



ICAN

International Children's Advisory Network

OVERVIEW

www.iCAN.health #iCANMakeADifference



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What is iCAN?

Empowering Pediatric Patients Worldwide

Started in 2014, the International Children's Advisory Network, Inc. (iCAN) is a non-profit 501(c)3 with its headquarters located in Atlanta, Georgia. With 47 chapters on four continents, our members are youth between the ages of ~8 and 18 who are living with chronic, rare, or complex medical conditions. We also welcome children without medical conditions, since they represent the voice of the child who receives a diagnosis later in life.

iCAN gives these youth the platform to share with industry, researchers, and regulators what it's like to live with a medical condition, device, drug, or just what it's like to be a kid. They comment on the design, implementation, and evaluation of research studies, clinical trials, and development of devices and drugs, educational materials, and marketing materials. They also share their stories at conferences and with industry, and some youth conduct their own research.

iCAN focuses on fostering innovation in healthcare, research, and policy by ensuring that the unique perspectives and needs of children are integrated into pediatric healthcare discussions.



What is iCAN? Cont.

At the heart of every successful organization lies an amazing group of dedicated, caring, and valued volunteers and community partners. iCAN's community partners amplify our reach and help us provide more opportunities for our kids to be heard. iCAN is proud to be a partner of the FDA through their Patient and Caregiver Connection and the new Total Product Life Cycle Advisory Program (TAP), which provides patients and caregivers with opportunities to share their experiences living with a condition, device, or drug.

Through our Young Professionals Network (YPN) Program, we also engage young adults aged 19 and up who were part of our original program as well as other young adults interested in healthcare careers. Our Parent and Siblings programs provide similar opportunities for the whole family. The remainder of this document describes these programs, as well as the iCAN Youth Council, iCAN's Seal of Approval, the annual iCAN Summit, *Ask the Experts*, the Duke Clinical Research Institute (DCRI) and iCAN Anthology for kids in clinical trials, the iCAN Curriculum, iCAN Partners, iCAN Leadership, and ways to contact iCAN for additional information. Please follow us on social media or visit our website for more information.

#iCANMakeADifference
#EmpoweringYouthWorldwide
#EveryChildEverywhere
#KidReviewedKidApproved

www.iCAN.health

Follow us on social media!

Email contactus@icanresearch.org
for any questions!



KIDS Chapter – Overview

What is a KIDS Chapter?

Every iCAN Chapter is a unique, dynamic organization housed within the global iCAN umbrella. iCAN allows each chapter to select activities that are of interest to its members in order to cultivate learning that is unique to them. iCAN has many suggestions for chapter activities on its website and also encourages participating in our activities such as sponsor surveys, focus groups, the iCAN curriculum, *Ask the Experts*, and the annual iCAN Summit. iCAN also provides opportunities to speak at various conferences (FDA, CDC, iCAN Summit, etc.). Youth members are able to engage directly with and make a significant impact in the extended world of healthcare.

Tips for a Successful KIDS Chapter

Meet at Least Once a Month

- In order to keep members active and engaged, it is important to meet on a regular basis either virtually, in person, or hybrid. It is up to you and your members how you would like to meet! iCAN recommends up to two hours per meeting. Some chapters choose to take the summer months off.

Recruit Youth Members

- KIDS chapters are often affiliated with a pediatric hospital, through the Child Life Specialist or Teen Advisory Board, a school as a club or friends at school, or another nonprofit that serves a similar population of youth as iCAN. iCAN also has a virtual chapter, KIDS Virtual, for those who do not live near a chapter, are unable to attend meetings in

Secure Funding

- Starting or joining a chapter is FREE! However, some chapters like to provide food and drinks at meetings. Often the costs will be covered by the hospital, or the chapter may decide to do a fundraiser to cover these costs. Fundraisers may also be used to help cover the costs of attending the summit, as our stipends will only cover a select number of members per chapter.

