



JUNE 27 – JULY 1

2016 iCAN RESEARCH & ADVOCACY SUMMIT

PROGRAM GUIDE

#iCANSummit2016

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KinderPharm



Schedule at a Glance

Monday 27 June

Abba Garden Hotel

2³⁰ PM – 4⁰⁰ PM

4⁰⁰ PM – 5³⁰ PM

5³⁰ PM – 6⁰⁰ PM

6⁰⁰ PM – 6³⁰ PM

6³⁰ PM – 9³⁰ PM

Volunteer Bracelet Making

Registration

Introductory Remarks

Keynote: Mr. Pep Torres

Welcome Reception

Tuesday 28 June

Sant Joan de Déu Children's Hospital

8³⁰ AM – 9⁰⁰ AM

9⁰⁰ AM – 11⁰⁰ AM

Break

11³⁰ AM – 1¹⁵ PM

Lunch at Abba Garden Hotel

2³⁰ PM – 4³⁰ PM

Welcome Address

Poster Presentations

Tour of Hospital

Adult & Youth Workshops

Wednesday 29 June

CosmoCaixa Museum of Science

8³⁰ AM – 10⁰⁰ AM

Break

10³⁰ AM – 11³⁰ AM

11³⁰ AM – 11⁴⁵ AM

11⁴⁵ AM – 12¹⁵ PM

12¹⁵ AM – 1³⁰ PM

Advocacy in Med. Research

Regulatory Science Panel

Musical Guest: Sparsh Shah

Pharma/Device Panel

Career Info Session/Lunch

Thursday 30 June

Fundació Alícia, Món St. Benet

9³⁰ AM – 1³⁰ PM

Lunch

Abba Garden Hotel

4⁰⁰ PM – 4³⁰ PM

4³⁰ PM – 5³⁰ PM

Healthy eating/other diets

EMA Patients & Consumers

iCAN Council Meetings

Friday 1 July

Sant Joan de Déu Children's Hospital

8³⁰ AM – 10³⁰ AM

Break

11⁰⁰ AM – 11⁴⁵ AM

11⁴⁵ AM – 12¹⁵ PM

5⁰⁰ PM – 6⁰⁰ PM

6³⁰ PM – 7⁰⁰ PM

Abba Garden Hotel

7⁰⁰ PM – 11⁰⁰ PM

Youth & Adult Workshops

EUPATI Toolbox Game

RCPCH Research Charter

Hosp. Clowns Presentation

Awards Ceremony

Closing Reception & Dance

Message from the Chairman

On behalf of the International Children's Advisory Network Board of Directors, welcome to Barcelona, Spain, and to the 2016 iCAN Research & Advocacy Summit! This innovative event will bring together close to 150 youth advisors, team leaders, parents, and scientific partners from 6 countries on 2 continents with a common purpose of providing children and families a global voice in health, medicine, research, and innovation. We are honored to partner with Sant Joan de Déu Children's Hospital to bring you an exciting program that will educate, stimulate, and empower you. Learn from the experts, get to know one another, let your voice be heard and have fun! Thanks for joining us this week and we hope you enjoy the Summit and the beautiful city of Barcelona.

Sincerely,



Charlie Thompson, MD FAAP

Welcome!

The International Children's Advisory Network has been under development since August 2013 when the first KIDS group was launched in Connecticut. KIDS stands for Kids and Families Impacting Disease through Science, and they are the local chapters which come together to form iCAN. KIDS was modeled after similar young person's advisory groups (YPAGs) in Europe and Canada, which are also members of the iCAN network. For more information about iCAN, please visit us on the web at www.icanresearch.org or email info@icanresearch.org.

The purpose of this event is to provide a structured setting for youth members and their parents to come together and share their experiences, learn from one another, and engage with world leaders in medicine, research, innovation and advocacy. With a successful Launch in 2015, we are excited to continue our mission and to further develop this learning opportunity year after year.

International Children's Advisory Network

Supported by the Foundation for Children
104 Hungerford Street
Hartford, CT 06106

Contact | info@icanresearch.org | +1 (860) 977-9206





Welcome to Hospital Sant Joan de Déu



Since 1867 our Hospital has played an important role for its citizens. We have been focusing our efforts to care for and treat those more vulnerable, children and mums. The story of Saint John of God has left its mark on us. The oldest pediatric hospital in Spain has become a reference center at national and international levels, where we provide integral care for patients, combining the essential human aspects of medical attention with the latest scientific advances. Research and innovation are important pillars of our activity as well, with a clinical research unit also referent and 17 consolidated research groups focused on rare pediatric diseases.

But on the basis of our values- quality, respect, hospitality and spirituality- we don't forget our reason of being: the patients and their families.

The patient is at the center of all our processes, and we encourage an empower them and the families to participate, decide, provide opinions, and contribute to the development of the Hospital, our priorities, our facilities, our strategic plan is totally driven by patients. KIDS Barcelona is one of the best examples about patient centered medicine, research and innovation.

We are glad to host the iCAN Summit 2016. So thanks you, for choosing our Institution for such an important event, and please take the opportunity to visit our Hospital, to meet our investigators, and to exchange your ideas of what you see with our patients and professionals.

