From Washington to Barcelona
June 2015 **iCAN Councils and Committees** established to bridge communication and promote partnership among all children, parents, and team leaders.

- 3 councils (Parent Council, Youth Council, and Team Leader Council),
- 5 committees (Communication and Technology, Conference, Education, Finance, and Membership),
- **Scientific Advisory Board** composed of top pediatric leaders in regulation, pharma, academia, hospitals, and more.
ICAN ACTIVITIES SINCE JUNE 2015 LAUNCH

• November 2015 into 2016 Summit Planning Committee established, including the Conference Committee and representatives from each other council and committee. This group meets biweekly to organize events for the Summit.

• February 2016 first iCAN Newsletter published by the Membership Committee

• 2015 into 2016 iCAN establishes new chapters in Michigan, Southwest Florida, Houston, Barcelona, Australia, and France
ICAn groups have been involved in more than 11 projects such as*:

• NIH-funded online educational tool aimed at teaching children about pediatric research. The resource plays out like a video game.

• pediatric assent survey in partnership with medical information companies. Results at the 2015 Eastern Societies for Pediatric Research Meeting and the 2015 Pediatric Academic Societies Meeting.

• guidance to Nuffield Council on Bioethics to help develop a magazine version of their study titled “Involving Children and Young People in Health Research- Getting it Right” (available here: http://nuffieldbioethics.org/project/children-research/)

• a smartphone app for a nutrition study and provided feedback via online survey

• a focus group with a medical device startup company to provide feedback from children on several mockups of auto-injectors.

• feedback on a study design for a clinical trial of a therapeutic for influenza. 123 people participated.

*Local chapters have been involved with many projects in addition to those listed here
Projects involvement

- Feedback on a **storyline for a study gamification** app which would be used in a pediatric clinical trial. The aim is increasing retention in the study. 147 young people participated in the survey.
- Online focus group with the company developing the **gamification app** to further develop the storyline and concepts.
- Online focus group to help develop an online, **interactive tool funded by the NIH** aimed at educating children about pediatric research.
- User testing on an **electronic assent program** and provide feedback from pediatric patients’ and families’ perspectives. Members are teaming up from Kansas City, Vancouver, and Michigan chapters to help develop a second phase of this project as well as write up a report to share at the 2016 iCAN Summit.

Communication activities:

- 12 Scientific Conferences and Societies Meetings
- 8 publications and presentations
Ican Summit 2016: research and advocacy

www.icanresearch.org
June 27 – July 1
2016 ICAN Research & Advocacy Summit

Children, young people, and families will have a world-class learning opportunity as they engage with pediatric professionals in healthcare, research, industry, academia, and regulation. The focus of the Summit is on healthy lifestyle and empowering young people to take part in medicine, research, and innovation.

#ICANSummit2016
icanresearch.org/summit
Barcelona, Spain

150 Child and Family Attendees
8 Countries Represented
17 Sponsors and other Partners

International Children's Advisory Network
104 Hungerford St
Hartford, CT 06106
www.icanresearch.org

● KIDS Chicago
● KIDS Connecticut
● KIDS Florida
● KIDS France
● KIDS Giorgia
● KIDS Houston
● KIDS Kansas City
● KIDS Michigan
● KIDS Ohio
● KIDS Sydney
● KIDS Canada
● ScotCRN (5 groups)
● GenerationR (UK)
● KIDS Barcelona
Ican Summit 2016… focused on a global concept of health: prevention and treatment.

Many diseases of adults should have healed before... ...let's say 50 years before they appear!
Ican Summit 2016

3 Topics of the congress:

- Innovation
- Patient Expert & Research
- Innovative treatments
Social community activity

Pulsera Solidaria
por la investigación
del cáncer infantil
We will show the Hospital and the main services…
Innovation day

Practical workshops about innovative therapeutic tools
CosmoCaixa Museum

Patient expert day
... y si RobotX pudiera encontrar el diagnóstico a enfermedades genéticas que hasta ahora se tardaban años en diagnosticar?

El Proyecto
Te presentamos RobotX, un robot muy pequeño que es capaz de analizar genoma y obtiene más información en unos lapsos de tiempo. Además, el proceso de diagnóstico, que normalmente se haría a través de células, con RobotX se podría hacer a través de células, con RobotX se podría hacer de una manera más eficiente y precisa.

Colabora
La mayoría de los que trabajamos en este proyecto somos voluntarios. Sin embargo, para que RobotX funcione correctamente, necesitamos invertir recursos en materiales, instrumentos y equipamiento. Si quieres ayudarnos, puedes hacerlo de diferentes formas. Acompaña a los diagnósticos, contrata a RobotX para un niño...

Pacientes
Si tienes un hijo, familiar o conocido con una enfermedad genética, podrías ser el próximo. Ayúdanos a la investigación, podemos diagnosticar una enfermedad genética en un niño con un RobotX para un niño...

Compartir para avanzar

Noticias
Dia Mundial de la Osteogénesis Imperfecta: futura nueva línea de investigación en Rare Commons
05/05/2016
La osteogénesis imperfecta (OI), también conocida como `enfermedad de los huesos de cristal`, es una patología que...

Celebramos el día del libro, con la historia de Jana...
22/04/2016
Con motivo de la conmemoración del Día Internacional del Libro, hemos publicado un nuevo cuento en Rare Commons. La historia...

Open pannel: patient expert
Experts panel: Pharmaceutical industry
Sport and scientific research focused on cognitive development.

Visit the stadium of Barça Football Club and sport activity focused on the sport contribution to cognitive development and other diseases prevention.

www.icanresearch.org
Interactive workshop of healthy and therapeutic nutrition (Fundació Alicia)

Alícia, Alimentació i ciència (Alice, Food and Science), is a research centre devoted to technological innovation in cuisine, to the improvement of eating habits and to the evaluation of the food and gastronomic heritage. We are a centre with a social vocation, open to everyone to promote healthy eating.
Interactive workshop of healthy and therapeutic nutrition (Fundació Alicia)
Other therapeutic options: clowns
Other therapeutic options: music therapy
Other therapeutic options: Child Life
Other therapeutic options: Mindfulness
Bioethics: pediatric clinical research