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iCAN

International Children's Advisory Network

Chapter Startup Guide

www.iCAN.health
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iCAN Overview

Who We Are

A global consortium of KIDS Chapters working together to provide a voice for children and families in pediatric medicine through synergy, communication, and collaboration.

Our Focus

To improve pediatric healthcare by providing a platform for children and their families to take ownership of their health and to share meaningful input in medicine, research, science, advocacy, and innovation.

Worldwide Reach

Established in 2014, our iCAN network has grown and continues to grow to include a robust team of expert youth leaders from around the world, including...

- 34 Chapters (including 1 Virtual)
- 14 Countries
- 4 Continents

Types of Chapters

KIDS (Kids and Families Impacting Disease through Science) Chapters (8-18), Young Adult Professionals (19-29), Siblings (8+), and Parents (of a child of any age)

- Local affiliation with children's hospitals, other nonprofits, and schools.
- Designed to foster a greater worldwide voice.

Chapter Network Outline

Starting a chapter and membership is **FREE!**

Our chapters are comprised of children, adolescents, and families who are focused on understanding, communicating and improving medicine, research, and innovation for children. iCAN is a collaboration between children's hospitals, other nonprofits with similar missions, as well as elementary, middle, and high schools across the globe.

iCAN youth membership consists of children who are between the ages of ~8 to 18 who have any or multiple of the following:

- Past clinical experience
- Experience using hospital services
- Chronic and/or rare medical conditions
- Take medication or use a medical device regularly
- No medical diagnosis but an interest in medicine and/or research

iCAN objectives are to...

- **Learn, teach, and advocate** for medicine, research, and innovation improving the health and well-being of children through our unique iCAN educational curriculum.
- **Engage** in the process through projects and consultation activities with industry, researchers, hospitals, and other nonprofits.
- **Provide** input on research ideas, innovative solutions, unmet pediatric needs, and priorities.
- **Contribute** to the design and implementation of clinical research studies for children.
- **Serve** as a critical voice for children and families in the medical, research, and innovation process through participation in iCAN global events, including our annual summit.

Global Membership

iCAN Chapters are unique to their local medical community, hospital, and clinical environment. Our goal is to bring a variety of cultural and learning environments together so that iCAN represents an active, diverse, and engaged global expert team. Our global pediatric diversity includes the following world-wide iCAN Chapter locations, with further growth and development planned throughout the upcoming years.

North America

KIDS Connecticut
KIDS Florida
KIDS Canada Francais
KIDS Michigan
KIDS Bay Area
KIDS Georgia
KIDS Illinois
KIDS Kansas City
KIDS Central Ohio
KIDS CAN
KIDS Vancouver
KIDS Los Angeles
KIDS Houston
KIDS Hope for Henry
KIDS Children's National
KIDS UP (Upper-Penninsula of Michigan)
KIDS CHOC-Rady
KIDS Nebraska
KIDS Childhood Cancer
KIDS Women in Technology (WIT)

Europe

KIDS Scotland
KIDS Barcelona
KIDS Bari
KIDS France
KIDS Germany
KIDS Albania
KIDS Moorefields Eye (England)
KIDS Generation R (England)

Africa

KIDS Uganda
KIDS DRC
KIDS Cameroon

Asia

KIDS Tokyo

Special Interest

KIDS Virtual
Young Adult Professionals
KIDS Siblings
Parents Council



KIDS Chapter - Overview

What is a KIDS Chapter?

Every iCAN Chapter is an 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 them. However, iCAN has many suggestions of chapter activities on its website, and we also encourage participating in our activities such as sponsor surveys and/or focus groups, the iCAN curriculum, as well as Ask the Experts. Outside of chapter meetings, 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 healthcare world.

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.

How to Recruit Youth Members

- Our youth are often recruited through the Child Life Specialist or Teen Advisory Board at hospitals, through a club or friends at school, or from membership in another nonprofit.

