RDI Youth Leadership Programme

These Terms of Reference outline the structure and functioning of the Youth Leadership Programme, developed by Rare Diseases International (RDI). The Programme is designed to engage and empower young people within the rare disease community, ensuring their perspectives are represented in global discussions and decision-making processes. It provides a platform for young leaders to contribute their insights and expertise while fostering capacity-building and collaboration across the rare disease ecosystem.

1.About RDI

RDI is the global alliance of people living with a rare disease of all nationalities across all rare diseases. RDI's mission is to be a strong common voice on behalf of rare disease patients around the world, to advocate for rare diseases as an international public health priority and to represent its members and enhance their capacities. RDI has more than 140 member organizations from 48 countries, that in turn represent rare disease patient groups in more than 150 countries worldwide. Throughout a lifetime, Persons Living with a Rare Disease (PLWRD) and their families face multiple forms of social discrimination, as well as common challenges in accessing diagnosis and care. As an alliance, RDI works to ensure greater equity for all PLWRD and their loved ones across the globe.

RDI's work is guided by the values of **equity, inclusion, community-centred practice, transparency, independence, collaboration, and innovation**. These values shape how we work, how we engage with communities and partners, and how we contribute to positive and sustainable change.

YLP participants will be expected to **uphold and represent RDI's values throughout their participation in the programme**. This includes demonstrating respect, integrity, openness, collaboration, and a commitment to equity and inclusion in their interactions with fellow participants, communities, partners, and RDI. Participants will also be expected to reflect these values in their **wider professional practice**, demonstrating them through their actions and interactions.

2.Programme objectives

The RDI Youth Leadership Programme empowers emerging leaders within the global rare disease community through capacity building, peer learning, mentorship, and practical leadership opportunities. The Programme equips participants with the knowledge, skills and networks needed to become effective advocates and contribute to positive change within the rare disease ecosystem.

The Programme aims to:

- Strengthen participants' leadership, advocacy and collaboration skills for rare diseases, through structured learning, mentoring and peer support.
- Facilitate participants' engagement in selected international forums, events and collaborative initiatives where RDI is active, expanding their professional networks across the global rare disease community and global health space more broadly, while representing youth voices in actions and discussion about rare diseases.

- Encourage innovation by integrating fresh perspectives and new ideas that help RDI remain responsive to the evolving needs of PLWRD.
- Foster meaningful youth engagement within RDI by ensuring that young people's perspectives contribute to discussions, priorities and activities that will shape the discourse and actions by the rare disease community into the future.
- Support participants in developing their own rare disease leadership journey, advocacy priorities or initiatives that create a meaningful impact within their communities and beyond.

Through these objectives, the Programme seeks to cultivate a diverse network of young leaders who are equipped to influence policy, strengthen patient advocacy and contribute to a more inclusive and collaborative global rare disease community.

3.Target Audience

Applicants to the RDI Youth Leadership Programme must be between 21 and 30 years old at the time of application and demonstrate basic proficiency in English, as the Programme's activities and discussions will be conducted in English. RDI Membership is not a firm requirement for eligibility, but priority will be given to applicants from RDI member organizations. The Programme aims to ensure a balanced representation of geographic diversity, gender, and diverse backgrounds among participants. Applicants should either have lived experience with rare diseases, whether as a PLWRD or as a relative or caregiver of a PLWRD, or possess relevant personal experience in the field of rare diseases as an advocate.

4.Application & Selection Process

The selection process will ensure transparency and equal opportunities. It will begin with a call for interest which will be published online and by email invitations sent to RDI members by the end of October 2026.

Applications will be open **until the 22nd of November 2026**. Once all submissions are received, applications will be reviewed by the RDI Team, and shortlisted candidates may be invited for an interview to assess their motivation and suitability for the Programme, as well as ensuring diversity in the cohort of emerging youth leaders.

Applicants should follow these steps to apply:

1. Complete the application form: https://form.typeform.com/to/wYYV0gGV
2. Create a video presentation (maximum 90 seconds) introducing themselves, their experience, and their motivation for joining the Programme.
3. Submit all materials through the application form.

The primary selection criteria will include:

- Motivation: passion for rare disease advocacy and clear leadership growth goals.
- Experience: proven leadership and contributions to advocacy or community initiatives, ideally through an RDI Member organization, but other relevant experiences would also be valued.
- Lived Experience: personal connection as a PLWRD, family member or caregiver.

- Diversity: representation across regions, socio-economic backgrounds, and genders.
- Alignment with YLP and RDI values, as described above.

Candidates will be notified of the final selection by the end of January 2027. The selected candidates will be publicly announced on Rare Disease Day 2027.