Elect Youth Officers

- iCAN encourages youth leadership! By structuring your chapter with youth leaders, you are giving a kid an opportunity to shine and participate in iCAN Learning.



KIDS Chapter - Details

iCAN's members are kids. Chapters include youth (~age 8-18), and families who are focused on understanding, communicating and improving medicine, research, and innovation for children. About 90% of our members have some sort of medical diagnosis, anything from something common like asthma to the rarest of the rare diseases. 10% of our youth have no medical diagnosis, but have an interest in healthcare or STEAM or are a friend or sibling.



Example KIDS Chapter Activities

All iCAN activities are voluntary. iCAN never makes a child share something that they are not ready to share. iCAN activities are designed to provide a safe environment with other youth to learn about how sharing your story can impact the health of children worldwide, so that they may one-day feel comfortable to do so.

- Organize field trips
- Explore local universities, research facilities, and hospitals
- Invite a Guest Speaker
- Attend the monthly Ask the Experts webinar
- Complete iCAN's Curriculum
- Participate in sponsor surveys, focus groups, and projects
- Conduct community service activities (iCAN can provide volunteer letters, if needed, for members)
- Raising money to support iCAN
- Writing thank you cards for hospital staff
- Running a donation drive, eg: wacky socks, Christmas presents, etc.



The Youth Council guides the decision-making process of iCAN and ensures that the organization reflects the voices of its youth members. Members of the Youth Council share their experiences in health care and research with medical providers, companies, hospitals, and iCAN. Their voices are used to impact and improve pediatric experiences in healthcare and research. Council members are the guiding voice of iCAN and influence the work that the organization does.

Pediatric voices are necessary to improve pediatric research and healthcare. Cross-collaboration with youth and pediatric medical professionals will enable better care and understanding on both parties' sides. The Youth Council provides valuable insights to iCAN and allows the organization to make informed decisions about its events and programming all of which directly impact pediatric patients.

The council meets on Zoom every other month for an hour. Additionally, members of the council are sent materials monthly to work on. Active participation in the council requires at most 2 hours of work a month.

To become part of this influential council, visit <https://www.icanresearch.org/ican-youth-council>.





iCAN is committed to empowering young people to become future leaders, researchers, innovators, advocates, and clinicians in a patient-centric model of healthcare. Therefore, iCAN's Young Adult Professional Program is designed for both youth, ages ~19-29, who have "graduated" from the original iCAN program and who want to remain a part of iCAN to continue to share their expertise and other young adults considering, or in the early stages of, a career in healthcare.

iCAN provides these Young Adult Professionals career networking opportunities, internships, and research opportunities to help develop skills, such as leadership and communication.

By connecting young people with their peers and the larger iCAN community, the Young Adult Professional Program empowers these future healthcare leaders to reach their full potential in their careers and know that the patient should be at the center of everything they do.

Email contactus@icanresearch.org to join today!

