

Terms of Reference

Retina International Youth Council - RIYC

1. Type

Retina International Youth Council (RIYC) is an advisory special interest group under the governance of Retina International (RI).

2. Purpose

The RIYC works to support the achievement and to endure the purpose of RI, which is to foster and promote research into retinal degenerative diseases. Besides, the RIYC works under the direction of the Board of Directors and is in line with the organisation's strategic plan, which is approved by the General Assembly at its annual meeting.

RIYC works to identify the needs and elevate the voices of young people in the retinal disease community by enhancing social and information networks, and increasing collaboration with other patient organisations and research communities across the globe. Finally, the RIYC works to increase youth participation and representativeness within the council and in relation to the RI members.

3. Scope

The scope of RIYC includes:

- a. Provide advice to the RI Executive and Board of Directors on strategic activities relevant to young people.
- b. Work with the RI Executive to build relationships with other organisations or groups with shared values and objectives.
- c. Form special temporary groups within the RIYC to address specific projects or goals, for instance, event promotion, social media campaigns, and advocacy projects. Always under the governance of the Board of Directors and with the support of the RI Executive team.
- d. Provide support, information and resources to enable members at the national level upon request.

4. Term

This Terms of Reference is effective from **October 2022** and will remain until the Retina International Board of Directors elects to terminate this special interest group.

5. Authority

The RIYC consists of three levels of participation:

Elected individual for officer positions: chairperson, vice-chairperson, secretary:

Nominated representatives from membership organisations:

Nominated representatives from RI candidate members

a. Description of roles: elected individuals

Chairperson

The role of the Chairperson is to provide leadership to the council, listen to each member's perspective and ensure that all have the opportunity to contribute to the development of the RIYC. The Chairperson must be an effective communicator and a good networker. They must regularly report to the executive team and the Board of RI.

Duties:

- Chair committee meetings so that everyone has a chance to present their views.
- Make a note of the decisions taken by the council and working groups, ensuring they are actioned.
- In liaison with the Executive team, oversee the outputs of all members of the RIYC to ensure implementation of agreed plans and provide support where appropriate.
- In collaboration with the Secretary, prepare and present quarterly and annual activity reports.
- Prepare meeting agendas with the Secretary and review meeting minutes prior to circulation.
- Be familiar with the RIYC Terms of Reference.
- Collaborate with the Executive Team to ensure strategic alignment of RIYC with the RI strategy and work plan.
- Represent the RIYC and/or RI at external forums at the request of the Board and Executive Team

Vice-Chairperson

The role of the Vice Chairperson is to assume the role and duties of the Chairperson in their absence, as outlined above. To support the Chairperson in their role where appropriate and to be a liaison with the members of the RIYC.

Duties:

- Accept duties of the Chairperson, as outlined above, delegated to them by either the Chairperson or Executive Liaison.
- To represent the RIYC and/or RI at external forums at the request of the Board and Executive Team.

Secretary

The role of the Secretary is to prepare agendas in consultation with the Chairperson, Vice-Chairperson and primary Executive Liaison.

Duties:

- To circulate agendas and any supporting papers to the council prior to meetings.
- To receive agenda items from other committee members.
- To minute meetings, review with the Chairperson and Vice-Chairperson and circulate the draft minutes to all committee members.
- To collect and circulate the minutes and the reports of working group meetings.
- To ensure that up-to-date records are kept of council membership and terms of reference.
- To make arrangements for meetings (logistics, accessibility, etc.).

b. Description of roles: nominated individuals

Nominated representatives from a membership organisation

Representatives should be between the age of 18 and 35 and/or have a Retinal Disease or be related (family or friend) with a person with a Retinal disease.

Once nominated, the representatives have a service term of one-two years, providing a substitute in case of resignation.

Duties:

- Elect representatives for chairperson, vice-chairperson, and secretary to be ratified by the RI Board of Directors.
- Participate in RIYC meetings, establish and participate in working groups and contribute to activities
- Support the facilitation of events, advocacy campaigns, and projects in their national organisations, reflecting and supporting the actions of RI.

Nominated representatives from RI candidate members

Nominated members from RI candidate members can neither vote nor be elected for the chair, vice-chair and secretary positions.

Representatives should be between the ages of 18 and 35 and or have a Retinal Disease or be related (family or friends) to a patient with a Retinal Disease;

Once nominated, the representatives have a service term of one-two years, providing a substitute in case of abdication.

Duties:

- Participate in RIYC meetings, participate in working groups and contribute to activities
- Organise and run events, advocacy campaigns, and projects in their national organisation, reflecting and supporting the actions of RI.

6. Governance

The RIYC governance works according to the following rules:

a. Nomination and Election procedures

Only RI members and RI candidate members can nominate up to two youth representatives for the RIYC.

Representatives from RI full members will have voting rights and be eligible to run for an Officer Position.

Representatives from RI candidate members will not have voting rights and will not be eligible to run for an Officer Position.

b. Eligibility criteria

All nominated representatives must:

- Be between 18 - 35 years old at the time of nomination.
- Have a working knowledge of the English language.
- Be affected by, related to, or a supporter of someone with a retinal degenerative condition.
- Be a registered member of the nominating organisation.

c. Nomination procedures

To be nominated, the individual must:

- Complete the nomination form.
- Provide an up-to-date CV/Resume.

