



T21RS Code of Governance 2026

The Trisomy 21 Research Society (T21RS) is an international non-profit organization for the promotion of scientific research on Down syndrome, operating under Dutch law. T21RS was founded on 17th April 2014 in Groningen, The Netherlands, under the auspices of Mr. Kraster, civil-law notary and member of The Royal Dutch Association of Civil-law Notaries. This T21RS code of governance (in Dutch: huishoudelijk reglement) follows the rules and regulations provided in the articles of association (Statute) and is in accordance with Dutch law.

The English translation of the official articles of association written in Dutch can be downloaded through our website: www.t21rs.org/about-us/statute

General aims of T21RS (in reference to Article 2 of the Statute)

T21RS has been established to stimulate and promote research on Down syndrome, and its aims are described in Article 2 of the Statute. These are achieved by engaging with and facilitating interactions between:

- preclinical and clinical researchers studying Down syndrome
- people with Down syndrome and their carers via Down syndrome associations
- general public, policy makers, and industry

In addition, the Society may support critical research activities and promote the development of common research protocols and advocate for optimal use of resources such as existing datasets and biobanks.

Diversity, Inclusion, and Equity

T21RS aims to improve the lives of all people with Down syndrome through research and improve knowledge regardless of gender, ethnicity, age or socio-economic background/status. We recognize that there are many parallels between the history of the disability movement and movements for civil rights across the world. Therefore, we see our position for an inclusive and anti-discriminatory scientific society as an integral part of our mission.

Conflict of interest (Col) policy

All members of the T21RS Executive Board, chairs and members of committees and workgroups shall abide by the T21RS conflict of interest policy, which is attached to this Code of Governance (Addendum 1).

Specific regulations

1. Composition and appointment of the Executive Board (in reference to Articles 10 and 11 of the Statute)

- 1.1. The Society shall be governed by an Executive Board comprising full members of T21RS, including the President, the Treasurer, the Secretary, and the Chairs of the six Standing Committees – all with voting rights (in reference to Article 4 of the Statute[RB2]).
- 1.2. The Past-President and the President-Elect attend the Executive Board meetings but have no official voting rights.
- 1.3. The Past-President is appointed automatically for two years on expiry of their term; the newly elected President is appointed as President-Elect upon their election until assuming the presidency. They participate in the Executive Board meetings but do not have the right to vote.
- 1.4. The Treasurer will serve for a maximum of six years. The Secretary and the Chairs of the six Standing Committees shall serve for a period of two years, renewable twice without election up to a maximum of 6 years if approved by Executive Board. The only exception is the Program Committee Chair who will not be eligible for re-election after their two-year term.
- 1.5. Other people (co-chairs of committees, chairs of workgroups, chair of the T21RS International Conference local organizing committee, chairs of local chapters etc.) may be invited to attend specific Executive Board meetings as needed, but do not have voting rights.

2. Election of Executive Board members (in reference to Article 11 of the Statute)

- 2.1. Executive Board members shall be elected by full members in good standing of T21RS.
- 2.2. A call for nominations shall be sent to the members of T21RS at least two months before the date of the election, specifying the format of nominations (usually biosketch and a short description of the qualifications of the nominees, their goals for the office and the acceptance of the responsibilities as Executive Board member). Nominations must be submitted to the Society's Secretary at least four weeks before the election.
- 2.3. Candidates may also be nominated directly by T21RS members.
- 2.4. Nominations will be considered by the Executive Board who will approve a list of candidates. Every nominee must have been a full member of T21RS in good standing for at least one year at the time of their appointment as Executive Board member.
- 2.5. Members shall be advised of the list of nominees and their applications at least two weeks before the election takes place.

- 2.6. Elections shall be held by electronic ballot (e-vote). Nominees with the largest number of votes for each position on the Executive Board will be elected. In case fewer than 10% of members vote, a new vote will be called, the number of T21RS full members in good standing being the one at the date of the election.