Parent Chapter



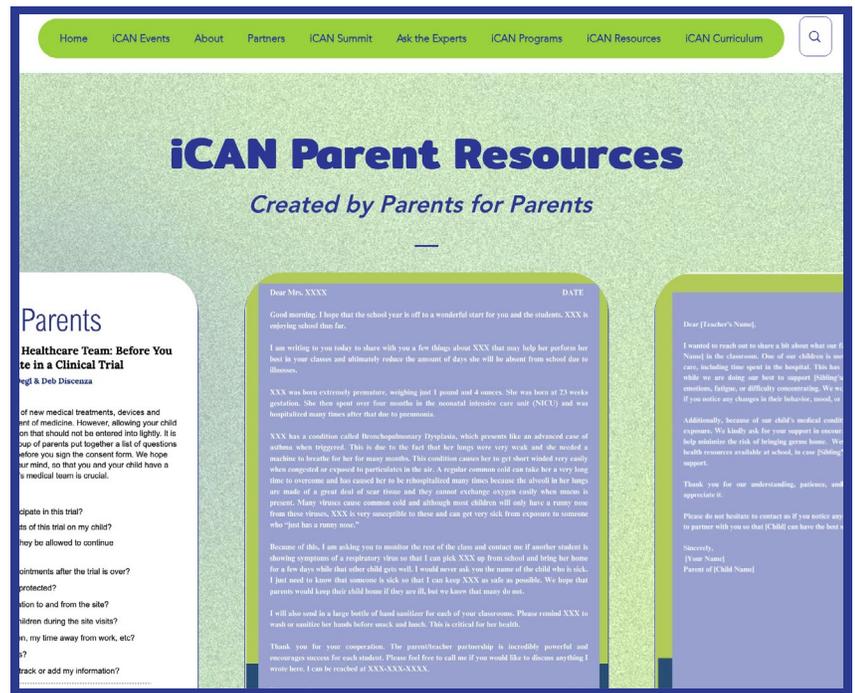
Jennifer Degl, Co-Chair

The iCAN Parent Council is an engaged group of parents and caregivers of ANY child, regardless of age or diagnosis, who have a medical journey to share, especially those whose child is unable to communicate themselves.

They are asked to share their stories through surveys and focus groups and speak at events, as well as creating best practices documents on topics such as, "When/how to approach a family about a clinical trial."

iCAN is looking for parents or caregivers who:

- Are committed to the iCAN Mission
- Support the youth voice
- Have their own experiences to share
- Want to support pediatric healthcare excellence
- Are engaged throughout their local community, nationally, and globally
- Are seeking opportunities through project participation, speaking experience, networking, and educational opportunities



Learn more at:
www.icanresearch.org/parents-families

Siblings Chapter

The iCAN Sibling Chapter serves as a platform that both celebrates and acknowledges the indispensable role of siblings within families, particularly within the realm of pediatric care. It provides a formal and structured avenue for siblings to share their own unique experiences and narratives, thereby giving due recognition to their valuable voices and distinctive perspectives.

Siblings Chapter Purposes:

- Acknowledging the Roles of Siblings
 - Sometimes referred to as "keystones," siblings are regarded as indispensable components of the family unit, highlighting their pivotal role.
- Establishing a platform for Siblings
 - The iCAN Siblings Chapter was designed as a platform for siblings to articulate their own unique narratives and experiences and meet others with similar experiences.
- Advocating for Recognition within Pediatric Care
 - The Sibling Chapter advocates for the recognition of siblings' roles within the realm of pediatric care.
- Promoting Awareness and Understanding
 - The chapter endeavors to draw attention to the unique challenges, joys, and invaluable contributions of siblings in the family unit that is managing medical diagnoses and treatments.

For individuals interested in affiliating with the Siblings Chapter detailed information and resources are available on our website at <https://www.ican-research.org/siblings-chapter>.



Seal of Approval



Seal of Approval Program

iCAN is a resource available to any organization, company, or group that seeks the input of children and families for their projects and products. When you work with iCAN, you know that your product is age appropriate, kid-friendly, and has key insights from our youth experts.

Kid Reviewed. Kid Approved.

To show everyone that you cared enough to include children in the development of your product, you can add the iCAN Seal of Approval! After our kids review your material, and you make any recommended changes, understanding that some changes might not be legally possible, your product can proudly display the iCAN Seal Approval.

What can be iCAN approved?

Clinical trial protocols, consent, assent, educational material, medical devices, videos, and more.

When your product is iCAN approved, you'll know it's age appropriate and favorably accepted by youth. The more you know, the better your product will be.

Choose iCAN. Three Easy Steps.



Kids review your material.

You make any kid-recommended changes.