Sincerely,
Manuel Del Castillo, MD

#iCANSummit2016

Barcelona, Spain

**150 Child and
Family Attendees**

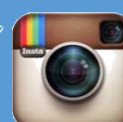
**6 Countries
Represented**

**8 Sponsors and
25 other Partners**

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SUMMIT ON SOCIAL
MEDIA!**



icanresearch.org/summit



DAY ONE: Monday, June 27th

Abba Garden Hotel Barcelona

2:30 pm – 4:00 pm

Volunteer Bracelet Building Activity

Optional activity for children and parents. The bracelets were designed by Candela, an oncology patient at the hospital, and they are now made by volunteers and sold as a fundraiser to support oncology research for other children.

Tina Parayre *Chief of Volunteer Services, Hospital Sant Joan de Déu*

4:00 pm – 5:30 pm

Registration

5:30 pm – 6:00 pm

Opening Remarks

Dr. Manuel del Castillo *CEO, Hospital Sant Joan de Déu*

Mr. Joaquim Erra *Brother Superior of the Community, Hospital Sant Joan de Déu*

Dr. Charles Thompson *Chair, Board of Directors, iCAN and Global Lead, Pediatric Center of Excellence, Pfizer*

6:00 pm – 6:30 pm

Innovation and Teenagers: The Best Model for Scientific Advancement

Mr. Pep Torres *Founder, MIBA: Museum of Ideas and Inventions of Barcelona*

6:30 pm – 9:30 pm

Welcome Reception at ABBA Garden Hotel

DAY TWO: Tuesday, June 28th

Sant Joan de Déu Children's Hospital

7:00 am – 8:30 am

Continental Breakfast at ABBA Garden Hotel

8:30 am – 9:00 am

Welcome Address

Dr. Charles Thompson *Chair, Board of Directors, iCAN and Global Lead, Pediatric Center of Excellence, Pfizer*

Mr. Félix Junquera *President, KIDS Barcelona*

9:00 am – 11:00 am

Poster Presentations

Each iCAN team will create a poster to introduce attendees to their team and city, highlighting any projects they have done or plan to do. There will also be several special posters presented by youth members involved in network-wide projects.

11:00 am – 11:30 am

Break

11:30 am – 1:15 pm

Tour of Sant Joan de Déu Children's Hospital

Children and adults will tour the hospital and learn about services provided to children in Barcelona.

1:15 pm – 2:30 pm

Lunch at Abba Garden Hotel

2:30 pm – 4:30 pm

Youth Workshops

- Lego computer engineering tool
- Funny Friends: cartoon respiratory therapy software
- Therapy with pets
- Therapy with robots

Adult Workshop: Clinical Research Design (Abba Hotel)

Interactive session where parents and other adults will learn about clinical research from medical providers' perspectives. In small groups, they will decide on a research question and design a strategy to answer it.

Dr. Sharon Smith *Emergency Department Research Director, Connecticut Children's Medical Center*

Dr. Susanna McColley *Associate Director, Cystic Fibrosis Center Division of Pulmonary Medicine, Ann & Robert H. Lurie Children's Hospital of Chicago*

Grace Wentzel *Director, Clinical Research Services, Nationwide Children's Hospital*

--Free evening from 4:30 pm--

DAY THREE: Wednesday, June 29th

CosmoCaixa Museum of Science

7:00 am – 8:00 am

Continental Breakfast at ABBA Garden Hotel

8:30 am – 10:00 am

Clinical Medicine, Research, and Advocacy

Interactive sessions where children and families will learn about how advocacy organizations tie into medical research and clinical practice.

Begonya Nafria *Patient Advocacy Manager, Hospital Sant Joan de Déu*

Dr. Jaume Mora *Oncologist and Principal Investigator, Hospital Sant Joan de Déu*

Julian Isla *President, Dravet Syndrome Foundation*

10:00 am – 10:30 am

Break

10:30 am – 11:30 am

Regulatory Science Panel

Youth members will interview medical regulators in a talk show-style forum to gain insights into the lifecycle of a new therapeutic from the regulatory perspective.

Nathalie Bere *Stakeholder & Communication Division, EMA*
Dr. John Alexander *Center for Drug Evaluation and Research, FDA*

Dr. Supriya Sharma *Senior Medical Advisor, Health Canada*

11:30 am – 11:45 pm

Break and Musical Guest

Sparsh Shah *Youth Patient Advocate and Musical Artist*

11:45 am – 12:15 pm

Pharmaceutical and Device Research Panel

Youth members will interview medical innovators and pharmaceutical experts in a talk show-style forum to gain insights into the lifecycle of a new therapeutic.

Dr. Alison Sampson *Senior Project Director, Premier Research*

Leanne West *Chief Engineer, Pediatric Technology Center, Georgia Tech*

Kirsten Cervati *Director, Global Strategic Site Collaborations, PPD*

Dr. Charles Thompson *Global Lead, Pediatric Center of Excellence, Pfizer*

12:15 pm – 1:30 pm

Career Info Session and Lunch

At the start of lunch, experts from health-related fields will introduce themselves and will be available during the break to answer questions from youth members in a casual setting.