3. Meetings of the Executive Board (in reference to Article 13 of the Statute)

- 3.1. Meetings shall be chaired by the President or, in their absence, the Secretary. If neither is present, the other Executive Board members shall decide amongst themselves who shall chair the meeting.
- 3.2. Meetings may (and usually will) be held virtually.
- 3.3. A quorum of a minimum of 2/3 of T21RS Executive Board members is required for voting decisions.
- 3.4. Executive Board has the ability of removal of an elected person in case of behavioral misconduct (e.g., neglect their obligations with the Society, scientific misconduct, harassment, etc.). The situation will be discussed in an extraordinary meeting and removal of the elected person must be approved by at least 2/3 of T21RS Executive Board members.

4. Responsibilities (in reference to Article 14 of the Statute)

- 4.1. The President represents T21RS externally and chairs the Executive Board.
- 4.2. The Secretary is responsible for giving notice of meetings, preparing and circulating agendas in advance, preparing and circulating minutes and for maintaining the documents of the Society, for the mechanics of elections and such other responsibilities as the Executive Board shall decide.
- 4.3. The Treasurer is responsible for T21RS's funds and bookkeeping, accounting and auditing services.

5. Committees (in reference to Article 16 of the Statute)

- 5.1. The Society consists of the following six Standing Committees:
- Program Committee
 - Committee for Science & Society
 - Committee for Sponsoring and Membership
 - Committee for Education and Training
 - Committee for Preclinical Research
 - Committee for Clinical Research
- 5.2. The Executive Board may delegate specific aspects of the Society's work to such committees.
- 5.3. The Executive Board may create workgroups for specific purposes. Candidate(s) for Chair of a workgroup is nominated and voted for approval by the Executive Board. A Chair of a workgroup does not have voting rights in the Executive Board but can participate in the Executive Board meetings if invited.

- 5.4. Appointment of Committee members: members may volunteer for a committee by contacting the Chair. The Chair will propose Committee members to the Executive Board for approval.

6. Voting rights (according to Article 4 of the Statute)

Every full member shall have one vote, subject to payment of any fees being up to date of the day of the election. Associate members, Honorary members and individuals representing Supporting members are entitled to attend the General Assembly, but do not have voting rights. Each Funding member organizations has one vote plus extra votes (one every 100 T21RS members at the time of the vote) in the General Assembly.

7. Organization of the T21RS International Conference

- 7.1. Members can suggest proposals for hosting the biennial International Conference of T21RS through a call for preliminary proposals. The Executive Board will review preliminary proposals and invite worthy ones to submit a formal full-written proposal. The Executive Board will review full proposals to invite consideration of final proposals. During the General Assembly taking place during the Conference, final proposals will be presented, and members will vote online within the time of the Conference for the place and tentative date. The final date will be decided by the Executive Board in coordination with the winning proposer.
- 7.2. The scientific program will be elaborated by the Program Committee whose chair will be elected 18 months in advance of the Conference and will be part of the Executive Board. Calls for symposia and abstracts and selection of the symposia, the scientific abstracts for poster or oral presentations will be done by the Program Committee. If there are travel funds based on merit, the Program Committee, together with the Education Committee will determine which applicants receive Travel Awards. In the event that travel is supported by grants with specific requirements, the Program Committee will consult with the Principal Investigator of the grant to assure that requirements are met.
- 7.3. Composition of the Program Committee will include the past chair of the Program Committee and the Past President of the T21RS to ensure continuity.
- 7.4. The organization will be shared with the Local Organizing Committee, appointed 18 months in advance of the Conference. The Chair of the Local Organizing Committee will be appointed by the Executive Board and will be responsible for selecting its members. The Chair will also attend Executive Board meetings.
- 7.5. The Local Organizing Committee will solicit competitive bids with conference organizing companies. Contract should be negotiated and approved by the Executive Board.
- 7.6. The chair of the Local Organizing Committee does not have voting rights in the Executive Board.
- 7.7. T21RS Conference will include a Science & Society symposium and family-oriented activities organized by the Committee for Science & Society in coordination with the Program Committee. Towards this goal, it will be desirable to consult with Founding and Supporting members when developing the program. The specific program of the Science

& Society symposium is decided by the Committee for Science & Society. Other specific symposia and pre-conference meetings or satellite activities can be proposed by the different Committees or by T21RS Workgroups and members and incorporated in the program if agreed by the Executive Board.