Your product can proudly display the iCAN Seal of Approval.*

Disclaimer of Liability: The iCAN Seal of Approval does not endorse nor approve legal, ethical, religious, or political statements, art, or video, nor other subject matter deemed controversial by iCAN. iCAN expressly disclaims any legal liability or responsibility to any and all use of the iCAN Seal of Approval (past, present, or future) including, without limitation, the company, its Board of Directors, and any special committee of board of directors.

Required Acknowledgement: The iCAN Seal of Approval is a trademark of the International Children's Advisory Network, Inc and signifies that this product has been reviewed by youth to be youth friendly. It does not reflect an endorsement of this clinical product or clinical trial.

To discuss how to give your product the iCAN Seal of Approval, please email us at contactus@icanresearch.org

The Summit

Bringing Youth Together From Around the World

Every summer, iCAN brings members, as well as siblings, young adults, and parents from all of our chapters together for the innovative and exciting iCAN Research & Advocacy Summit, where interactive activities and sessions are made for the youth with guidance from the youth.

Since 2014, iCAN has hosted the iCAN Summit, alternating sites between the US and EU, where one of our chapters is located. Averaging around 150-175 attendees, the Summit provides industry and researchers in medicine, health, and technology the unique and enlightening opportunity of working with young people from around the world to improve the health of all children who are medically complex, have chronic medical conditions, and/or rare disease. This unique annual event provides our youth members with an invaluable opportunity to learn from one another and to network with leading professionals in healthcare from around the globe. In turn, the iCAN Summit offers the scientific community an opportunity to engage directly with children and parents, to learn from their expertise at living with a diagnosis, medication, device, or just what it's like to be a kid to improve their healthcare interactions and developing products intended for pediatric patients in research, medicine, and innovation.

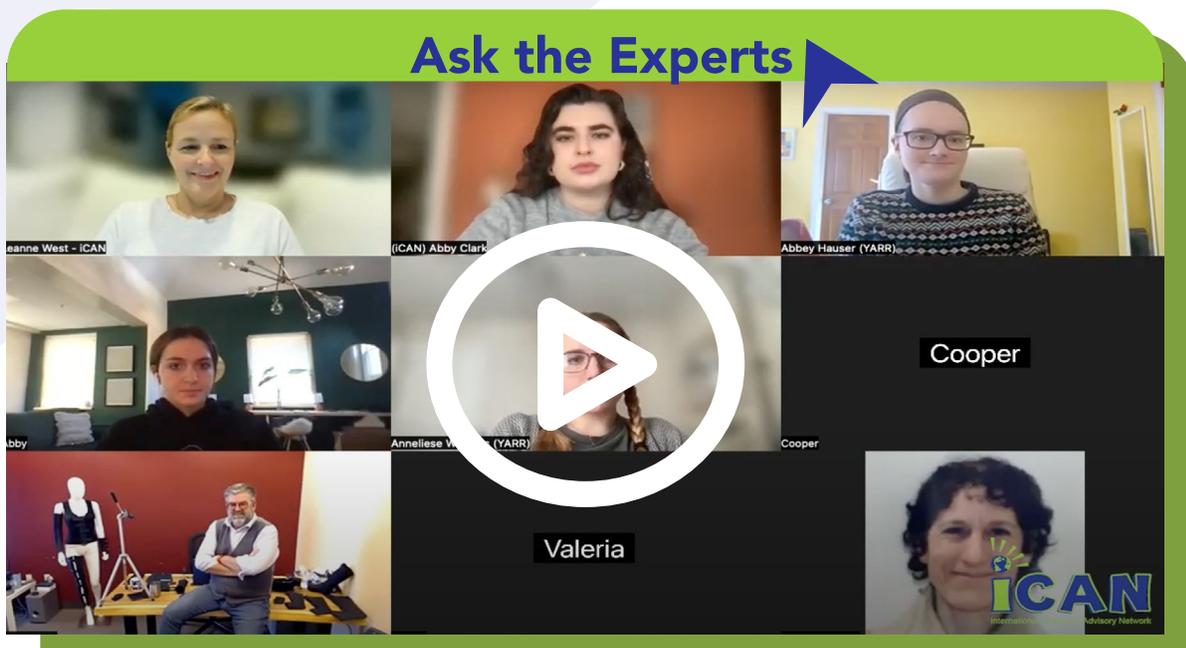
The 2026 Summit will be in person, at Barretstown in Co. Kildare, Ireland July 12-17!