Sherry Farrugia *Director, Pediatric Technology Center, Georgia Tech*

--Free afternoon/evening from 1:30 pm--

DAY FOUR: Thursday, June 30th

Fundació Alícia, Món St. Benet

7:00 am – 8:30 am

Continental Breakfast at ABBA Garden Hotel

9:30 am – 1:30 pm

Fundació Alícia Healthy Eating Habits (break included)

Children: Improving Dietary Habits for Children & Teens

Adults: Mediterranean Diet, Nutrition, & Healthy Food

1:30 pm – 2:30 pm

Lunch at Món St Benet

2:30 pm – 4:00 pm

Travel back to ABBA Garden Hotel

4:00 pm – 4:30 pm

Young Patients' Involvement in EMA PCWP

The Patients and Consumers Working Party (PCWP) within the EMA is organizing a network of young people to respond to questions regulators may have regarding clinical trials for young people, or new medicines, or the information on such medicines.

François Houyez *Treatment Information and Access*

Director/Health Policy Advisor, EURORDIS

4:30 pm – 5:30 pm

Business Meeting: iCAN Councils

All attendees are welcome and encouraged to attend one of the following iCAN Council meetings, which will run concurrently: Team Leader Council, Parent Council, or Youth Council

--Free evening from 5:30 pm--

DAY FIVE: Friday, July 1st

Sant Joan de Déu Children's Hospital

7:00 am – 8:30 am

Continental Breakfast at ABBA Garden Hotel

8:30 am – 9:30 am

Children/Youth: Singing as a Therapeutic Activity

Singing is a powerful tool which can lower patients' stress and anxiety, and it can help improve concentration, relaxation, and development of creative and social skills.

Giorgio Elmo *Professional Singer, Hospital Sant Joan de Déu*

Adults: Child Life Therapy and Transition to Adult Care

(Held in Abba Garden Hotel) This session will focus on the specific challenges faced by children and families who are research participants or hospital patients. Solutions to some of these problems will be discussed.

Amanda Woelk *Child Life Specialist, Children's Mercy Hospital*

Núria Serrallonga *Child Life Specialist, Hospital Sant Joan de Déu*

David Nadal *Social Work Services Head, Hospital Sant Joan de Déu*

9:30 am – 10:30 am

Children/Youth: Mindfulness Workshop

Topics on keeping a healthy life balance, techniques for focusing awareness on the present moment, and embracing thoughts, emotions, and sensations in a healthy manner.

Dr. José Angel Alda *Section Chief, Psychiatry and Psychology Department, Hospital Sant Joan de Déu*

Dr. Anna Huguet Miguel *Psychology Researcher, Sant Joan de Déu Research Foundation*

Dr. Maria Angeles Mairena *Clinical Psychologist, Hospital Sant Joan de Déu*

Adults: Bioethics (Held in Abba Garden Hotel)

Parents will work through a number of ethical dilemmas with one another, gaining an appreciation for the complexity of decisions regarding medical practice and research.

Kate Harvey *Senior Research Officer, Nuffield Council on Bioethics*

10:30 am – 11:00 am

Break

11:00 am – 11:45 pm

EUPATI Toolbox Game

Children and parents together will play a trivia-style game to show off their knowledge of all things related to medical research, which they will gain prior to and throughout the conference with the aid of EUPATI's newly released patient toolkit (www.eupati.eu)

Jan Geissler *Director, European Patients' Academy on Therapeutic Innovation (EUPATI)*

11:45 am – 12:15 pm

Infants, Children and Young People's Research Charter

Lindsey Hunter *Research Development Manager, RCPCH*

Emma Sparrow *Children and Young Person Advocacy Manager, RCPCH*

--Free afternoon from 12:15 pm until 5:00 pm--

5:00 pm – 6:00 pm

Hospital Clowns Presentation

The Pallapupas are trained artistic and medical professionals belonging to a non-profit organization whose goal is to bring laughter to pediatric hospitals and improve the quality of life of children and families.

Clown performers with Angie Rosales *Chair, Pallapupas*

6:00 pm – 7:00 pm

Awards Ceremony

7:00 pm – 11:00 pm

Closing Reception and Dance at ABBA Garden Hotel

The International Children's Advisory Network would like to thank the following sponsors for their generous support of the 2016 iCAN Research & Advocacy Summit:



We would also like to extend our gratitude to the following organizations for their tireless efforts in putting together engaging sessions or providing other forms of support for this event:

Abba Hotels
Children's Mercy Hospital
CT Children's Med. Center
CosmoCaixa
CTAC
Dravet Syndrome Found.
EnprEMA
European Medicines Agency
EUPATI
EURORDIS
FC Barcelona Foundation

Foto Booth Atelier
Fundació Sant Joan de Déu
GA Institute of Technology
Health Canada
HP
MIBA
Nuffield Council on Bioethics
Pulseras Candela
Rare Commons
RCPCH
Unofficial Cardboard
US FDA



VENUES

Abba Garden Hotel Barcelona

Abba Garden Hotel Barcelona
Carrer de Santa Rosa, 33,
08950 Esplugues de Llobregat

Conveniently located adjacent to our partner children's hospital in Barcelona, the four-star Abba Garden is the official hotel of the 2016 iCAN Summit. Most participants will be housed at the Abba Garden, and there are also several meetings here throughout the week. The outdoor garden will be the stage for the opening and closing receptions, and the awards ceremony and other presentations will be held in indoor conference rooms.

Hospital Sant Joan de Déu

Passeig de Sant Joan de Déu 2
08950 Esplugues de Llobregat

Sant Joan de Déu Children's Hospital is the host institution for the summit, and conference activities will take place within the hospital on June 27th, 28th, and July 1st. Sant Joan de Déu is a pediatric hospital treating patients from birth to 21 years old and it is affiliated with the University of Barcelona.