7.8. Members of the Program Committee will serve for 2 years, with extensions requiring approval by the Executive Board.

8. T21RS Full Members

Full members of T21RS are academic or clinicians who are working or studying in the field of research and/or health care in connection with Down syndrome. Full members will get access to several benefits: 1/ Be part of the only worldwide Down syndrome research network, 2/ Discounts for T21RS biennial Conferences, 3/ Complimentary T21RS webinars, 4/ Online subscription to the T21RS Newsletter, 5/ Access to common protocols and documents established by the various T21RS Committees.

Members will renew annually.

Membership options:

- Full membership with different fees depending on the status (student, postdoctoral fellowship, academic staff members or clinicians). A reduced rate is applied to membership fees for low- and middle-income countries.
- Multiyear renewal for Principal Investigators and permanent staff members for two or three years,
- Laboratory memberships. Under this option, the Principal Investigator may co-enroll students (both pre doctoral and postdoctoral) and pay a rate linked to the number of students named under the Principal Investigator. This option is only available on a year-by-year basis.
- Details of the fees are provided in Addendum 2.

9. T21RS Founding, Supporting, and Associate Members

- T21RS values close and supporting relationships with Down syndrome foundations and other organizations supporting research or health care for individuals with Down syndrome. These foundations or other legal entities can become members of the Society.
- A small number of organizations and associations have been designated as Founding Members, having been instrumental in providing the financial support to found and sustain the Society. Founding members contribute a yearly fee to the maintenance of T21RS. All the monetary contributions of Founding Members are regulated under specific agreements.
- A small number of organizations and associations have been designated as Supporting Members, having been instrumental for financially supporting the Society. Supporting members contribute a yearly fee to the maintenance of T21RS. All the monetary contributions of Supporting Members are regulated under specific agreements.

- Associate Members are organizations or associations with an interest in research and/or health care related to Down syndrome, and with which the Society wishes to enter into a relation that will benefit the aims of the Society. An Associate Member pays an annual membership fee (see Addendum 2).
- Individuals representing Founding Members, Supporting Members, and Associate Members can attend T21RS General Assembly. Founding Members have one vote plus extra votes (one every 100 T21RS total members at the time of the vote). Supporting Members and Associate Members do not have voting rights.
- Individuals representing Founding, Supporting or Associate members are not eligible for election to executive positions of the Society.
- The benefits for Founding Members and Supporting Members are set out in a separate document (Addendum 3).

10. Grants, prizes and awards

Grants, prizes, and awards are awarded to T21RS full members.

10.1 T21RS Award Program for Outstanding PhD Theses

- The T21RS Award Program for Outstanding PhD theses includes two awards - the Annette Karmiloff-Smith and Michael Harpold Dissertation Awards. The calls for the awards are biennial and announced in December, the year before the biennial International Conference.
- Each recipient will receive an honorarium of 1,000 EUR and the opportunity to present their results during the T21RS International Conference that will take place in the year following the application deadline.
- The topic of the dissertation must be in the field of Down syndrome and applicants must be Full Members of T21RS at the time of application.
- Members of the evaluation committee will be chosen among the members of the Executive Board and the Education Committee. The decision of the Committee shall be final, with no possible appeal.
- Awardees should attend the award ceremony held at the biennial T21RS International Conference and should write an article about their thesis for the T21RS Bulletin. Registration fees are waived.
- The awardee should fill in a T21RS Thesis Award form and return this to the T21RS Technical Secretariat. The Treasurer will subsequently transfer the award (by bank transfer) to the awardee.

10.2 T21RS Young Investigator Travel Award

- The T21RS provides Travel Grants to attend the T21RS International Conference for students, postdoctoral fellows, and junior scientists to recognize excellence in Down syndrome research and promote greater interaction among researchers.
- The travel grants provide partial support for attending the International Conference and are typically limited to 1,000-2,000 EUR.