Youth Members 2023 Summit

Ask the Experts

Presented by iCAN, *Ask the Experts* is a monthly, interactive, online web series designed to provide a casual platform where iCAN youth members and the broader iCAN community can engage and seek insights on a wide range of topics. This series brings together youth and professionals from diverse backgrounds, including medical practitioners, researchers, advocates, regulatory authorities, and more. Sometimes the Experts are the professionals; othertimes, the Experts are our youth.



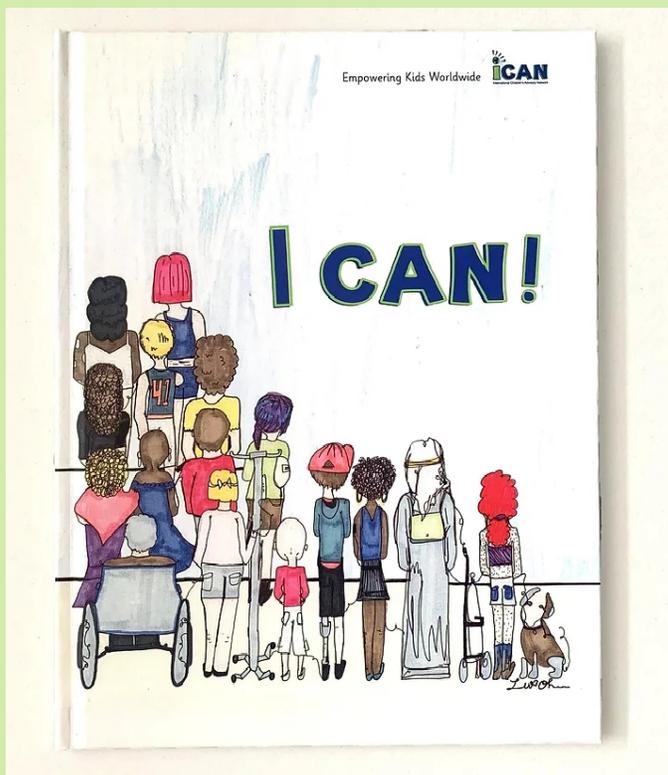
Each session revolves around subjects selected by iCAN's youth members, reflecting their curiosity and desire to delve deeper into various fields. Previous sessions have explored topics like Transition of Care, Mental Health, the Role of Artificial Intelligence in Healthcare, How to Be an Effective Advocate, Turning Adversity into Strength, and Careers in Healthcare.

Please reach out to us via email at contactus@icanresearch.org or visit our website at www.icanresearch.org-ask-the-experts for more information on how to participate. You can also explore the archive of past "Ask the Experts" sessions by visiting the iCAN YouTube channel to view the engaging discussions and valuable knowledge shared in previous sessions.

iCAN Book and Anthology

iCAN is a vibrant community filled with young individuals possessing diverse creative talents, ranging from writing and drawing to jewelry making. Our mission is to fully showcase the multifaceted talents of iCAN youth members, providing as many young individuals as possible with opportunities for growth and meaningful engagement in the healthcare realm. The iCAN Book and Anthology represent collaborative projects where children have shared their experiences and insights for others.

iCAN Book, Titled iCAN!



iCAN! is a book authored and illustrated by iCAN members hailing from various corners of the globe. This book tells the reader about things that iCAN youth were told they couldn't do, but they can! These personal stories of patients who have gone beyond what was thought possible are beautifully illustrated by two of our youth in KIDS Bari, with the cover design winning the Rare Artist Award from the EveryLife Foundation. With every \$25 donation to iCAN, the iCAN! book is shipped to the generous contributor.