CosmoCaixa Museum of Science

CosmoCaixa Museum of Science
Carrer d'Isaac Newton, 26, 08022

CosmoCaixa is a science museum in Barcelona which aims to educate people about science in engaging and interactive ways. The building itself is over 100 years old but was renovated in 2004. Summit programming will take place in CosmoCaixa on Wednesday, June 29th. Those wishing to remain and explore the museum after the conference ends that afternoon are welcome at no additional charge.

Fundació Alcía

Complex Món Sant Benet
Camí de Sant Benet,
08272 Sant Fruitós de Bages

Fundació Alcía is a research center whose aim is to educate and advocate for healthy eating for everyone. Their three areas of focus are scientific and gastronomic research (food science), health and eating habits, and food heritage. Children & parents will attend separate nutrition workshops here on Thursday, June 30th, and lunch will be served at Fundació Alcía's restaurant, Món St. Benet.



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we don't try to
do everything
for everybody.

We focus on doing
what we do best.

As leaders in pediatric research, we salute iCAN for its dedication to children's health, medicine, research, and innovation. We're proud to be a Silver Sponsor of the 2016 Research & Advocacy Summit.

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SPEAKERS

Dr. Manuel Del Castillo



is the CEO of Sant Joan de Deu Hospital in Barcelona from 2003. He is also a member of the

Board of the General Directorate of Provincial Curia of the Hospitaller Order of Saint John of God from 2014.

He is a specialist in family and community medicine, and Master in Management. He has received a number of awards: Arthur Andersen Medical Journal (2001), BearingPoint (2003), Professor Barea (2008), Fundación Factor Humà Mercè Sala (2012).

Joaquim Erra

is a Brother of St. John of God and now he is living and working in the community of monks of the Sant Joan de Déu Hospital.



He studied nursing and worked first with people with disabilities and before with pediatric patients. Nowadays he is doing different tasks of leadership and management, and when he can he helps in the emergency department of the hospital.



Pep Torres

is founder and director of Stereonoise. Born in 1965 in Barcelona, Pep

responds to a specific profile of renaissance man; he works as a professional inventor, musician, designer, writer, artist, and TV and radio program collaborator.

His inventions and creative proposals have traveled the world, and multiple times he has appeared on the front page of prestigious newspapers such as The Wall Street Journal. In 2005 he create Stereonoise; a company working on the invention of new products to create media impact. In 2011, Mr. Torres founded MIBA, the museum of ideas & inventions of Barcelona.

Dr. Charles Thompson

is a pediatrician at Connecticut Children's Medical Center and a Clinical Instructor of Pediatrics at the



University of Connecticut School of Medicine. Currently, Charlie serves as the Global Lead for the Pfizer Pediatric Center of Excellence. He is also the Chair of the Executive Committee for the American Academy of Pediatrics Section on Advances in Therapeutics and Technology, a member of the Board of Directors for the Hezekiah Beardsley Connecticut Chapter of the American Academy of Pediatrics, the Founder and Chair for KIDS and iCAN, and a Steering Committee Member for the Global Alliance for Pediatric Therapeutics.



Felix Junquera

is a 16 year old teenager, currently in 10th grade and president of KIDS

Barcelona. He has been an active member of this chapter since the very beginning, always trying to participate and do his best. He is also a fellow of the Youth Council Committee. Moreover, he had the chance to

attend the ICAN summit hosted in Washington D.C.

Felix is very fond of biology and his main hobbies are playing the piano, traveling and learning foreign languages, such as English and German.

Dr. Sharon Smith

is a pediatric emergency medicine physician at Connecticut



Children's Medical Center and is the Research Director for the Emergency Department. Dr. Smith is also Professor of Pediatrics at the University of Connecticut School of Medicine and an Associate Program Director for the Pediatric Residency Program. She teaches clinical and translational research to undergraduates, medical students and residents

Dr. Susanna McColley

is Professor of Pediatrics at Northwestern University Feinberg School of Medicine and Associate Chief



Research Officer at the Stanley Manne Children's Research Institute of Ann & Robert H. Lurie Children's Hospital of Chicago. She is a pediatric pulmonologist who has designed, conducted and analyzed data many clinical trials of new treatments for cystic fibrosis. She has published numerous scientific articles and served as author and editor for textbooks and education programs on cystic fibrosis and other childhood lung diseases. Among her awards are Presidential Commendations from the American Thoracic and the Breath of Life Award from the Greater Illinois Chapter of the Cystic Fibrosis Foundation.

SPEAKERS

Begonya Nafria

holds the degree of Educational Sciences, a Master in Engineering Training and a Master in Multimedia and Internet edition. She has solid experience in coordinating and managing projects on clinical research on rare diseases. She is the Patient Advocacy Manager, Coordinator of the Rare Commons project (www.rarecommons.org) and in KIDS Barcelona (YPAG). She is also a member of the Spanish National Platform of Eupati, member of the Course Committee of Eupati and Chair of the Educational Committee of iCAN.



than 20 consultants. He also represents a voice for patients with rare diseases as a member of the European Medicines Agency's Committee for Orphan Medicinal Products (COMP).