- The Scientific Committee of T21RS International Conference, together with the Education Committee, is charged with evaluating the grant applications.
- After the T21RS International Conference has finished, the awardee should fill in the T21RS Travel Award reimbursement form and return this to the T21RS Technical Secretariat together with receipts (travel / hotel etc.). The Treasurer will subsequently transfer the award (by bank transfer) to the awardee within one month after the T21RS International Conference has ended.
- Candidates could be asked to write a short article aimed at general scientific audience about their work for the T21RS Newsletter and Bulletin no later than six months after the International Conference.

10.3 T21RS Poster Awards

- At the T21RS International Conference, junior researchers will have the chance to win a Poster Award. These awards are given on-site to the posters of the highest scientific excellence and most effective presentation.
- The Program Committee and Education Committee will nominate an evaluation panel.
- Each poster award may consist of either a monetary award up to 500 EUR or free registration for the subsequent T21RS International Conference at the discretion of the Program Committee and Education Committee. Up to six poster awards are expected to be funded.
- Candidates could be asked to write a short article aimed at general scientific audience about their work for the T21RS Bulletin or Newsletter no later than six months after the International Conference.

10.4 Charles J. Epstein Award for Early-Stage Investigators

- The Charles J. Epstein Award is a biennial award sponsored by the National Down Syndrome Society (NDSS) in collaboration with the Trisomy 21 Research Society (T21RS) initiated in 2026. It honors an exceptional early-stage independent researcher whose work shows outstanding dedication and potential to advance science in the field of Down syndrome.
- Eligibility/Requisites. The candidate must be a full member of T21RS and classified as an early-stage investigator (received terminal degree \leq 10 years prior to application and/or not yet promoted to Associate Professor or equivalent), The award is open to candidates of all nationalities, backgrounds, and beliefs. Self-nominations are not accepted.
- Evaluation. Applications are reviewed by a joint NDSS–T21RS ad hoc committee and evaluated based on scientific excellence and originality of research, demonstrated commitment to Down syndrome science. evidence of leadership potential and future impact.
- The awardee will receive an honorarium of 5,000 USD cash generously provided by NDSS plus a personalized plaque, and an invited presentation at the T21RS International Conference. They must attend the T21RS International Conference in person to receive the award. Registration fees are waived. They must provide a short research summary within 6 months after the International Conference for sharing through NDSS and T21RS networks.

10.5 Jérôme Lejeune lecture

- The Jérôme Lejeune Keynote lecture is supported by the Jérôme Lejeune Foundation as part of their biennial International Conference support.
- It typically should cover the registration, travel and accommodation expenses of an outstanding researcher in the Down syndrome field.
- The Jérôme Lejeune lecturer is chosen by the current T21RS President.
- The researcher giving the Jérôme Lejeune Keynote lecture will sign an agreement with the Jérôme Lejeune Foundation not to present research on fetuses or human embryonic cells.

10.6 T21RS grants to support Scientific Events

- T21RS provides funding to T21RS full members for the organization of scientific and dissemination events, such as scientific meetings and other events, which will contribute to increasing the public visibility of Down syndrome research and of T21RS.
- The activities must target a wide audience, and the activities may range from local activities on specific topics to multidisciplinary scientific activities. The maximum amount funded for each event is 500 EUR, with two calls per year. Founding, Supporting or Associate Members cannot be awarded funding, but they can be co-applicants with Full Members. Successful applicants cannot apply in the next call. Approximately 10 awards can be made per call, but the number of awards may vary.
- After official announcement and after the specific event has taken place, the awardee should fill in the T21RS Events Award reimbursement form and return this to the T21RS Technical Secretariat together with receipts from the meeting. The Treasurer will subsequently transfer the award (by bank transfer) to the awardee within one month after the meeting has taken place.

