

EXIT

Welcome  
to



**iCAN**

International Children's Advisory Network

**2022**

**iCAN Chapter Startup  
Guide**

*"If I can get some student interested in science..., then my job's been done". - Christa McAuliff*

Visit [www.icanresearch.org](http://www.icanresearch.org)

[info@icanresearch.org](mailto:info@icanresearch.org)

[www.iCANResearch.org](http://www.iCANResearch.org)

[#iCANMakeADifference](https://twitter.com/iCANMakeADifference)



### **Who we are:**

A global consortium of Young Person Advisory Groups (YPAGs) 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 network has grown to include a robust team of expert youth leaders from around the world, including (and still expanding).

- 31 chapters
- 1 virtual chapter
- 8 countries
- 4 continents

### **KIDS Chapters, Young Person Advisory Groups (YPAGs) and Virtual Childhood Specialty Groups:**

- Ages 8-18
- Local affiliation with children's hospitals, researchers, other partners
- Global connection to other YAGs
- Virtual Childhood Specialty Groups designed to foster a greater worldwide voice.
- Young Adult Professionals Group (New in 2021 for ages 18+)



## Overview of Chapters

Our Young Persons Advisory Groups of children, adolescents and families are focused on understanding, communicating and improving medicine, research and innovation for children. iCAN is a collaboration between the American Academy of Pediatrics (AAP), Section on Advances in Therapeutics and Technology (SOATT), local AAP Chapters, children's hospitals, local schools and other partners.

## iCAN membership consists of children ages 8 to 18 (and their parents) who have:

- \* Past clinical experience, and/or,
- \* Experience using hospital services, and/or,
- \* Chronic medical conditions and/or take medication regularly, and/or,
- \* Interest in medicine and/or research, and,
- \* Have active, engaged and involved parents/guardians to participate.

## The 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 hospitals, researchers, and other partners in the public and private sectors.
- \* **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 community, hospital, and clinic environment. Our goal is to bring a variety of cultural and learning environments together so that iCAN represents an active and engaged global expert team.

Our global diversity includes the following iCAN Chapter locations, with further growth and development planned throughout the upcoming years.

**All kids from anywhere are welcome to join iCAN.**

| <b><u>North America</u></b>           | <b><u>Europe</u></b> | <b><u>Asia Pacific</u></b> | <b><u>Special Interest</u></b> |
|---------------------------------------|----------------------|----------------------------|--------------------------------|
| KIDS Connecticut                      | KIDS Scotland        | KIDS Tokyo                 | KIDS Childhood Cancer          |
| KIDS Florida                          | KIDS England         |                            | KIDS WIT                       |
| KIDS Canada Francais                  | KIDS Barcelona       |                            | KIDS Virtual                   |
| KIDS Michigan                         | KIDS Bari            |                            |                                |
| KIDS Bay Area                         | KIDS France          |                            |                                |
| KIDS Georgia                          | KIDS Germany         |                            |                                |
| KIDS Illinois                         | KIDS Albania         |                            |                                |
| KIDS Kansas City                      | KIDS Netherlands     |                            |                                |
| KIDS Central Ohio                     | KIDS Rome            |                            |                                |
| KIDS CAN                              | KIDS Moorefields Eye |                            |                                |
| KIDS Vancouver                        | <b><u>Africa</u></b> |                            |                                |
| KIDS Los Angeles                      | KIDS Uganda          |                            |                                |
| KIDS Houston                          | KIDS DRC             |                            |                                |
| KIDS Hope for Henry                   | KIDS Cameroon        |                            |                                |
| KIDS Children's National              |                      |                            |                                |
| KIDS UP (Upper Peninsula of Michigan) |                      |                            |                                |
| KIDS CHOC-Rady                        |                      |                            |                                |
| KIDS Nebraska                         |                      |                            |                                |



### **Current Young Person Advisory Councils New Chapter Start-Up:**

If you have an existing or established young person's advisory council (*TIP: to better understand your community, check with the local area hospital and the staff within the ChildLife department to know if there is a local level group of youth advisors*), there are only a few steps to take to add to your council to the international network of iCAN. Remember, chapters may be started at any time and there is NO COST to create a chapter within iCAN.