Nathalie Bere



has been working at the European Medicines Agency (EMA) for over 18 years and is currently responsible for the Agency's engagement with patients and consumers. Nathalie is dedicated to ensuring that there are opportunities for including the patients' voice along the medicines regulatory lifecycle. Her work involves not only the daily interactions with patients as they participate, but also developing and monitoring the scope of involvement of these stakeholders within the various Agency activities, such as participation in scientific advisory groups, committee consultations and the review of medicines information for patients.

Dr. Jaume Mora



is the Scientific Director of the Hematology and Oncology Dept. at Hospital Sant Joan de Deu (HSJD) Barcelona. He is also an associate member of the oncology program at the Institute for Research in Biomedicine (IRB). Dr. Mora leads a research team dedicated to clinical, translational and basic research on developmental tumors. Their goals are to develop molecular and cellular biology techniques necessary for the diagnosis, prognosis and monitoring of developmental tumor patients, and to conduct research addressed to improve the diagnostic, prognostic and treatment processes of such patients.

Julian Isla

is the Chairman of the European Delegation of the Dravet Syndrome Foundation. Mr. Isla works as a computer engineer for Microsoft, where he manages a team of more



pediatric infectious diseases in 1998 and stayed with FDA as a full-time medical officer. Dr. Alexander also obtained a Master's in Public Health degree from the George Washington University School of Public Health in 2001. Dr. Alexander has been involved in drug regulation and pediatric drug development for over 20 years.



Sparsh Shah, aka "PURHYTHM" is a 13 year old child prodigy who has been learning

Hindustani classical music for last seven and a half years and American vocal music for three years. He has multiple talents such as performing in various live events (over 60 live performances, including The Next Generation Emerging Artist at Grammy Park), appeared on several radio and television shows (including BBC, NBC, and Sony), hosted shows as an MC, memorized 250 digits of Pi, he has written songs, several poems, short stories, and motivational/funny speeches. Sparsh has won several local singing competitions and was honored to be named the Youth Ambassador for St. Jude Children's Research Hospital. Despite of all the challenges in life, Sparsh's spirit is unbreakable and he aspires to inspire billions of people all over the world with his musical talent. Sparsh has been a catalyst in helping raise over half a million dollars and several performances for philanthropic organizations such as Literacy Drive for orphanages in Guyana, Fund Raisers for St. Jude's, Nepal earthquake victims, Chennai flood victims, The Heart and Hand for Handicapped, Share and Care Foundation, Sankara Eye Foundation, Lakeview 5K Charity for New Jersey Institute for Disabilities, and South Asian American Community Outreach.



Dr. John Alexander

Is the Acting Deputy Director of the Division of Pediatric and Maternal Health at FDA. He received his MD degree from the University of South Florida, College of Medicine in 1991 and completed a pediatric residency program in 1994. After a year of working in various pediatric clinical setting across the US through a locum tenens agency, Dr. Alexander began a pediatric infectious disease fellowship run jointly between the Children's National Medical Center in Washington, DC and the Division of Anti-Infective Drug Products at FDA. He completed his fellowship in

SPEAKERS

Dr. Alison Sampson has over 20 years Clinical Research Experience in all phases I-IV, including global studies, in roles such as CRA, Project Manager, Senior Project Manager and Senior Project Director. As an experienced Project Manager and Line Manager, she has led both clinical and cross-functional teams. Alison's work experience includes roles in Contract Research Organizations (CROs), Biotech and Blue Chip Pharma. Dr. Sampson has significant experience researching a number of therapeutic areas, but she has a particular interest in oncology. Over the last few years she has gained expertise in developing patient recruitment strategies using social media to boost recruitment in rare or difficult to recruit patient populations.



Kirsten Sherman Cervati

Has over 21 years of experience in drug development, the past 15 of which have been at PPD where she is currently the Global Head of the Strategic Site Collaborations department. Kirsten's tenure at PPD includes positions of increasing global responsibility for development of site networks, site intelligence, clinical study feasibility and relationship management. Kirsten leads the development and oversight of PPD's Pediatric Investigator Network (PIN), a group of children's hospitals and major academic centers specializing in pediatric clinical research and rare diseases across the globe. Kirsten, as a mother of a child with a chronic disease, is especially passionate about advancing clinical research for children such that there are safer and more suitable treatment options available to this under-served population.



Leanne West

is a Principal Research Scientist in the Georgia Tech Research Institute and the Chief Engineer of Pediatric Technologies for Georgia Tech. Her background includes remote sensing, mobile health applications, and algorithm development. She serves as the technical liaison between Georgia Tech and Children's Healthcare of Atlanta. Ms. West has served as the twice-elected Chair of the Georgia Tech Executive Board. She was recognized by Georgia Trend magazine as one of Georgia's "40 Under 40" in 2004; she received Georgia Tech's Outstanding Achievement in Research Enterprise Enhancement Award in 2014, and she was Women in Technology's Woman of the year in 2014. She also started her own company, Intelligent Access, to take her invention of a wireless personal captioning system to market.



Núria Serrallonga

is a nurse and psychologist. She is now working to help children cope with medical procedures and surgeries at Sant Joan de Déu Children's Hospital, following the model of a Child Life specialist.

David Nadal

is the Head of Social Work and a Patient Experience team member in Sant Joan de Déu Hospital. He is a teacher of Health Social Work Master (UOC) and Postgraduate of Social Pediatrics (IL3-UB).