10.7 T21RS Scientific Exchange Grants

- The aim of this program is to support the ability of young investigators to initiate and sustain collaborations between existing laboratories focused on Down syndrome research. Under this initiative, a young investigator and, if applicable their mentor, would propose a visit to another laboratory to gain expertise, launch a collaboration or some other activity that would enhance the young investigator's work in Down syndrome.
- Young investigators considered eligible include MSc students, MD students, PhD students or postdocs no more than 5 years after their PhD or MD degree has been granted.
- A budget to cover the cost of travel and lodging, up to a maximum of 5,000 EUR, will be allowed. Up to 3 applications will be awarded by year. A short report on progress made during the visit will be required written to be shared in the T21RS Newsletter.

10.8 T21RS Early Investigator Award

- The aim of this grant program is to support early-stage investigators in pilot projects that allow access to reagents and expertise important for completing preliminary studies whose

results would support applications for funding from other entities – e.g., foundations, public grants, etc.

- Applicants should hold full-time positions at an academic research center.
- Funding will not exceed a maximum of 10,000 EUR for the entire project period, which will usually be completed within one year. We anticipate funding up to three such applications per year. A full report of progress is required at the time of project completion.

10.9 Support for Knowledge Exchange visits

- T21RS provides funding to enable researchers at any stage of career development to familiarize themselves with everyday health and social issues experienced by individuals with Down syndrome. Investigators whose work is in fundamental, translational, or clinical research in Down syndrome are eligible to apply. Only T21RS Full Members can apply.
- A budget to cover the cost of travel and lodging, up to a maximum of 5,000 EUR, will be allowed. Applications will be received on a continuing basis. We anticipate funding up to three such applications per year. A full short report of progress is required at the time of project completion written to be shared in the T21RS Newsletter.

10.10 Travel fellowship to attend scientific meeting the year when T21RS does not have its International Conference to present research on Down syndrome

- T21RS offers funding to support clinicians, researchers, students, and postdocs at any career stage to attend scientific meetings where they will present research on Down syndrome.
- Funding includes a budget of up to 3,000 EUR to cover registration, travel, and lodging expenses. Applications are accepted on a rolling basis for meetings held in years when T21RS does not organize its International Conference. We expect to fund up to three applications.
- After the meeting, a certificate of attendance should be sent to the T21RS Technical Secretariat, and the presenter is required to acknowledge T21RS funding.

10.11 T21RS Honorary Membership

- Honorary Members of T21RS are living and retired scientists and clinicians recognized for their outstanding contributions to the field of Down syndrome research and care. Honorary members are exempt from any membership fees and are entitled to attend the General Assembly but have no voting rights.
- A call for Honorary Member nominations will be placed before T21RS in the International Conference. T21RS members in good standing may nominate candidates for Honorary Membership to be considered by the Executive Board. Approved candidates are voted online by members during the General Assembly of T21RS in the International Conference.

11. Chapters

11.1 Role

- T21RS local Chapters are regional communities of scientists interested in Down syndrome research. They provide opportunities to educate and inform the public about the importance of Down syndrome research through outreach activities.
- Those wishing to establish a new Chapter should notify the Executive Board in writing specifying 1) the region represented; 2) the names of at least 5 people within the region with acknowledged interest and expertise in DS; 3) that each of those named are Full Members of T21RS; 4) the need for the Chapter and the benefits expected from establishing the Chapter; 5) the plans for recruiting additional members within the region; and 6) the kinds of activities and events that are to be planned by the Chapter.
- A representative from each Chapter will be invited to two meetings of the Executive Board yearly. Once yearly they will be asked to provide brief oral and written reports outlining Chapter activities over the past year. Chapters may wish to speak to challenges that confront those with Down syndrome and the Down syndrome research and clinical communities within the region.
- Chapters host outreach events such as Brain Awareness Week, World Down Syndrome Day, and more. T21RS Chapters are critical to the success of T21RS advocacy and membership. In 2020 four local chapters were created: China, Europe, India, South and Central America.