Securing Funding

- Although some chapters run on a \$0 budget, others 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.

KIDS Chapter - Details

Attend the iCAN Annual Research and Advocacy Summit

The iCAN Research & Advocacy Summit is iCAN's yearly event, which brings members together from all iCAN KIDS Chapters to engage with one another, as well as industry, regulator, and healthcare professionals. This week long event is a life-changing experience. iCAN provides a stipend to each chapter to help offset costs of bringing youth members to the Summit. Participation counts; iCAN wants to reward our most active chapters. The local chapter selects which members receive the stipend. Additionally, iCAN provides two scholarship opportunities to youth members through a competitive process.

Example KIDS Chapter Activities

- Organize field trips
 - Explore local universities, research facilities, and hospitals
- Invite a Guest Speaker
- Be involved in 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, ex: wacky socks, christmas presents, etc.
- Elect Youth Leaders/Officers or develop a team hierarchy
 - iCAN encourages youth leadership, and by structuring your chapter with youth leaders, you are giving a kid an opportunity to shine
- Participate in iCAN Learning Activities
 - Attending the monthly Ask the Experts series
 - Completing iCAN's Curriculum
 - Participating in sponsored survey's, focus groups, and projects

Youth Member Guidelines

General Guidelines

- iCAN youth members are recommended to be between the ages of 8-18 years old; however, this guideline is flexible and up to each individual chapter.
- iCAN youth members are affiliated with a local or virtual chapter, and as such, are held accountable to the stated institutional, behavioral, ethical, and moral rules of the chapter.
- iCAN youth members are encouraged to contribute to at least one (or more) iCAN focus group/research project yearly; however, all activities are voluntary and based on the interest of the child. While not required, iCAN asks that youth members participate in all sponsor activities, as participation is a determining factor in stipends for the conference.
- iCAN youth members are eligible and may apply to be a part of the Youth Council for additional activities. Other committees and leadership opportunities also occur on an annual basis.

Youth Council

The iCAN Youth Council acts as the North Star for iCAN and its mission. Youth Council members are seen as leaders in iCAN. iCAN turns to the Youth Council members whenever we want advice on things such as if an activity will be of interest, if media is appealing to youth, and when we want to confirm topics of interest for Ask the Experts and the Summit. Council members are also given special opportunities to respond to sponsor activities that do not go out to the entire iCAN community. Being a member of the Youth Council is a leadership role within iCAN for all ages. We like our Youth Council to reflect the demographics of iCAN as a whole.

Join the Youth Council at www.icanresearch.org/councils-committees.

Additionally, iCAN Youth Members, ages 18+ may be eligible to join the iCAN Young Adult Professionals Group. See page __.

Young Adult Professionals

As our iCAN youth members have grown and graduated high school, we noticed the need to have a group dedicated to those young adults who would like to continue to participate with iCAN. Thus, iCAN developed the Young Adult Professionals group to meet that need. iCAN offers the Young Adult Professional members opportunities in mentorship, leadership, and professional enrichment. Our goal is to provide avenues of professional growth, such as internships and speaking opportunities, as well as leadership roles within the iCAN community.

- Examples of opportunities iCAN Young Adult Professionals have participated in include interning with the Pediatric Trials Network (PTN) and conducting research with a children's hospital in Rome about social media and trusted health information.

iCAN Young Adult Professionals Are...

- iCAN members that are between ages 18 - 29, currently in college, or are just starting out in their professional careers.
- Diagnosed with a chronic or rare disease, but it is not necessary to be a part of the group
- Committed to the iCAN Mission.
- Creating and participating in opportunities to support pediatric healthcare excellence.
- Engaged throughout their local community, nationally, and globally.
- Seeking growth through mentorship, internships, project participation, speaking experience, networking, and educational and career growth opportunities.