Dr. José Angel Alda

is the Section chief and coordinator of the ADHD unit of the psychiatry and psychology department at Hospital Sant Joan de Déu. He is the Treasurer of the Spanish Association of Child and Adolescent Psychiatry (AEPNYA). He has been principal investigator in several clinical trials under both public and private funding. He leads the project: Influence of a program of mindfulness on nuclear symptoms, executive functions and the hypothalamic-pituitary-adrenal axis in children recently diagnosed with ADHD. Dr. Alda coordinated the Clinical Practice Guideline on ADHD in children and adolescents published by the National Health System of Spain in 2010.

Dr. Anna Huguet Miguel



is a Psychology Researcher at Sant Joan de Déu Research Foundation. She completed a graduate degree in psychology and clinical psychology and a Master's Degree in General Health Psychology. She is a Practitioner and instructor, conducting training programs in mindfulness for children and adolescents.

Dr. Maria Angeles Mairena

works as clinical psychologist at Hospital Sant Joan de Déu, in Barcelona. She attends children with different somatic pathologies through the Consult Liason Department and is also specialized in neurodevelopmental disorders, attending children with

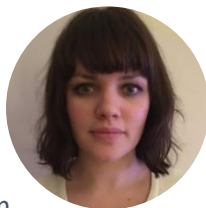


SPEAKERS

Attention Deficit Disorder and Hiperactivity and children with Autism Spectrum Disorder. Besides her clinical work, she collaborates in different research projects.

Kate Harvey

is a Senior Research Officer at the Nuffield Council on Bioethics. From



2013-2015, she worked on the Council's project examining ethical issues around children's and young people's involvement in clinical research. During the project, Kate particularly focused on involving young people in the project and producing outputs aimed at young people in the form of written materials, films, and an animation.



Emma Sparrow

is an experienced children and young people's engagement manager

from the UK where she works for the Royal College of Paediatrics and Child Health (RCPCH) as Children and Young People's Engagement Manager. Her career has included working for a range of organisations such as local authorities, a Police Force, national and local charities and working freelance across a range of sectors to ensure that children and young people's voice is central to service design, delivery and evaluation. Emma has a Masters in Youth and Community Research and a BA Hons in Applied Social Science, Community Development and Youth Work - both of which support her high quality service user involvement projects and UK consultation with children, young people and families.

Lindsey Hunter

manages the research and evaluation team at the RCPCH, overseeing all research activity at the RCPCH, and ensures that children and young people are actively involved in the research design, development and delivery. Lindsey has a background in psychology and has worked in healthcare services research for the past six years. This has involved working with patients and clinicians, as well as designing research methodology, analysing data, systematically reviewing evidence, writing and publishing research reports.



Angie Rosales

studied drama between 1988-92, but studying drama is a challenge that never ends. She had the honor to study theater with two important teachers: Javier Dualte and Javier Galitó, who made a turn in the concept of the theater in Catalonia. In 2000 she created the company "Pallapuas" which fuses the concepts of medicine and drama, her two passions, into one.



Grace Wentzel

has been with Nationwide Children's Hospital for 25 years and is the Director for Clinical Research Services which provides investigators with all of the services they need to conduct a clinical research project. Grace also holds a position as an associate instructor in the division of Pharmacy Practice and Science in the College of Pharmacy at

The Ohio State University and is certified as a CCRP through SoCRA.

Giorgio Elmo

Started singing pop and soul music when he was 14. He began his musical studies in the choir of Maestro Fabio De Angelis and performed there for ten years. At age 25 he began to pursue his classical training, studying as a lyric tenor with Professor Carlo Desideri (Conservatorio di Roma). In 2008 he attended the "Istituto Nazionale del Melodramma" Paola and Alberto Del Monaco studying with Maestro Nazzareno Antinori. Since 2009, Mr. Elmo has lived in Barcelona where he has continued his musical training, vocal technique and stage studies in several master classes. Since 2011 he has been dedicated to the creation and management of the project "Singing Therapy" which is a "Workshop Song" as a therapeutic activity for patients in the Psychiatric Unit of the Hospital San Joan de Deu de Barcelona.



Amanda Woelk is a Child Life Specialist at Children's Mercy Hospital in Kansas City, where she also runs the hospital's Teen Advisory Board. Amanda is a co-lead for the KIDS Kansas City team, which is composed of those same Teen Advisory Board members, and she also chairs the iCAN Conference Committee. This year, she worked with young people from multiple iCAN teams to develop a travel policy for families representing iCAN at conferences, she contributed to biweekly meetings to help iCAN leadership plan for the Summit, and through the Conference Committee she got more young people involved with planning various aspects of the Summit.

SPEAKERS

Sherry Farrugia

is the Chief Operating Officer of the Children's Healthcare of Atlanta Pediatric Technology Center at Georgia Institute of Technology. She has 25+ years of experience working in healthcare, particularly as it relates to Healthcare IT, data analytics, and consulting to the self-insured market place. In her current role, Ms. Farrugia provides executive level leadership for business and operational functions such as budget planning and organization of team process around a function. This includes providing insight into the innovations, new technologies and start up developed as a result of the partnership. Prior to Georgia Tech, Sherry was a senior VP for a behavioral health solutions company for the self-insured. She also founded and sold a health care IT company to McKesson HBO & Company in the early '90s whose technology was focused on point-of-care documentation and tracking both clinical and financial outcomes – technology McKesson is still using in their systems today.