11.2 The missions of local chapters are to

- Organize meetings during off year (i.e. between T21RS International Conferences) for dissemination of scientific results and programs.
- Help members broaden their knowledge by hosting scientific lectures, poster sessions, and workshops.
- Announce local grant opportunities, local funded scientific programs, scientific reports for these funded programs, local clinical trials.
- Conduct local lobbying advocacy activity. Chapters can host laboratory tours and invite policymakers to see the benefits of research first-hand.
- Foster networking for students, academics, researchers, and other professionals to exchange information, research, and career opportunities and help expand T21RS membership.
- Provide opportunities for scientists to educate and inform the public about Down syndrome research.
- Contact scientists that are new in the field.

11.3 Funding

- Local Chapters may apply for funding from T21RS to organize specific events (typically through the Scientific Events grant program); they can also apply for local funding support.

11.4 Executive Board attendance

- Chairs of local Chapters are invited twice a year to participate in the Executive Board to provide feedback and report on specific questions.
- Chairs of local Chapters do not have voting rights.

12. Industry Supporters

- T21RS is keen to actively engage industry and to foster their support for and engagement in research activities to improve the health and quality of life of people with Down syndrome and their caregivers.
- Companies and other commercial or funding entities may therefore apply to be industry Supporters of the Society and be supporters of the T21RS International Conference.
- An important benefit for Industry Supporters is that their contribution will be recognized on the T21RS website/ materials, and they will also benefit from exposure to members who are key opinion leaders and experts in various aspects of Down syndrome.
- Direct advertisements of products or services to members are not allowed other than via Conference where industry can have the option of manned stands, if approved by the Executive Board.
- Benefits and expectations associated with Industry Support are explained in an addendum (Addendum 4).
- In addition, individuals from companies may become Full Members of the T21RS and contribute to Workgroups (except for the Communication Workgroup), if approved by the Executive Board. For such roles, they will be expected to abide by the T21RS conflict of interest policy.

Attachments:

1. Addendum 1: Conflict of Interest Policy
2. Addendum 2: Membership Fees
3. Addendum 3: Founding and Supporting Membership Benefits
4. Addendum 4: Industry Supporter Benefits



Addendum 1: THE T21RS CONFLICT OF INTEREST POLICY

1) General

- a. This policy relates to all Committees and Workgroups (including Chapters) of the T21RS, their chairs and members.
- b. The purpose of this document is to minimize the potential for conflicts of interest and to protect T21RS and those associated with it from any perception, real or otherwise, that the external interests and affiliations of its committee members might interfere with their ability to work towards the furtherance of the Society.

2) Declaration of interest

- a. Any person covered by this policy, as defined in paragraph 1(a), must declare any disclosable existing or arising external interest upon their appointment to T21RS and throughout their term of service. A register of interests shall be maintained and kept up to date by the Chair of each Committee, who shall report to the Executive Board annually.
- b. Interests that should be disclosed by T21RS officers include:
 - Equity interests (if worth 5,000 USD or more (or equivalent), or more than 1% of the total issued capital) in enterprises with involvement in pharmaceuticals, healthcare, biotech or related areas, or in any other enterprise that may have a real or perceived interest in the work of the charity. Third party investments (e.g., as part of a combined investment vehicle) should be held exempt from this.
 - Consultancies and other external appointments (other than academic/faculty appointments) whether paid or unpaid, if directly related to or potentially in conflict with the work of the T21RS.
 - Being in the employment of external organizations (other than academic/faculty appointments) that are also active in the Down syndrome research or funding arena and thus could be perceived to be a conflict of interest.
- c. Committee members should also adhere to the spirit of this document and declare any other interests which they feel may be a source of conflict, or which might be perceived to conflict with the interests of the charity. This includes interests held by the panel members' immediate family including partner/spouse or dependent children.

3) Discussion of T21RS business and documents

- a. Details of meeting papers, minutes, committee decisions on awards or grants and related correspondence should be assumed to be confidential (unless approved for public access, such as our finalized Annual Reports, or Newsletters) and should not be discussed with persons outside the T21RS.

- b. Committee members and chairs should report potential breaches of confidential information to the Executive Board.