"The book is a must-read for any parent and any child who may be working through a condition. The big takeaway - we all have challenges, but together we can make a huge difference in care and research for kids everywhere."

iCAN Curriculum

Pathways to Success

The iCAN Curriculum is a comprehensive program designed to empower advocates of all ages with the knowledge, skills, and confidence to actively engage in promoting causes and creating positive change in a patient-centered healthcare model. Rooted in the belief that anyone can make a difference, this curriculum offers a structured pathway for personal growth and empowerment. New modules are introduced every year at the Annual Summit.

Curriculum Structure

- Customized Content
 - The curriculum takes into account the distinct requirements and competencies of advocates at various life stages and abilities. Age-specific activities in each module, such as coloring pages for the youngest to youth-led projects for the oldest, ensure that participants receive content and tasks tailored for them.
- Adaptable Learning Options
 - Whether one's preference is for independent study or group participation, this curriculum accommodates both approaches. Youth Members can complete activities at their own pace or engage with fellow students during chapter meetings.
- Certification Awards
 - As youth members progress through the curriculum, they have the opportunity to earn formal recognition in the form of Certificates. These Certificates, issued by iCAN, signify the successful completion of module activities within specific age groups and categories.

Getting Started!

- **Select Your Age Group:** Choose the appropriate age group to access content tailored to your developmental stage.
- **Choose Your Curriculum:** Decide which categories align with your interests and goals.
- **Complete Activities:** Engage with the curriculum's activities, whether individually or as part of your local iCAN chapter.

iCAN Curriculum Cont.

Curriculum Categories

1. Telling Your Story
 - A. Advocacy frequently commences with personal narratives. This category provides participants with a structured approach to harnessing the power of storytelling, enabling them to effectively communicate their experiences and inspire positive change. It also provides the practice of speaking in front of audiences in a low-stress environment.
2. Understanding Clinical Trials
 - A. Advocates gain insight into the pivotal role of medical research and clinical trials in healthcare. This module educates youth on what a clinical trial is and gives them essential knowledge in the event they may consider participating in a trial. This module also equips participants with the knowledge and skills to advocate for informed choices in healthcare, emphasizing the importance of research in advancing medical science.
3. Becoming a Leader
 - A. Leadership stands as a cornerstone of advocacy with impact. Just by being a member of iCAN, youth have let us know they are emerging leaders. In this category, participants delve into the principles of leadership, acquiring essential skills to initiate and drive positive change within their communities. Videos of internationally-known leaders in the healthcare sector round out this module. Here you'll discover a curated collection of video clips featuring profound insights from youth and globally-recognized leaders in healthcare. These clips provide a unique opportunity to tap into the collective wisdom of trailblazers who have left an indelible mark on the healthcare landscape.
4. Careers in Healthcare
 - A. Recognizing that many iCAN members develop their interest in careers in healthcare due to personal medical experiences, this module aims to nurture their passion and curiosity, guiding them toward fulfilling career choices as they progress through different stages of growth and helping them understand that there are many ways to be involved in healthcare beyond being a doctor or nurse. Whether you are interested in a typical medical career, public health, biomedical engineering, research, regulatory sciences, drug development, or advocacy, this module explores various career paths.

iCAN Partners

At the core of every thriving organization lies an exceptional group of dedicated, compassionate, and generous volunteers, donors, and like-minded partners. iCAN's resilience and effectiveness are deeply rooted in the support and commitment of these individuals who play a crucial role in guiding our young participants as they learn to express their voices and expertise on local, regional, and global stages.

We actively collaborate with a diverse community of organizations, forging partnerships that aim to amplify the voices of young individuals and facilitate improved access to advancements in treatments, research, technology, science, and innovation. Our esteemed Community and Sponsoring Partners share our unwavering dedication to enhancing the health and well-being of pediatric patients worldwide. Together, these partnerships extend our reach and provide additional avenues for our youth to make their voices heard.