Dr. Supriya Sharma is the acting Associate Assistant Deputy Minister, Health Products and Food Branch for Health Canada, and she is Senior Medical Advisor to the Deputy Minister of Health Canada. Dr. Sharma joined Health Canada in 2002 as Director of the Marketed Biologics and Biotechnology Products Division of the Marketed Health Products Directorate. She has since held various leadership roles in the Health Policy branch and the Therapeutic Products Directorate. Trained as a Pediatrician in Calgary and Australia, Dr. Sharma worked in Hematology Research in thalassemia and sickle cell disease in a number of multicenter international

clinical trials, including one in Sri Lanka in collaboration with Oxford University. She completed a Masters of Public Health in International Health from the Harvard School of Public Health in 2001, and went on to work on a research project for the Kennedy School of Government on implementing strategies relating to the reduction of medical errors and patient safety in large scale health organizations.

François Houÿez

is Director of Treatment Information and Access, Policy Advisor. He has always been working as a patient advocate since the early 90s. He joined EURORDIS in May 2003.

He represents EURORDIS at the Patients' and Consumers' Working Party at the European Medicines Agency (EMA) and has been appointed external expert for the evaluation of marketing authorisation applications. He co-chairs the stakeholders' forum of the EUnetHTA Joint Action.

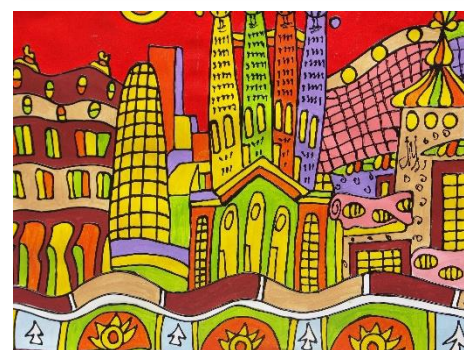
He pioneered patient advocacy with the European Medicines Agency as part of the first patients' delegation that engaged dialogue with the Agency back in 1996 and has continuously been involved in the agency activities during the last 26 years.



Jan Geissler

Is working for the European Patients' Forum as director of the 'European Patients Academy on Therapeutic Innovation' (EUPATI), a project funded by Innovative Medicines Initiative. EUPATI develops educational material and training courses to educate patient and patient

advocates about medicines development processes. He is also founder and managing director of Patvocates, acting as advisor on cancer policy, patient advocacy and social media. After his university diploma in Business studies in the UK and Germany, Jan held various management positions in telecom, R&D and media think tanks before he focused his professional life on patient advocacy in 2008. Being a leukemia survivor who took part in various clinical trials, Jan founded the online patient community Leukaemie-Online.de in 2002, which has become one of the most frequented communities for leukemia patients on in German speaking countries. In 2003, he co-founded the European Cancer Patient Coalition.





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Infants', Children's and Young People's Child Health Research Charter

Remember it's about me; involve and support me at every stage and keep me safe from harm.

Empower me, my family, and the people caring for me; help us to understand and feel more confident about research.

Support me, my family, and the people caring for me; give us time to understand research processes, how to assess risks and benefits, and what it will mean to be involved.

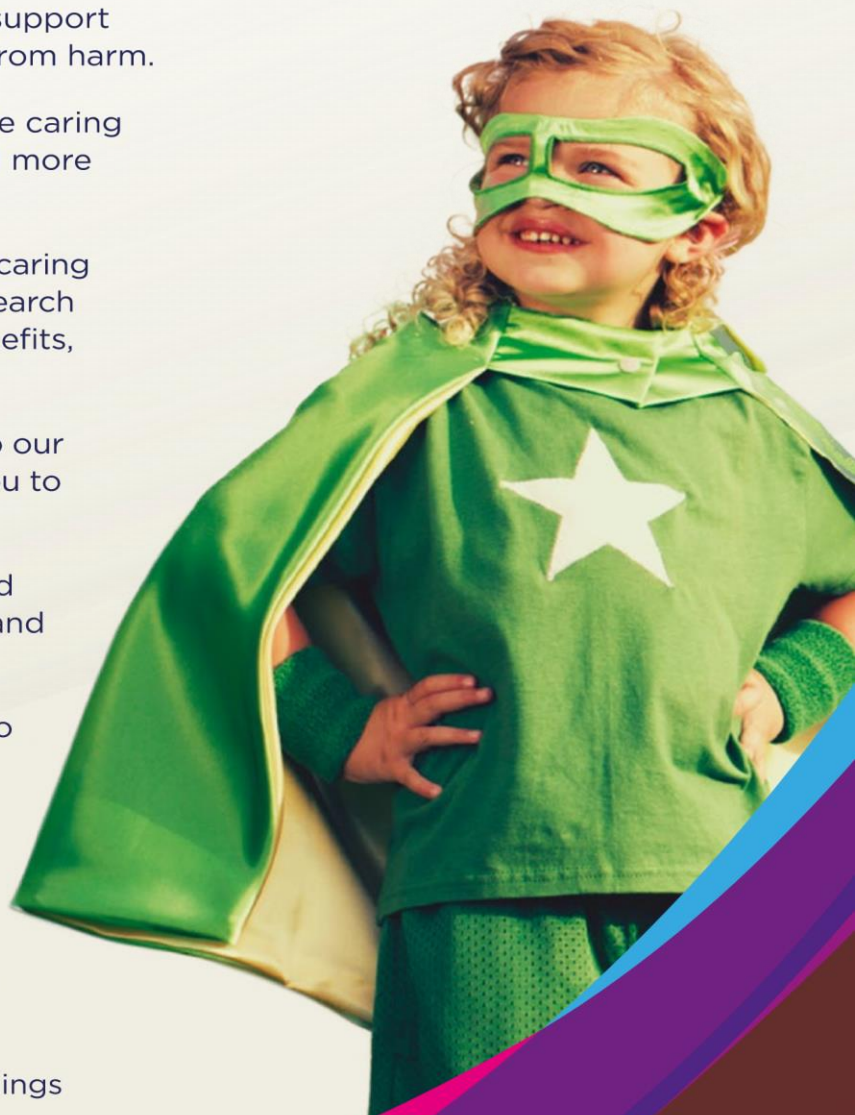
Engage with me and my family; listen to our questions and ideas, so we can help you to help us benefit from research.