- 1.) Complete the "Establishment of a New Chapter Agreement" form.
- 2.) Identify your chapter name as KIDS \_\_\_\_\_ (typically the name of your local state or city).
- 3.) Determine chapter leadership names, email, phone as contacts for iCAN.
- 4.) 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.
- 5.) Plan for attendance at the annual iCAN Research & Advocacy Summit. Location varies and details may be found on [www.icanresearch.org](http://www.icanresearch.org).
- 6.) There is no need to create by-laws as your new iCAN chapter will follow the existing hospital/school council and code-of-conduct agreement.



## **New Chapter Start-Up (non-existing youth advisory council affiliation):**

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/university or other institution is so different from one to the other.

### **Six Easy Steps to Establish an iCAN Chapter:**

- 1) **Identify adult Team Leader to act as meeting facilitators.** This is approximately 1-2 adults who have experience within the medical or research fields and have a passion for championing youth within medicine.
- 2) **Establish partner clinic/hospital(s).** 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) **Secure funding (as needed).** Some teams run on a \$0 budget, others have partnerships with their partner hospitals, which provide the chapter with a source of funding for meetings, events, travel to conferences, etc. Teams are expected to be self-sustained, so it is recommended to try and secure funding from the hospital, or from other sources like fundraisers. There is NO COST to creating a chapter within iCAN.
- 6) **Recruit Youth Members.** Unlike many organizations, recruitment is easy. Our youth have a vested interest in improving their medical care and are often recruited through hospitals and schools by social work, providers, and teachers.
- 7) **Send Youth Members to Annual iCAN Research & Advocacy Summit.** This event allows members to engage with one another throughout the global iCAN consortium. The selected members will be chosen through an application and review process at the Chapter Level. It is recommended that Chapters, along with members, begin fundraising early to help offset the member costs of travel, (including transportation such as airfare) hotel, and registration fees.



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

**Establishment of an iCAN Chapter Agreement**

We are pleased you are interested in collaborating with the International Children's Advisory Network (iCAN). iCAN is a non-profit, worldwide consortium of youth advisory groups working together to provide a voice for children and families in medicine, research, science, and innovation through synergy, communication, and collaboration.

**Date of iCAN Chapter Establishment:**

Effective from this date, \_\_\_\_\_, this document outlines the relationship and expectations of conduct between \_\_\_\_\_ KIDS Chapter, and associated members, and the International Children's Advisory Network regarding collaboration within the global participation of the iCAN Young Person Advisory Group (YPAG) Network.

**Role of iCAN Chapter:**

iCAN Chapters, supported by adult team leaders, youth members and parents/caregivers, will work both locally in partnerships with children's hospitals and communities, and collaborate together network-wide to have a global impact. Through our iCAN Chapters, youth-led councils, committees and focus groups, we will address needs of pediatric clinical research and healthcare, influence state and federal regulations, and advocate for pediatric patients across the globe. Our goal through each iCAN Chapter is to educate the world about the importance of children's involvement in the development of research trials, and to provide our children and families with resources and opportunities to provide their feedback and input into studies and products intended for children. iCAN Chapters will self-fund group expenses and will actively engage, participate, and support the annual iCAN Summit.

**iCAN Chapter Website:**

All iCAN Chapters will have access to a dedicated page on [www.icanresearch.org](http://www.icanresearch.org) to help share new ideas, recruitment information, learnings and opportunities.

**Conduct of iCAN Chapter:** iCAN Chapters and members are expected to follow a high code of legal, and, ethical conduct, including but not limited to, infringing on copyrighted materials or proprietary information, not spamming other members or not assigning the membership to anyone else. If any of the requirements are broken, iCAN reserves the right to immediate termination of an iCAN chapter team and/or individual membership.

**Approvals**

iCAN and \_\_\_\_\_ agree to these terms.