Selected candidates will be required to sign these Terms of Reference to confirm their understanding of, and commitment to, the roles, responsibilities, and expectations of the Programme.

In addition, participants must submit a signed endorsement form from a senior leader of their member organization. This endorsement confirms the organization's support for the participant's involvement in the Programme and their commitment to enabling the participant to actively engage in the Programme and represent the organization in its activities.

5.Commitment & expectations

Participation in the RDI Youth Leadership Programme is voluntary and spans a two-year term.

Participants are expected to actively engage throughout the Programme by attending meetings, contributing to learning activities, collaborating with fellow cohort members, and representing the perspectives of young people within the rare disease community at national, regional, and global levels.

The Programme includes a minimum of four virtual meetings per year, held via Microsoft Teams, and one annual in-person meeting. The dates of the first virtual meetings and the annual in-person event are provided in Section 9.

Participants are expected to:

- Attend at least 75% of the virtual meetings.
- Participate in the annual in-person meeting (Youth Academy 2027, and in person event in 2028), unless exceptional circumstances (e.g., health or disability) prevent attendance.
- Actively contribute to discussions, workshops, and peer-learning activities.
- Engage respectfully, professionally, and collaboratively with fellow participants, mentors, and RDI staff and members.
- Embody the YLP and RDI values in their participation and interactions with others.
- Inform the RDI Secretariat as early as possible if they are unable to participate in a scheduled activity.
- Complete any agreed reflections, assignments or learning activities throughout the Programme.
- Develop and implement a personal leadership goal, advocacy priority or initiative during the Programme, with support from mentors and peers.
- Share the outcomes of their leadership journey, advocacy work or initiative at the conclusion of the Programme.
- Act as ambassadors for the rare disease community, RDI and the Programme by representing their member organization and the perspectives of young people within the rare disease community, where appropriate.

The Programme is built on peer learning, collaboration, and mutual support. Participants are expected not only to benefit from the opportunities provided, but also to contribute actively to the learning and development of their peers by sharing their experiences, knowledge, and perspectives. Through this collaborative approach, the Programme aims to foster a strong and connected network of emerging leaders committed to advancing the global rare disease community.

Participants are expected to contribute their own perspectives while recognizing the diversity of experiences within the rare disease community. Where participants represent an RDI Member organization, they should clearly distinguish organizational positions from their personal views.

6.Programme overview

6.1 Programme's Pillars

The aim of the **RDI Youth Leadership Programme** is to elevate the role and voices of youth in shaping the rare disease agenda at global, regional, national, and local levels, while supporting RDI in aligning its strategies with the next generation's needs. To achieve this, the Programme will center its efforts around three key Pillars:

- **Leadership & Empowerment**: enhancing leadership capabilities among youth in the rare disease community through structured mentoring, training, and practical experience. The goal is to equip young leaders with the skills, confidence, and tools needed to assume leadership and advocacy roles, empowering them to drive impactful initiatives and meaningful change in the rare disease community;
- **Collaboration & Networking**: strengthening connections among youth leaders, RDI members, external organizations, researchers, and key stakeholders to foster meaningful collaboration. By promoting collaborations that amplify youth voices and impact, the objective is to build a robust ecosystem for advancing the rare disease agenda through knowledge sharing, joint initiatives, and networking;
- **Advocacy & Visibility**: empowering youth leaders to become influential advocates for rare diseases by highlighting the challenges faced by PLWRD and championing their recognition as a global health priority. The goal is to elevate the visibility of rare diseases at local, national, and global levels while equipping youth leaders with the tools and strategies needed to drive impactful advocacy efforts.

6.2 Timeline & activities

In the first half of 2027 (Q1–Q2), the Programme will focus on welcoming participants and preparing them for the Youth Academy, the annual in-person event designed to strengthen their leadership, advocacy, and collaboration skills. These initial sessions will provide participants with the knowledge, tools, and confidence needed to engage effectively in the Programme and to build meaningful connections with their peers and mentors.

Following the event in June 2027, the Programme's content will focus more dynamically reflecting the specific needs and interests of its members. This adaptive phase will allow for a more participant-driven approach, where the topics and activities will be directly shaped by the feedback and expressed interests of the youth leaders. This could include more specialized workshops, or further training, depending on what the participants identify as most valuable for their development and impact in the rare disease community. This flexible structure ensures that the Programme remains relevant and engaging, fostering a proactive and empowered group of young leaders in the rare disease field.

6.3 Leadership Journey

Each participant will be encouraged to identify an area of leadership, advocacy or community impact they wish to develop during the Programme.