4) Managing conflicts of interest

- a. Where a committee member, or chair, is identified to have a potential conflict of interest when decisions are to be made, they should declare this and may be expected to be excluded from voting / be involved in the relevant decision; this includes prizes and awards, or the awarding of contracts. The Executive Board can be asked to judge whether the conflict of interest is significant, or not.

A disqualifying conflict of interest for a specific proposal exists if the individual (chair, committee member or referee):

- Was involved in the preparation of the proposal
- Stands to benefit directly should the proposal be accepted or awarded
- Has a close family relationship with the applicant
- Is a director, trustee or partner of an applicant

Furthermore, a disqualifying conflict of interest for a specific proposal exists if the individual is in any other situation that could compromise his or her ability to evaluate the proposal impartially, such as the individual:

- Has close family ties or a personal relationship with the promoter or beneficiary of the proposal
- Is a former supervisor of the promoter or beneficiary of the proposal
- Is a close collaborator of the promoter or beneficiary of the proposal.

5) Resolution conflicts of interest

- a. T21RS recognizes that most conflicts or potential conflicts will relate to a particular issue and as such will not present any long-term restrictions on an individual's ability to work for the Society or to sit on its committees.
- b. In a small number of cases, major conflicts of interest may arise that compromise an individual's ability to continue in their position within the Society. Where such a situation arises, the case will be referred to the Executive Board as a whole, who will decide whether the person is able to continue in their role.
- c. Members of committees are expected to declare any potential conflicts of interest as soon as the existence of a conflict becomes apparent; in any case, committee members will report conflicts of interest annually.
- d. In cases where an individual is uncertain as to whether a conflict of interest exists, they should report this to the Executive Board and its chair, who shall discuss the matter with the individual and then decide on a course of action.
- e. If an individual is concerned about a possible conflict of interest involving another member, then he or she should raise the matter with the chair of the relevant committee, or the T21RS President, whichever is most appropriate.

6) Updating the policy

- a. T21RS will endeavor to review this policy, if necessary, every two years.



Addendum 2: MEMBERSHIP FEES

T21RS offers different memberships depending on your role (e.g., academics and clinicians, or associate members). T21RS also provides the option to purchase 2- or 3-year membership at a discounted rate. In addition, laboratories may include up to four students under a single membership.

Full membership fees

- Academic staff members and clinicians: 100 EUR (1 year), 180 EUR (2 years), 260 EUR (3 years)
- Postdoctoral fellows: 80 EUR (1 year)
- Students (Master students and PhD-students): 40 EUR (1 year).

Membership discounts are available based on the World Bank income classification of the country of residence:

- 50% discount for upper-middle-income countries
- 75% discount for lower-middle- and low-income countries.

Laboratory Memberships. Under this option, the Principal Investigator (PI) may co-enroll students (both pre-doctoral and post-doctoral) and pay a rate linked to the number of students named under the PI at a rate that does not differ between pre-doctoral or post-doctoral students. This option is only available on a year-by-year basis.

- PI + 1 Student: 150 EUR
- PI + 2 Students: 200 EUR
- PI + 3 Students: 250 EUR
- PI + 4 Students: 300 EUR.

Associate membership fee

An Associate Member is a member designated by an organization or association with an interest in research and/or health care related to Down syndrome,

- Fee: 50 EUR (1 year).



Addendum 3:

T21RS FOUNDING MEMBER AND SUPPORTING MEMBER BENEFITS

A. FOUNDING MEMBER BENEFITS

In return for a fee laid out in a specific agreement, the T21RS shall express its gratitude to the Founding Member with the following benefits:

1. Founding member recognition

Display of logo with active link to the Founding Member web site:

- Homepage of T21RS website(s) (e.g., www.t21rs.org)
- Promotional material related to the biennial T21RS International Conference, such as the Conference program or pdf
- Monthly T21RS Newsletters.

2. T21RS Membership

Free membership as Associate Member for one representative selected by the Founding Member.

3. T21RS International Conference

- 3.1. Free attendance at the biennial T21RS International Conference for two representatives selected by each Founding Member.
- 3.2. First Right of Refusal. All Founding Members will be offered, simultaneously, the first right of refusal to sponsor conferences, workshops, meetings, etc.