Chapter Leader Responsibilities

Responsibilities of the Chapter Leader

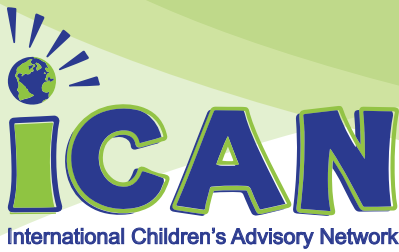
- Recruit new members
- Frequently update member roster (located on google share drive – contact iCAN Coordinator for link)
- Communicate with members and co-leaders with updates (email, facebook, etc.) regarding iCAN projects, as well as local chapter projects
- Communicate frequently with iCAN Coordinator to help facilitate network-wide initiatives among your local chapter
- Participate as a member on a council or committee (optional)
- Monitor achievement towards iCAN Educational Curriculum
- Investigate and network to secure group activities and projects that pertain to pediatric medicine, health, advocacy, research, and innovation (to be worked on during monthly meetings)
- Ensure that all new members have received a basic orientation to provide a foundation of knowledge in research, clinical trials, etc. (create these materials to suit the needs and focus of your local chapter)
- Involve parents to help facilitate certain aspects of meetings (food, transportation, fundraising, etc.) Parent Leaders also recommended to help delegate tasks
- Secure meeting locations

Steps to Starting a KIDS Chapter

The process for starting up a new iCAN chapter has quite a bit of variation, just as the nature of each team and partnering hospital, school, or other nonprofit is so different from one to the other. This just means that there is an abundance of flexibility when it comes to starting a KIDS Chapter! iCAN does not interfere with current activities, we only provide additional opportunities for growth and learning. Remember, chapters may be started at any time, and there is NO COST to create a chapter within iCAN. All activities provided by iCAN are FREE. Chapters are for Every Kid. Every Where.

6 Easy Steps to Establish an iCAN Chapter

- 1 Identify an adult Team Leader to act as meeting facilitator. This is approximately 1-2 adults who preferably have experience within the medical or research fields and/or have a passion for championing youth within medicine. Send chapter leadership names, email, and phone numbers to iCAN Coordinator.
- 2 Although unnecessary, it can be helpful to establish a partner organization. This could be a children's hospital, other nonprofit, or a school. This will likely be the location(s) of monthly meetings with youth members.
- 3 Determine the structure of the team. The options are endless.
 - Will this group be solely kids from the partner hospital(s),
 - Pediatric patients from the entire region (including those from other hospitals),
 - Or a mixture of patients and students interested in pursuing careers in medicine or research?
- 4 Create chapter constitution/bylaws. Most hospitals require something of this nature in order to approve funding/support/partnership. Sample by-laws are included within this packet.
- 5 Complete the "Establishment of a New Chapter Agreement" form. (See page 10)
- 6 Once established through iCAN, chapter leadership will begin to receive monthly and/or weekly email updates on projects and opportunities for youth members to share their voices.



International Children's Advisory Network, Inc. (iCAN)
317 Faw Lane,
Marietta, GA 30060

We are pleased you are interested in establishing a chapter with the International Children's Advisory Network, Inc. (iCAN). iCAN is a non-profit, worldwide consortium of Kids and Families Impacting Disease through Science (KIDS) chapters working together to provide a voice for children and families in medicine, research, science, and innovation through synergy, communication, and collaboration.

iCAN Chapter Agreement.

I. Date of iCAN Chapter Establishment:

Effective from this date, _____, this document outlines the relationship and expectations of conduct between KIDS _____ (New Chapter Name), its associated members, and the International Children's Advisory Network Inc.

II. Role of iCAN Chapter:

iCAN Chapters (supported by adult team leaders, youth members, and parents/caregivers) will work both locally in their community and together with the greater iCAN community to have a global impact. Through our iCAN Chapters, youth council, young adult professionals, siblings chapter, and parents council, we work to address the needs in pediatric clinical research and healthcare for patients around the globe. Our goal through each chapter is to educate the world about the importance of children's involvement in healthcare. iCAN does this by providing chapter members with opportunities to engage in sponsored survey and focus group activities, in presenting and conducting research, in speaking at conferences (such as the FDA, CDC, and the annual iCAN Summit, etc.), in participating in Ask the Experts, and in attending the Annual Summit. All activities are voluntary; however, iCAN highly recommends Chapters participate in sponsored activities.