This may include: an advocacy initiative; an awareness campaign; organizational development; research dissemination; community engagement; policy work; another initiative aligned with the Programme objectives.

Participants will have opportunities to share progress, receive peer and mentor feedback, and present their journey upon completion of the Programme.

6.4. Completion and Alumni

Participants who successfully complete the Programme will be recognized as RDI Youth Leadership Programme Alumni. Successful completion requires participants to:

- Meet the Programme's requirements as set out in this ToR, as well as modeling RDI's values both in the Programme and in their work at home;
- Fulfill the Programme requirements, including regular attendance and active participation in Programme activities.
- Complete any required reflections or assignments.
- Contribute to the learning and development of the cohort.
- Present their leadership journey, advocacy priority or initiative at the conclusion of the Programme.

6.5. Withdrawal and Termination

Participants may withdraw from the RDI Youth Leadership Programme at any time by notifying the RDI Secretariat. RDI reserves the right to terminate a participant's involvement in the Programme under the following circumstances:

- Failure to comply with the Programme's Terms of Reference, values, policies or expectations.
- Repeated failure to participate in Programme activities or meet the minimum attendance requirements without a valid reason.
- Lack of respectful, professional or constructive engagement with fellow participants, mentors or RDI representatives.

- Any conduct or circumstance that may significantly affect the integrity, reputation or effective functioning of the Programme.

Where appropriate, RDI will seek to discuss concerns with the participant and provide an opportunity to address them before making a decision regarding termination.

7. Structure

The Youth Leadership Programme is composed of a Secretariat, and a cohort of 10–15 participants. The Programme is coordinated by the RDI Secretariat, which is responsible for its overall management and implementation. The Programme is designed to support leadership development, collaboration, and youth engagement within RDI and does not function as a decision-making body or have authority over the independent activities of participants or their organizations outside the scope of the Programme.

7.1 The Secretariat

The RDI Secretariat will oversee the activities of the Youth Leadership Programme and provide administrative, logistical, and organizational support to ensure the smooth functioning of the Youth Leadership Programme.

More specifically, key responsibilities of the Secretariat are as follows:

- Serve as the primary administrative and operational support, coordinating all logistical aspects of the RDI Youth Leadership Programme, including meeting organization and preparation of materials;
- Facilitate communication between the Youth Leadership Programme members, the RDI team, the RDI Council, and external stakeholders, while managing communication platforms and materials to foster collaboration and promote the programme's initiatives;
- Coordinate participation of Youth Leadership Programme members in RDI meetings, or other events including workshops, in-person meetings, and campaigns providing technical and logistical support;
- Oversee the implementation of the programme's objectives and monitoring, and ensure alignment with RDI's strategic priorities;

8. Tools

RDI will provide the Youth Leadership Programme members with a range of tools and resources to ensure that they are well-equipped to succeed in their roles and contribute effectively to the objectives of the Programme. RDI will provide guidance and advice in procuring any additional tools deemed necessary by the members.

8.1 Online collaboration tools

- A dedicated platform (Microsoft Teams; WhatsApp group chat) for communication and collaboration;
- A shared drive for storing documents, resources, and presentations, ensuring that all members have easy access to materials and can collaborate in real time;

9. Meetings

Participants will take part in a combination of virtual and in-person meetings throughout the two-year Programme. During the first half of 2027 (Q1–Q2), the Programme will focus on onboarding participants and preparing them for the Youth Academy through a series of introductory webinars.

The Q1–Q2 2027 schedule includes:

- Welcome Webinar – Introduction to the Programme (TBC).
- Pre-Academy Webinar 1 – Topic 1 (TBC).
- Pre-Academy Webinar 2 – Topic 2 (TBC).
- Pre-Academy Webinar 3 – Topic 3 (TBC).
- Youth Academy (In-person) – Barcelona (Spain), 14 to 17 June 2027 (TBC).

Following the Youth Academy, participants will continue to meet through **regular virtual sessions**, **with a minimum of four online meetings per year**. The topics and format of these meetings will be informed by participants' interests, learning needs and emerging opportunities, while continuing to support their

leadership development, peer learning and engagement within RDI and the global rare disease community.

Additional meetings, mentoring sessions, or collaborative activities may be organized throughout the Programme as opportunities arise.

The Programme will include an in-person meeting, expected in 2028 (date and location TBC).

Annual in-person meeting

Travel costs for members of the Youth Leadership Programme and their careers as necessary will be covered by RDI. A detailed agenda outlining the schedule and activities will be communicated closer to the event.

Signed Agreement

Full Name _____

Signature _____

Date _____