4. Other benefits

- 4.1. T21RS will provide access to the T21RS periodic publications (Newsletter and Bulletin) which present information regarding important research in a balanced way.
- 4.2. T21RS General Assembly. T21RS is a professional organization for researchers, and the membership of the organization is intended for scientists. However, Founding Members will receive one General Assembly vote plus extra votes (one every 100 T21RS total members at the time of the vote).
- 4.3. Participation in T21RS Committees. Founding Members can suggest ideas to the chairperson of the various T21RS Committees, such as the Committee for Sponsoring and Membership, the Committee for Education and Training, the Committee for Science & Society and the Communication Work Group. These Committees and Work Groups consist of scientists who are Full Members of the Society. However, the Committees welcome Founding Members to provide ideas and suggestions

for future initiatives, for instance topics for the Science & Society Bulletin or the Science & Society Symposium in the biennial T21RS International Conference.

4.4 T21RS will share information on Founding Member's events in T21RS Newsletter and/or website.

4.5 T21RS Committees will provide answers to questions raised by the Founding Member and sent to the Secretary of T21RS, cc the Technical Secretary every 3 months.

B. SUPPORTING MEMBER BENEFITS

In return for a fee laid out in a specific agreement, the T21RS shall express its gratitude to the Supporting Member with the following benefits:

1. Supporting members recognition

Display of logo with active link to the Supporting Member web site:

- Homepage of T21RS website(s) (e.g., www.t21rs.org)
- Promotional material related to the biennial T21RS International Conference, such as the Conference program or pdf
- Monthly T21RS Newsletters.

2. T21RS Membership

Free membership as Associate Member for one representative selected by the Supporting Member.

3. T21RS International Conference

- 3.1. Free attendance at the biennial T21RS International Conference for two representatives selected by each Supporting Member.
- 3.2. First Right of Refusal. All Supporting Members will be offered, simultaneously, the first right of refusal to sponsor conferences, workshops, meetings, etc.

4. Other benefits

- 4.1. T21RS will provide access to the T21RS periodic publications (Newsletter and Bulletin) which present information regarding important research in a balanced way.
- 4.2. T21RS General Assembly. T21RS is a professional organization for researchers, and the membership of the organization is intended for scientists. However, each Supporting Member will be able to designate one Supporting member, i.e., a representative, to attend the General Assembly without voting rights.
- 4.3. Participation in T21RS Committees. Supporting Members can suggest ideas to the chairs of the various T21RS Committees, such as the Committee for Sponsoring and Membership, the Committee for Education and Training, the Committee for Science & Society and the Communication Work Group. These committees and work groups consist of scientists who are full members of the Society. However, the Committees welcome Supporting Members to provide ideas and suggestions for future initiatives.
- 4.4 T21RS will share information on Supporting Member's events in T21RS Newsletter and/or website.
- 4.5 T21RS Committees will provide answers to questions raised by the Supporting Member and sent to the Secretary of T21RS, cc the Technical Secretary every 3 months.



Addendum 4: T21RS INDUSTRY SUPPORTER BENEFITS

Companies and Corporations that have an interest in Down syndrome research and comorbidities may apply to the T21RS for Industry Supporter status. An official request for Industry Supporter status should be sent to the T21RS Secretary. The decision and vote on Industry Supporter status are made by the Executive Board of T21RS.

Benefits:

1. Publicity and Exposure

- A listing in the biennial International Conference Program
- Industry Supporter logo and website listed on T21RS website.

2. Biennial Conference

- Fifty-percent reduction in registration fee for one representative to attend the T21RS Conference
- Priority housing for one representative in T21RS blocked off hotel rooms
- An enhanced listing on the biennial International Conference exhibitor page.

3. Advertisement in T21RS Newsletter

- Advertisement in two issues of T21RS Newsletter for Platinum Industry Supporters (750 EUR Annually)
- Advertisement in one issue of T21RS Newsletter for Gold Industry Supporters (500 EUR Annually).