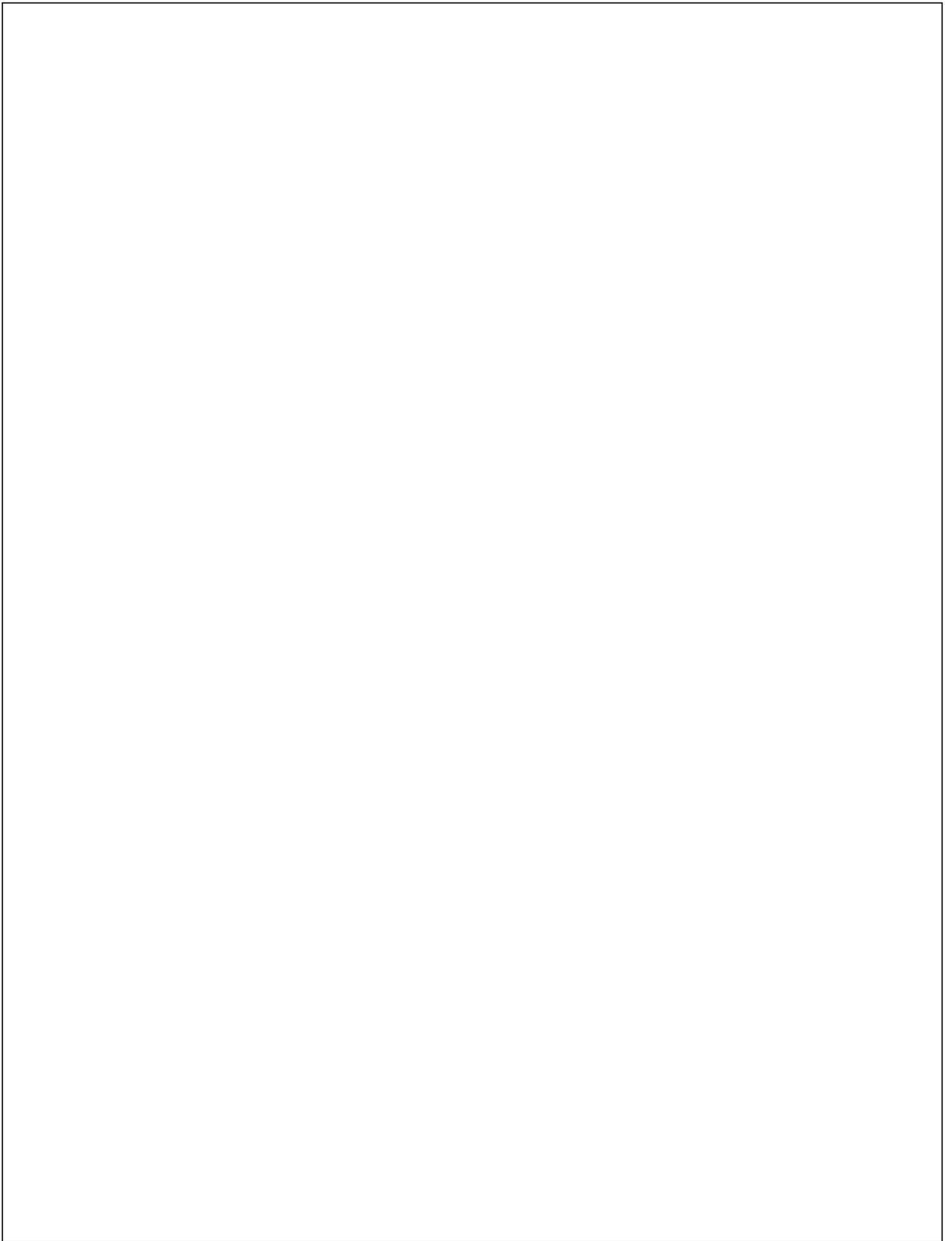
\_\_\_\_\_ Partner Organization (Print)

\_\_\_\_\_  
Representative of Partner Organization (Print & Sign)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Leanne West, President, iCAN (Sign)  
317 Faw Lane  
Marietta, GA 30060  
[info@icanresearch.org](mailto:info@icanresearch.org)

\_\_\_\_\_  
Date





International Children's Advisory Network

*iCAN KIDS* \_\_\_\_\_ *Chapter*

(State/Province/Country)

***SAMPLE CHAPTER***  
***Bylaws***

**Local Chapter of:**  
**The International Children's Advisory Network, Inc.**

**[www.icanresearch.org](http://www.icanresearch.org)**

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### 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 about 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 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. They may NOT vote in meetings, except for elections. The chain of command will be, from top to bottom: 1) President 2) Vice President 3) Secretary 4) Treasurer 5) All Committee Chairs 6) General Members 7) Associate Members.

Officers must uphold General Member requirements, have  $\frac{3}{4}$  attendance at meetings & events, and fulfill their respective duties (below):

- 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.