- Provide a motivation letter (one A4 page maximum) with a personal introduction and explain why the individual wants to be part of the RIYC.

A completed nomination form with a CV and Motivation Letter must be sent by a representative of the nominating organisation to a member of the RI staff.

All nomination documents must be sent by a representative of the nominating organisation. Nomination documents sent by the nominee directly will not be considered.

The responsibility is on the nominating organisation to recruit suitable candidates for nomination to the RIYC.

Any changes in representation to the RIYC must be reported by the nominating organisation in writing to the Chair of the RIYC, and CEO of RI.

It is the responsibility of the nominating organisation to ensure that all eligibility criteria listed above are met by the nominee.

7. Elections

- Only representatives from RI full members can run for the three officer positions.
- Each full-member organisation is entitled to 1 vote for each officer position, independent of the number of representatives on the RIYC.
- Election for chairperson, vice-chairperson and secretary will occur each year with a term of 1 year.
- Elections will occur during a meeting of RIYC.
- The vote will be carried out by an anonymous online ballot
- Elections will proceed in the following order: chairperson, vice-chairperson, and secretary.
- Results are announced immediately after the voting.
- The candidate with the most votes will be recommended to the RI Board for approval.
- The RI Board will approve the appointment of the elected chairperson, vice-chairperson, and secretary of the RIYC.
- A member of the RI executive team or Board of Directors should conduct the elections and guarantee its transparency.

a. Running criteria and procedures

In order to run for the officer positions, candidates must:

- Be a representative of a RI full-member organisation.
- Understand the role and responsibilities of each role.
- Send an Expression of Interest (EoI) to the RI Executive Liaison.

On the day of the election:

Candidates will be granted up to 90 seconds of verbal address to the council for each position of interest (unless they have already been successfully elected to another role).

8. Setting up and closing of working groups.

Working groups will be settled by the RIYC members and the RI Executive Liaison. Groups will work to fulfil their proposal being closed after it has achieved its objective. All members of the RIYC can integrate the working groups.

9. Code of Conduct

Members of the RIYC are volunteers of RI and should maintain the highest standards of behaviour in the performance of their duties by:

- Performing their volunteer role to the best of their ability in a safe, efficient and competent way.
- Following the organisation's policies and procedures as well as any instructions or directions were reasonably given to them.
- Acting honestly, responsibly, and with integrity.
- Treating others with fairness, equality, dignity and respect.
- Raising concerns about possible wrongdoing witnessed by the volunteer in the course of the volunteer's role with Retina International.
- Meeting time and task commitments and providing sufficient notice when they will not be available so alternative arrangements can be made.
- Acting in line with the purpose and values of RI, enhancing its work.
- Communicating respectfully and honestly at all times;
- Observing safety procedures, including any obligations concerning the safety, health and welfare of other people.
- Reporting any health and safety concerns.
- Directing any questions regarding Retina International's policies, procedures, support or supervision to the RI executive team of the Board of Directors.
- Addressing any issues or difficulties about any aspect of their role or how they are managed in line with Retina International's grievance procedures.
- Keeping confidential matters confidential.
- Exercising caution and care with any documents, material or devices containing confidential information and returning any such documents or material in their possession at the end of their involvement with Retina International.
- Seeking authorisation before communicating externally on behalf of Retina International.
- Maintaining an appropriate standard of dress and personal hygiene.

10. Membership

The RIYC will be made up of the following:

- Up to two (2) representatives from each Full Member organisation of RI. These members will have voting rights and will be eligible to run for an Officer position.
- Up to two (2) members from each Candidate Member organisation of RI. These members will not have voting rights and will not be eligible to run for an officer position.
- A member of the Executive Team of Retina International (Nominated by the CEO of RI).
- Specialists (upon invitation/request)

11. Meetings and Agreements

- Meetings will be held at least 4 times per calendar year.
- The meeting agenda should be sent to all RIYC members at least 1 week in advance.
- The meeting agenda should be decided by the chairperson with the collaboration of the secretary and vice-chairperson, if necessary, in accordance with the job description outlined in session 5.a of this Terms of Reference.
- Meetings should be run by the chairperson;
- The meeting minutes should be recorded and disseminated via email by the secretary in accordance with the job descriptions outlined in session 5.a of this Terms of Reference. All official correspondence and communication should be carried out by email via email addresses provided to RI at the time of nomination.
- All minutes for all meetings, including working groups, are to be disseminated within **30** days after the meeting to the council and RI Executive Liaison and issued to the Board of Directors.

12. Reporting

The RIYC reports all operational actions and daily activities to RI Executive Liaison. The RIYC reports to the RI Board of Directors with a quarterly written report from the chairperson. The report summarises the RIYC activities, accomplishments and other relevant topics over the related period and should be written by the chairperson.

13. Deliverables

The RIYC will commit to delivering:

- a. Annual report to Annual General meeting
- b. Quarterly report to the RI Board of Directors
- c. Approved Minutes of all RIYC Meetings to the RI Executive Liaison.
- d. Organise and deliver a Youth Programme at the biennial RI World Congress.

- e. Organise and deliver an annual Virtual Youth Conference

14. Amendment, modification or variation

This Terms of Reference may be amended, modified or varied in writing after consultation and with the approval of the RIYC members and the RI Board of Directors.

The RIYC members approved this Terms of Reference on October the 2nd, 2022.