Michigan Adolescent Health Initiative (AHI), held at Eastern Michigan University’s Eagle Crest in Ypsilanti, Michigan. ICAN member Hadleigh Thompson flew in from Florida to join sisters Reece and Olivia Ohmer, along with presenters Dr. Joyce Lee, Kelly Parent and Dr. Charlie Thompson. On day one of AHI, Reece and Olivia participated as speakers on the Adolescents in Research panel, with Kelly, Dr. Lee, and Dr. Thompson, and shared their personal story of being involved in research and how it has led to the creation of a Diabetes Emoticon App. This app is helping both children and adults in communicating chronic illness tasks more effectively. On day two of AHI, Hadleigh spoke as a Keynote Presenter on the many reasons that kids need to be involved within research. Together, Hadleigh, Olivia and Reece were able to impart a thoughtful and impactful presentation that provided the AHI attendees with clear direction for pediatric inclusiveness in all future research projects.

Upcoming projects include both the implementation of a brand-new KIDS Michigan – TAC website and sending three of our members as Michigan representatives to Barcelona, Spain at the second annual ICAN Summit! We can’t wait to share the exciting international learning to our entire council!
Committee Updates

Volunteers on the iCAN committees have continued to do great work, even in the craziness of preparing for the end of the school year. Most of the committees are working on projects for the Summit. The Conference Committee has been participating in bi-weekly teleconferences with iCAN leadership, KIDS Barcelona, and others to help plan for the Summit. They wrote content for and designed the Summit program, and they wrote an official Travel Policy to explain rules and procedures for traveling to academic conferences with iCAN. The education committee sent a survey to all team leaders to help them understand which materials are currently being used to educate their members about clinical research, patient advocacy, and other relevant topics. They will share the data from that survey at the Summit. Thank you, team leaders, for participating! The goal is to create a repository of educational resources for all teams to share. The Finance Committee worked very hard to secure enough grant funding to not only host the summit, but sponsor travel for over 75 children, parents, and team leaders. They are already looking ahead for funding opportunities for the 2017 Summit.

The Youth Council now has representation from 14 different chapters across the network. They have recently compiled biographies for members of the iCAN Scientific Advisory Board, as well as bios and interview questions for the experts who will be interviewed on the regulatory and pharmaceutical/innovation panels during the 2016 Summit. The Youth Council has also reviewed the activities, events, and prize items for the Summit and collaborated with the Board of Directors to plan youth-friendly activities in Barcelona. They have also discussed communication strategies and challenges. The Youth Council has worked with the Communication and Technology Committee to test out and open up a new communication portal called Slack for communication across teams. The Communication and Technology Committee is also working to revamp the iCAN website.

Last but not least, the Membership Committee has been working to gather updates, pictures, letters, and editorials from all of you to include in the newsletter. Thank you to all who have contributed content to the newsletter!
Hi, this is Michelle again. I am happy to bring to you the second edition of our newsletter. This time it is dedicated mostly to the Barcelona Summit since this is such an important event for our organization. I hope to meet you all in Barcelona!

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

- Heather Marney: Information for iCAN Committee Updates
- Jeremiah Kalbach: Chapter Updates, Summit Information
- Nick Frederico: Committee Updates Text, Pictures, Meet A Member
- Charlie Thompson: A Word From Our Chairman
- Michelle Janusz: From the Publisher’s Desk
- Hadleigh Thompson: Farewell Nick

I would like to re-emphasize that we are all owners and contributors of the information. Our team is very interested in hearing your thoughts and suggestions on how to improve the content and the format so that it serves the entire network well and is relevant. All commentaries are welcome and appreciated!

We still haven’t found any volunteers to draw cartoons to the ‘Humor’ section. I am sure that there are some hidden talents among us who could put their creativity to good use. If you are interested in contributing, please contact us via email.

Our next newsletter will be released after summer vacation, around September 15th.

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

Thanks!