The VALUE of iCAN: From Our Sponsors

To me, iCAN has been incredibly powerful, inspiring, and humbling. It gave me the ability to speak to the smart, engaged kids who are battling various illnesses.

“

I can think of no better way to truly be patient centric and centered.

”

Antoniou Fantana, Advisor-GPS Analytics ,
Epidemiology-GPS , Eli Lilly and Company

Having the opportunity to watch youth and their parents, learn and grow in their knowledge of clinical research and how they can impact outcomes was an amazing experience. The passion that they have to improve clinical care for children is inspiring, and I believe our future is in great hands.

“

”

Phyllis Kennel, Pediatric Trials Network

We obtained such rich and valuable input from all interview participants!

“

Jessica Kofi & Nicole Goedhart,
PARA-DIGM International Liaison Group

”

iCAN Partners Cont.

As a partner of iCAN Research, you become an integral part of our global consortium, linking with youth, families, caregivers, healthcare providers, researchers, and pediatric support organizations worldwide. iCAN's distinctive approach unites stakeholders from across the globe, fostering collaborative efforts to elevate the voice of pediatric patients on a global scale.

We extend our heartfelt gratitude to our community partners and volunteers, who, through their unwavering dedication, uplift and empower pediatric patients. Your support is instrumental in our mission to advocate for and amplify the voices of young individuals in the healthcare community. We would like to express our appreciation to the following organizations for their partnership and commitment to our cause:

Thank You from the Entire iCAN Team!

Titan



Warrior



Steward



Guardian



Ally



The Joe Kiani Foundation

Friend



PERRY ELLIS INTERNATIONAL

In loving memory of
Kate Palermo



In loving memory of
Emory Speer Nesbit



iCAN's Board of Directors



**Charles Thompson,
Founder and Chairman**

Paragraph:Charlie is the Founder of the International Children's Advisory Network and has been the Chairman of the Board of Directors since its inception. In addition, Charlie is the Founder and Global Lead for the Pfizer Pediatric Center of Excellence. Throughout his 25+ year Pfizer career, Charlie has taken on diverse roles in clinical development, clinical safety/risk management, and medical affairs.

He is also the Founder and Past Chair of the American Academy of Pediatrics Section on Advances in Therapeutics and Technology and a former member of the Board of Directors for the Hezekiah Beardsley Connecticut Chapter of the American Academy of Pediatrics. Charlie served multiple terms as a governor-appointed member of the Connecticut Pharmaceutical and Therapeutics committee and served on the State of Connecticut Immunization Task Force following an appointment by the Speaker of the House.

Charlie is a board-certified pediatrician who earned his M.D. at the University of Connecticut School of Medicine and completed his pediatric residency at Connecticut Children's Medical Center in Hartford. He is a Clinical Instructor of Pediatrics at the University of Connecticut School of Medicine and served as a member of the medical staff at Connecticut Children's Medical Center. Charlie and his wife, Heather, have four children and a grandchild.

Leanne West holds the position of Pediatric Innovation Catalyst at the Global Center for Medical Innovation and serves as the Chief Engineer of Pediatric Technology at Georgia Tech. In her capacity, she acts as the technical intermediary between Georgia Tech and children's hospitals, with a focus on identifying unmet clinical needs and developing appropriate solutions. She serves as the President of the International Children's Advisory Network (iCAN), a nonprofit organization dedicated to promoting the significance of the pediatric patient experience and input in the realm of medical research and development.

iCAN is actively engaged as a partner in the FDA CDRH Patient and Caregiver Connection and the Total Product Life Cycle Advisory Program. Leanne is an esteemed member of several distinguished committees and boards, including the International Society for Pediatric Innovation Executive Team, the Patient-Focused Medicines Development Board, the steering committees for both the Pediatric Trial Network (PTN) and the Multi-Regional Clinical Trials (MRCT) Center of Brigham and Women's Hospital and Harvard (MRCT).

