

From Washington to Barcelona

ICAN ACTIVITIES SINCE JUNE 2015 LAUNCH



- 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



A Word from Our Chair

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



- 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

Projects involvement



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.



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





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 Georgia
- ✓ 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...

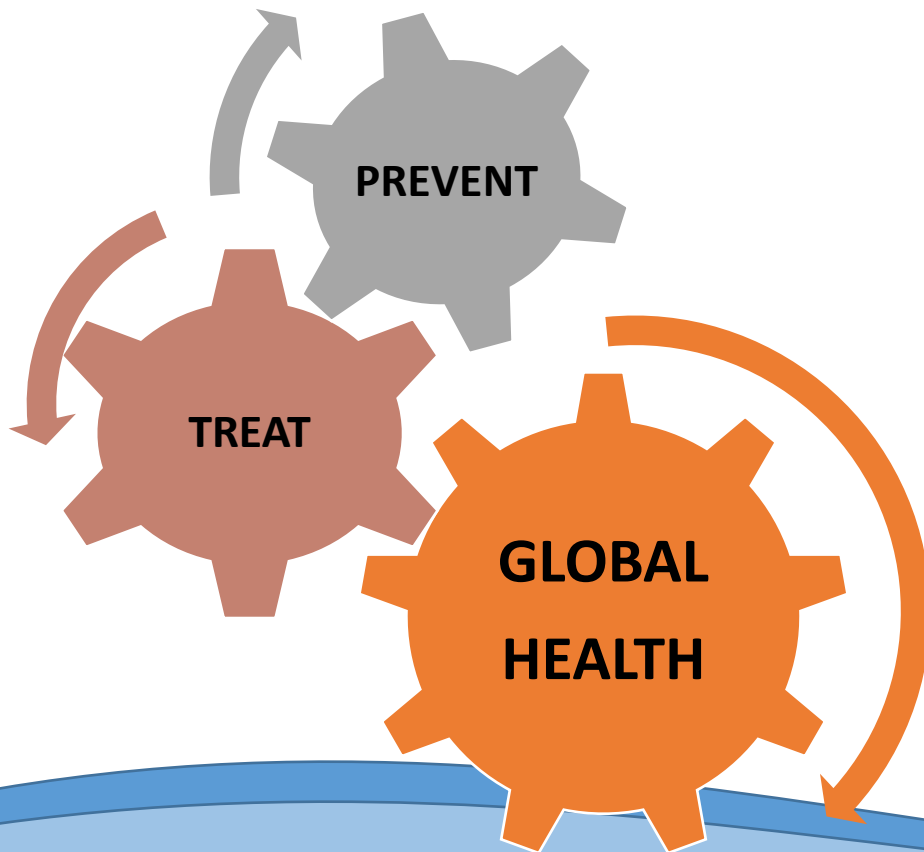
...let's say 50 years before they appear!



Ican Summit 2016

3 Topics of the congress:

- ✓ **Innovation**
- ✓ **Patient Expert & Research**
- ✓ **Innovative treatments**



Social community activity



We will show the Hospital and the main services...



Barcelona Ican Summit 2016



Innovation day

Barcelona Ican Summit 2016



Practical workshops about innovative therapeutic tools

CosmoCaixa Museum



Patient expert day



... y si RobotX pudiese encontrar el diagnóstico a enfermedades genéticas que hasta ahora se tardaba años en diagnosticar?



El Proyecto

Te presento a RobotX, un robot muy potente que es capaz de analizar genes y síntomas, y aprender de lo que analiza, así cada vez se vuelve más listo y es capaz de diagnosticar más enfermedades. RobotX se ha propuesto diagnosticar a 1000 pacientes en los próximos dos años!

Conoce más sobre nuestro proyecto. ¡Ayúdanos a conseguir diagnósticos!

[Read More >](#)



Colabora

La mayoría de los que trabajamos en este proyecto somos voluntarios, sin embargo, el proceso para obtener el diagnóstico requiere costes en material médico, sanitario, instalaciones y máquinas, instrumentos indispensables para conseguir el éxito en el diagnóstico.

Apadrina un diagnóstico. ¡Compra un RobotX para un niño!

[Read More >](#)



Pacientes

Si tienes un hijo, familiar o conocido con una enfermedad genética pendiente de diagnosticar y quieres un RobotX para él, o simplemente te sientes comprometido con el proyecto y quieres ayudar con una aportación, esto es lo que tienes que hacer.

Quiero un RobotX ¿Cómo puedo conseguirlo?

[Read More >](#)



Compartir para avanzar

Ya somos 440 usuarios

[¡ÚNETE!](#) [ACCEDER](#)

- [INVESTIGACIÓN EN ENFERMEDADES RARAS](#)
- [FAMILIAS](#)
- [CLÍNICOS](#)
- [INFORMACIÓN](#)
- [RESULTADOS](#)

Noticias

más noticias



Día Mundial de la Osteogénesis Imperfecta: futura nueva línea de investigación en Rare Commons

05/05/2016

La osteogénesis imperfecta (OI), popularmente 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...

Resultados

ENACH-PKAN

PKANDRS: escala de evaluación clínica testada en 45 pacientes.

• • • • •

[ver todos](#)

Open panel: patient expert



Experts pannel: Regulatory Agencies



Experts pannel: 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.

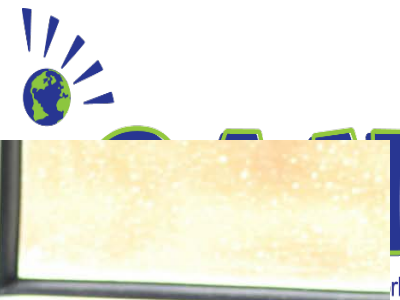
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Interactive workshop of healthy and therapeutic nutrition (Fundació Alicia)



Workshop for teenagers

Workshop for adults



Other therapeutic options: clowns



Other therapeutic options: music therapy



Other therapeutic options: Child Life



Other therapeutic options: Mindfulness



Bioethics: pediatric clinical research



KiDS



Barcelona Ican Summit 2016

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