III. Role of iCAN Chapter Leader:

The team Leader is required to be a part of the Chapter Leadership Meetings that happen every other month. This is in order to answer any questions, to share ideas and topics among team leaders, and to learn about upcoming opportunities. The team leader is also responsible for scheduling and hosting monthly meetings that engage the kids in optional iCAN activities. We ask that all chapter leaders disseminate sponsored activities to their youth members.

IV. Expenses:

Creating an iCAN chapter is FREE to youth and their families, chapter leaders, and their affiliated organizations. However, some chapters have food and drinks at meetings, which would require funds fundraised by the chapter. Based on year-long participation, iCAN will provide funding for a certain number of youth members and/or chapter leaders to attend the annual summit. However, iCAN strongly encourages local fundraising to help offset additional expenses or to send more youth members to the annual Summit.

V. iCAN Chapter Website:

All iCAN Chapters have a dedicated web page on www.icanresearch.org to help share new ideas, recruitment information, learnings, and opportunities. Please initially send and continue to send abbyclark@icanresearch.org any photos of your chapter and any other information you would like to share. As iCAN is a global organization, we recognize that your Chapter's first language may not be English. We welcome any translations you would like to provide.

VI. Conduct of iCAN Chapter:

iCAN Chapters and members are expected to follow a code of conduct that upholds iCAN's legal and ethical ideals; including but not limited to, infringing on copyrighted materials or proprietary information and inappropriate cyperconduct (such as spamming, false identification, illegal usage, and bullying etc). We advise for the protection of all that any adult should never be alone with any child. If any of the requirements are broken, iCAN reserves the right to immediate termination of an iCAN chapter team and/or individual membership. The iCAN Code of Conduct will continue to develop in a manner that involves all stakeholders in the development and implementation of fair and clear regulations, and all iCAN Chapters will be notified of any amendments to the Code of Conduct.

VII. Representative Contact Information

Email _____

Phone Number _____

VIII. Approvals

iCAN and _____ (Chapter Name) agree to these terms.

Representative of Chapter (Print)

Date

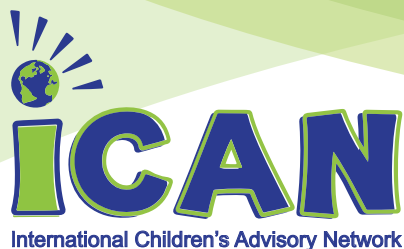
Representative of Chapter (Sign)

Date

Leanne West, President, iCAN (Sign)

Date





Sample Chapter Bylaws

iCAN KIDS (state/province/country)

_____ Chapter.

Local Chapter of the International Children's Advisory Network, Inc.

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2. Size and Roster
3. Executive Board Members
4. General Members
5. Executive Board Meetings
6. Voting Procedure - EB Meetings
7. General Board
8. Voting Procedure - GB Meetings
9. Events and Attendance
10. Amending or Suspending the Bylaws
11. Dissolution

1. Name and Purpose

The Organization will be named KIDS (Kids and families Impacting Disease through Science), and will be a local chapter of iCAN (International Children's Advisory Network, Inc.).

The purpose of the Organization is to learn and teach others about health, to engage in pediatric health through consultations and projects, to provide input on research ideas, to contribute to research and clinical trials, and to serve as a voice for kids.

2. Size and Roster

The membership limit of all youth members (including officers) is _____. The Secretary will keep a current list of all members and contact information.

3. Executive Board Members

The Executive Board (EB) is composed of the Officers (President, Vice-President, Secretary, & Treasurer) and Committee Chairpersons. To become an Officer, you must have been a General Member through at least _____ monthly meetings OR have represented KIDS/iCAN at an academic conference and attended _____ monthly meetings. Officers may vote in Executive Board meetings, nominate members for the EB, and present a proposal to amend the by-laws.