Actively gain my consent or assent and explain my right to change my mind and withdraw at any time.

Rights are important to me; my right to understand research, be involved in decisions, be respected, and to help others benefit from research.

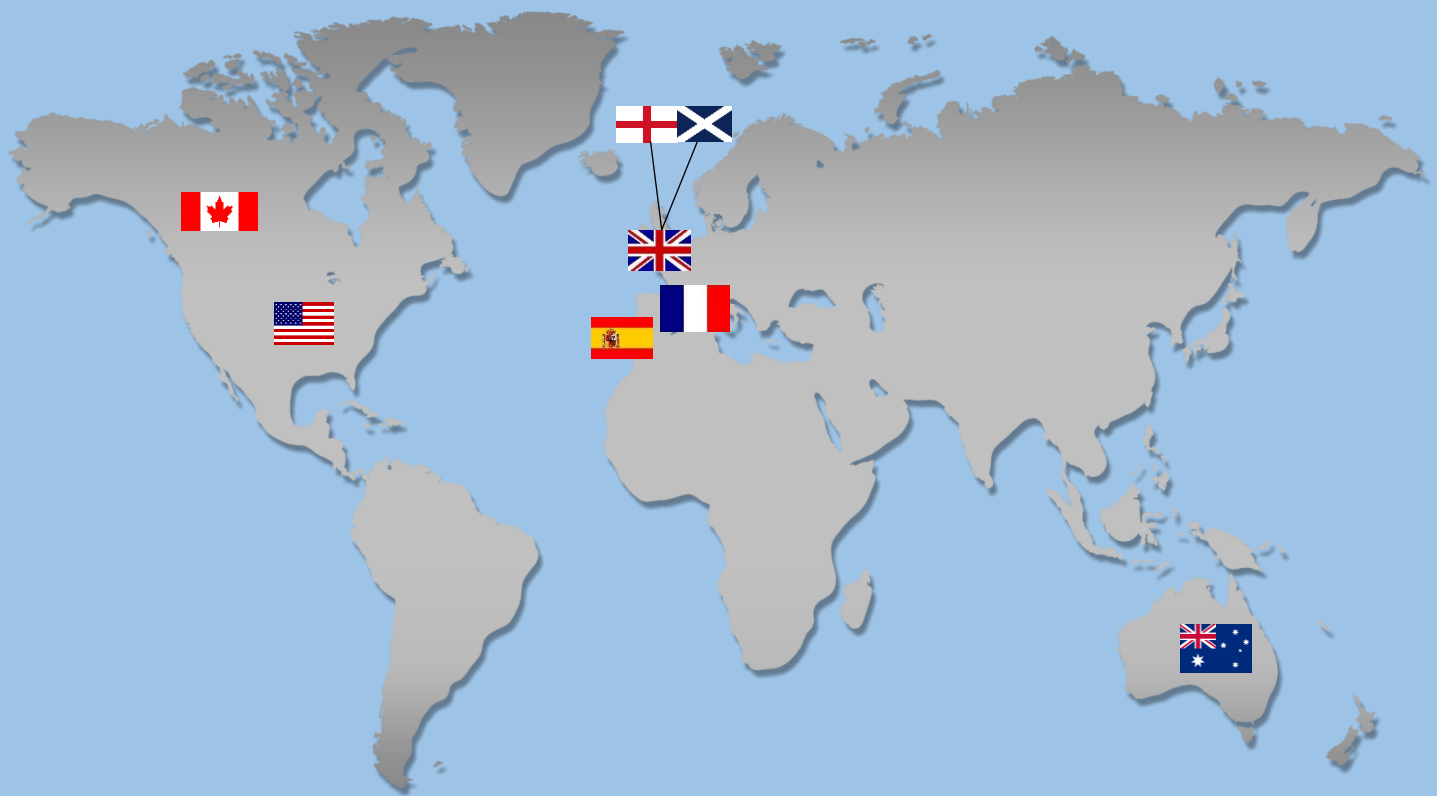
Communicate with me directly and clearly; make it easy for me to talk to someone about the research when I have questions or ideas.

Help others by sharing our stories; the things that worked and the things that didn't.



Go to www.rcpch.ac.uk/cyp-research-charter for more information about external resources and useful links to support child health research.

iCAN Around the World



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