#### **4. General Members**

General Members are members of the Organization who are truly committed and have been Associate Members for at least \_\_\_\_\_ months or such a duration that is deemed appropriate by unanimous vote of the Executive Board members. General Members must be voted into this status at the first Monthly Meeting following their probationary term. 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. Associate Members**

Associate Members are members of the Organization serving a probationary term of three months. Associate Members must be within 8 and 18 years of age, have a parent who approves their membership, and have 2/3 attendance at mandatory meetings & events. They may present a proposal to amend the bylaws. They may NOT vote in EB meetings, vote in Monthly Meetings, nominate members for EB positions, run for EB positions, or call for an EB member to be impeached.

#### **6. Inactive Members**

Inactive Members are members of the Organization who have earned General Member status, but cannot participate in meetings and activities because of other obligations. Inactive Members must be unable to fulfill General Member requirements due to internships, education programs, extended leave, illness, etc. They must submit a written statement to the Secretary describing their need for Inactive Membership, including when they plan on being able to return to General Membership, and have their Inactive Member status approved by the EB by majority vote. Inactive Members may vote in EB elections. They may NOT vote in EB meetings, vote in General Board meetings, run for an EB position, call for an EB member's impeachment, or present a proposal to amend the bylaws.

#### **7. 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. During the EB Meeting, the Secretary shall discuss the reasoning behind the EB member's absence and the EB members shall vote on whether to excuse it. Any EB member that receives three or more unexcused absences to EB meetings in one school year shall be removed from his or her position on the EB and returned to General Member status.

### **Voting Procedure**

Any EB member may bring any issue to a vote. To conduct any vote at an Executive Board meeting a quorum of  $\frac{1}{2}$  of EB members (not including the President, who will not vote except in a tie or when unanimous vote is required) must be present. To conduct a vote at any General Board meeting, a quorum of  $\frac{1}{3}$  of the active members (Executive and General) must be present. A simple majority in a vote will determine the outcome.

## **8. 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.

### **Voting Procedure**

To vote at a GB Meeting, a quorum of one third of the total number of General Members must be present. Except in EB elections, 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. Members in Poor Standing and Member Expulsion**

Any Officer not maintaining his or her eligibility requirements and/or receives three or more unexcused absences for meetings or events in one school year will be removed from their EB position and returned to General Member status as a member in poor standing.

Any General Member not maintaining his or her eligibility requirements and/or receives three or more unexcused absences for meetings or events will be placed in poor standing immediately by unanimous vote of the EB.

Any member in poor standing will have all membership privileges suspended.

Members in poor standing will have six months to earn restoration by unanimous vote of the EB; if a member ends the allotted time still in poor standing, they will be expelled from the Team.

The EB may expel any member at any time with a unanimous vote where the President is present. The EB must give the expelled member at least one week's notice, in writing or via email.

A member who has received a letter of expulsion may petition the action in writing or email before the expulsion becomes effective. The EB will make a unanimous vote to decide the fate of the member or deliberate until the vote is unanimous; the EB's decision will be final.

## **10. Executive Board Elections and Impeachment**

EB Elections will be held during the Annual Meeting. The motion to nominate an Officer or Committee Chair will be given orally by an Officer or a General Member present at the Monthly meeting before the Election meeting; members may nominate themselves. Nominations must be seconded by an Officer or General Member and accepted by the member in question.

Voting will be conducted by secret ballot; absentee ballots collected prior to the election meeting will count towards the total vote. A simple majority of the total vote wins. If there is only one nominee, the person will be automatically elected.

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. There is no emergency election process; the President will preside over all emergency elections and decide on a process that will allow for a fair and efficient election.

Any Officer or General Member may call for an EB member to be impeached if that member is not fulfilling his or her duties. First, the Executive Board will vote to determine if the impeachment is in the best interest of the organization. The member being impeached may not vote and may not count towards the quorum. If the Executive Board votes to impeach, the General Board will have a final vote at the next Monthly meeting. Each Executive Board member, including the one being impeached, may make his or her case for or against impeachment. All General Members will then vote (or abstain) to determine if the Executive Board member in question will be relieved of his or her position. The vote will be final.

## **11. 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, in writing, if they will be absent from a required event or meeting.

If notification is not given in an acceptable manner, that member will be given an unexcused absence for that event or meeting and may not petition the EB to excuse the absence. Any eligible absence may be submitted for review before one week to the absence date and will be voted upon by the Executive Board to determine if that absence will be excused.