- The President will lead all meetings, cast the deciding vote in a tie, oversee the other Officers, publish an agenda for each meeting, and anything else necessary.
- The Vice President will perform any duties asked of by the President or Advisors.
- The Secretary will keep and distribute detailed minutes of all meetings and the Team Roster, take attendance, and keep attendance records, ensure the bylaws are being upheld and distributed, keep Associate Member performance records, and perform any other duties necessary.
- The Treasurer will keep records of the Team's finances, collect all money and issue receipts if needed, give a financial status brief at monthly meetings when needed, organize fundraisers when needed, keep record of which members attend fundraisers, and any other duties deemed necessary.

All EB terms of office begin at the first meeting of the school year; terms will be one calendar year. All EB members will have the option to run for office multiple times.

If there is a vacant position on the Executive Board, the President will appoint someone to fill the spot until an emergency election meeting can be held to elect someone to fill the position in question.

4. General Members

General Members are members of the Organization who are truly committed. They must uphold eligibility requirements and have ½ attendance at meetings and mandatory events. General Members may vote in General Board meetings, nominate members for EB positions, run for EB positions, call for impeachment of an EB member, and present a proposal to amend the bylaws. They may NOT vote in EB meetings.

5. Executive Board Meetings

The President will determine the time, location, and frequency of EB Meetings, which any member may attend. Attendance will be mandatory for all EB members; if an EB member cannot attend, they will notify the Secretary or President in a timely manner.

6. Voting Procedure - EB Meeting

Any EB member may bring any issue to a vote. To conduct a vote at any General Board meeting, a gathering of 1/3 of the active members (Executive and General) must be present. A simple majority in a vote will determine the outcome.

7. General Board Meetings

The General Board (GB) will consist of all General Members and Associate Members. The GB will meet at least monthly either in person or by telecon, and these meetings will be mandatory for all Team Members, including Officers, except Inactive Members. If a member cannot attend a Monthly meeting, they must follow the Attendance Policy set forth in the Attendance section of these bylaws.

8. Voting Procedure - GB Meeting

To vote at a GB Meeting, one third of the total number of General Members must be present. General Members must be present for their vote to count. Associate Members and Officers may not vote, and a simple majority of the total vote wins. In the event of a tie, the President shall cast the deciding vote.

9. Events and Attendance

The Advisor(s) and/or EB will determine the type, time, and location of all meetings and official events for each school year and determine which events will be considered mandatory. All Officers, General Members, and Associate Members must notify the President, Vice President, or Secretary BEFORE HAND, if they will be absent from a required event or meeting.

The Advisor(s) at the Chapter Level will determine youth member attendance (includes all Officers, General Members, and Associate Members) to annual iCAN Research & Advocacy Summit based on internal chapter application and review process. The number of attendees may be limited according to space and availability at the Summit.

10. Amending or Suspending the Bylaws

Any member can suggest a change to the bylaws. If the Executive Board agrees on a change to the bylaws, the new bylaws will be given to the General Board for consideration. The General Board will have one week to read over the proposed change, after which the General Members will vote to accept or reject the new bylaws. Amendments to the Bylaws will be passed by a simple majority vote when a quorum is present.

11. Dissolution

The Organization may be dissolved only if the Advisor(s) authorizes it at a special meeting called for that purpose, and with approval by at least two-thirds (2/3) vote of the General Board and Executive Board members.

Contact

For Additional Information

International Children's Advisory Network, Inc.
317 Faw Lane
Marietta, GA 30060

You can create/join a chapter through our website:

www.icanresearch.org

Email:

Leanne West, President

- lwest@gatech.edu

Abby Clark, Comm. and Digital Design Coordinator

- abbyclark@icanresearch.org

Jon Haygood, Treasurer

- finance@icanresearch.org

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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