Additionally, she contributes her expertise as a member of the Medical Device Innovation Consortium (MDIC) Patient Preference Information Committee and the MDIC National Evaluation System for Health Technology Coordinating Center (NESTcc) governing committee. Her involvement extends to the Technology Association of Georgia Digital Health Board and the Georgia Technology Authority Board. Leanne's remarkable contributions have been acknowledged in her recognition as Women in Technology's Woman of the Year in 2014. Notably, she brings a unique perspective to her work, as she herself is a patient contending with two rare diseases. In recognition of her insights and experience, she serves on the Foundation for Sarcoidosis Research Patient Advisory Council.



**Leanne West,
President**



**Chester J. Koh,
Secretary**

Paragraph: Dr. Chester Koh is a pediatric urologist and “physicianeer” at Texas Children’s Hospital (TCH), and Professor of Urology, Pediatrics, and OB/GYN at Baylor College of Medicine (BCM). He also holds adjunct titles at UT Houston and in the Rice University Department of Bioengineering as well as serves as an External Advisory Board Member for the Texas A&M Department of Biomedical Engineering and a member of the TMC Venture Fund Investment Advisory Committee. Dr. Koh received his B.S. with Honors in Mechanical Engineering from UC Berkeley, his MD from Tufts University School of Medicine, and completed his urology residency at USC, and his pediatric urology fellowship at Children’s Hospital Boston / Harvard Medical School, as well as his MBA from the University of Illinois.

His clinical area of expertise is in minimally invasive surgery in children for pediatric urologic conditions, and especially with robotic surgery and the device needs in this area. He is also the founder, contact principal investigator, and executive director of the Southwest National Pediatric Device Innovation Consortium (SWPDC) which is a FDA P50 grant-supported multi-institutional consortium that includes TCH and BCM, Texas A&M, Rice, University of Houston, and University of Minnesota. SWPDC is dedicated to improving children’s health by supporting pediatric device innovators in creating novel pediatric medical devices with local, regional, and national institutional and innovation partners.

Jon Haygood serves as the Assistant Treasurer for Atlanta-based Southern Company (NYSE:SO), a leading U.S. energy company serving 9 million customers with clean, safe, reliable, and affordable electricity and natural gas. He is currently serving or has served on the board of directors for multiple small start-up companies in treasury/financial advisory roles. Jon holds a bachelor’s degree in Industrial Engineering from Georgia Tech and is married to his high school sweetheart Emily. Together they have two grown sons, Jake and Sam, who were both involved in KIDS Georgia and iCAN.

Jon began involvement with iCAN and KIDS Georgia in 2014 as a parent, has attended all but one research and advocacy summits with his family, and has personally seen the benefits of sharing and hearing experiences of other parents and kids.

iCAN has created educational, social, and professional opportunities for his family that are challenging to find outside of the organization. Jon also sees the immense impact the organization can have on the future of pediatric research and medicine and endeavors to ensure iCAN remains on strong financial footing well into the future.



**Jon Haygood,
Treasurer**

Contact

For Additional Information

International Children's Advisory Network, Inc.
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You can create/join a chapter through our website:

www.icanresearch.org

Contact

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- finance@icanresearch.org

Sabina Schmidt Goldstein-Becerra, Executive Director

- sabina@icanresearch.org

Abby Clark, Director of Operations

abbyclark@icanresearch.org

General Email

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See iCAN Research on Social Media too!

- Twitter: <https://twitter.com/iCANResearch>
- LinkedIn: <https://www.linkedin.com/company/icanresearch/>
- Instagram: <https://www.instagram.com/icanresearch/>
- Facebook: <https://www.facebook.com/icanresearch/>
- Youtube: <https://www.youtube.com/@icanresearch8679/>

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