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.

## **12. 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.

## **13. Dissolution**

The Organization may be dissolved only if the Advisor(s) authorize 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.



International Children's Advisory Network

## Youth Members

### General Guidelines

- iCAN youth members must be between the ages of 8-18 years old and,
- iCAN youth members must actively be working towards completion of high school diploma. \*
- iCAN youth members must be affiliated through membership within a local chapter, and as such, are held accountable to the stated institutional, behavioral, ethical, and moral rules of the local chapter.
- iCAN youth members must contribute to at least one (or more) iCAN youth led council, committee, and focus group/research project as a member.
- iCAN youth members may apply for youth led council or committee leadership roles on an annual basis.

iCAN offers an educational curriculum for all iCAN youth members. *As of 2020, the first module (thank you to Eli Lilly and Jumo health) for learning is available under resources on [www.icanresearch.org](http://www.icanresearch.org). iCAN youth members should be encouraged to complete the age adaptive educational curriculum as part of their broader iCAN membership responsibility. In 2021, iCAN members were provided with the second module on Understanding Clinical Research. For 2020, iCAN will be unveiling a third module of Becoming a Leader. All information can be found on [www.icanresearch.org](http://www.icanresearch.org).*

iCAN Youth members that complete the educational curriculum modules, will be eligible for a certificate of completion, to be provided by local chapter leadership. The certificate is available online under resources at [www.icanresearch.org](http://www.icanresearch.org). This can be signed and validated by the iCAN Chapter Leader.

*\*Once iCAN Youth members graduate from high school, they are still able to attend the annual iCAN Summit during the summer immediately following graduation, depending upon the restrictions of the local chapter membership policy. Please note, not all local chapters will be able to accommodate this request, specifically hospitals that may have local age restriction rules or travel policies to their own KIDS chapters and/or are following an organizational transition program.*

*Additionally, iCAN Youth Members, ages 18+ may be eligible to join the iCAN Young Adult Professionals Group. To learn more, email [info@icanresearch.org](mailto:info@icanresearch.org).*



## **iCAN Young Adult Professionals Members**

*iCAN has created an iCAN Young Adult Professionals section for 18 years +. Interested individuals can sign up through [info@icanresearch.org](mailto:info@icanresearch.org).*

### General Guidelines:

- iCAN Young Adults ages 18+
- Interested in learning more about careers in healthcare, medicine, research, innovation, science and advocacy.
- iCAN Young Adults must be actively working towards earning a higher degree or beginning their careers.
- iCAN Young Adults must be adhere to their institutional (employer and/or educational institutions), behavioral, ethical and moral rules of the local chapter.
- iCAN Young Adults must be signed up as a virtual Young Adult Professional through [www.icanresearch.org](http://www.icanresearch.org).
- Opportunities for iCAN Young Adult Professionals will be shared throughout [www.icanresearch.org](http://www.icanresearch.org) and on the webpage Young Adult Professionals on a revolving basis.



## Chapter Leader

### Responsibilities

- Recruit new members
- Frequently update member roster (located on google share drive – contact Amy Ohmer 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 (on [www.icanresearch.org](http://www.icanresearch.org))
- Call in for bi-monthly Chapter Leader meetings
- Contribute to Summit planning (optional)
- Create content to be included on your local chapter's web page ([www.icanresearch.org/chapters/yourteamname](http://www.icanresearch.org/chapters/yourteamname))
- Secure meeting locations
- Select a “Chapter Scribe” and ensure that scribe submits meeting summaries to iCAN Director quarterly
- Lead chapter fundraising efforts
- 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)
- Partner with local children's hospital (if applicable)
  - Helpful to recruit new members (patients), meeting location, etc.
- Organize trips to research facilities and other hospitals (if desired)
- Involve your chapter in community service activities (if desired)
- 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)
- Elect youth leaders/officers, or develop a team hierarchy
- Involve parents to help facilitate certain aspects of meetings etc. (food, transportation, fundraising, etc.)
  - Parent Leaders also recommended to help delegate tasks



**For Additional Information:**

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

 [amyohmer@icanresearch.org](mailto:amyohmer@icanresearch.org)

 (+1)734.545.2831

 [www.icanresearch.org](http://www.icanresearch.org)

See iCAN Research on Social Media too!  
#iCANMakeADifference #iCAN #iCANSummit