



T21RS Code of governance

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 (with reference to article 2 of the statutes)

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

- researchers studying Down syndrome, both clinical and preclinical
- 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 improved 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.

Specific regulations:

1. Composition of the Executive Board (in reference to Article 10)

1.1. The Society shall be governed by an Executive Board comprising members of T21RS, including the President, the Treasurer, the Secretary and the Chairs of the six Standing Committees – all with voting rights (Article 5).

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 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 organising 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)

2.1. Executive Board members shall be elected by the 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 nominee, their goals for the office and the acceptance of the responsibilities as Executive Board member). The deadline for receipt of nominations to the Society's Secretary shall be at least 4 weeks before the election takes place.

2.3. Candidates may also be nominated directly by a minimum of 1/10 of T21RS members, the number of T21RS members in good standing being the one at the date of the call for nomination.

2.4. Nominations will be considered by the Executive Board who will approve a list of candidates. Every nominee must have been a member of T21RS in good standing for at least one year at the time of his/her 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 in the Executive Board will be elected.

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

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 electronically.

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 misconducting behavior (e.g., neglect their obligations with the society, scientific misconduct, harassment, etc.). The situation will be exposed in an extraordinary meeting and removal of the elected person has to be approved for at least 2/3 of T21RS Executive board members.

4. Responsibilities (in reference to Article 14)

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 book-keeping, accounting and auditing services.

5. Committees (in reference to Article 16)

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. 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)

Every Full member shall have one vote, subject to payment of any fees being up to date. Associate members and Honorary members are entitled to attend the General Assembly, but do not have voting rights.

7. Organization of the T21RS International Conference

7.1. Members can suggest proposals for hosting the Conference through a call for proposals, but the place, and the date will be decided by the Executive Board upon considering the bids.

7.2. The scientific program will be elaborated by the Program Committee whose chair will be elected 18 months in advance of the meeting 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 Meeting Organizer appointed by the Executive Board. A chair of the local organising committee will be appointed, also 18 months in advance of the conference. The chair of the local organising committee will also attend Executive board meetings.

7.5. The chair of the local organising committee does not have voting rights in the Executive Board.

7.5. T21RS meetings will usually include a Science & Society symposium and family-oriented activities organized by the Committee for Science & Society in coordination with the Program Committee. It will be desirable to consult with supporting and founding members when developing the program. The specific program of the Science and Society 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.

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

8. Membership

T21RS 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 for researchers and clinicians with different fees depending on the status (student, postdoctoral fellowship, academic staff members or clinicians)
- Multiyear renewal for PIs and permanent staff members for two or three years
- Lab memberships. Under this option, the PI may co-enroll students (both pre-doctoral and postdoctoral) and pay a rate linked to the number of students named under the PI. This option is only available on a year-by-year basis.

9. Founding and associate members (supporting organisations)

- T21RS values close and supporting relationships with Down syndrome foundations. These foundations, or their individual members, can become associate members of the society; a small number has been designated as Founding members, having been instrumental in providing the support to found the society. Supporting organisation associate members are non-profit organizations dedicated to significantly improving the lives of people with Down syndrome through Research, Medical Care and/or Advocacy, that contribute a yearly fee to the maintenance of T21RS.
- The relationship and benefits associated with different levels of support is set out in a separate document – see addendum 2. All the monetary contributions are regulated under specific agreements.
- Individuals representing founding, supporting or associate members can attend our general assembly, but do not have voting rights. Individuals representing founding members or associate members are not eligible for election to executive positions of the society.

10. Grants, prizes and awards

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 annual conference.
- Each recipient will receive an honorarium of 1000 Euro and the possibility to present their results during the T21RS meeting 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 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 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 to attend the annual meeting, and is typically limited to 500 -1000 Euros.
- The scientific committee of T21RS International Conference, together with the Education committee, is in charge of evaluating the grant applications.
- After the T21RS International Conference has finished, the awardee should fill in the

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T21RS Travel Award reimbursement form and return this to the T21RS 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 an article about their work for the T21RS newsletter and bulletin no later than six months after the meeting.

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 Programme committee and Education committee will nominate an evaluation panel.
- After official announcement, the awardee should fill in the T21RS Poster Award form and return this to the T21RS Secretariat. The Treasurer will subsequently transfer the award (by bank transfer) to the awardee within one month after announcement.
- Candidates could be asked to write an article about their work for the T21RS bulletin or newsletter no later than six months after the meeting.

10.4 Monserrat Trueta award

- Supported by the Catalan Down Syndrome Foundation (FCSD), T21RS launched the Monserrat Trueta Outstanding Career Award. Montserrat Trueta was the founder of the FCSD. This award recognizes outstanding scientists in the field of Down syndrome, for their sustained and distinguished career, including groundbreaking scientific contributions, leadership, and mentoring. It also reflects the strong DS research alliances that T21RS is building.
- The Montserrat Trueta Award is awarded every two years, and the awardee will receive €8,000. This agreement commenced on 1 February 2019 and shall continue until 30 June 2023 and can be renewed.
- The payment to the awardee will be made directly by the Sponsor to the awardee after his/her selection by an ad hoc committee created by the T21RS. Applicants must be members of T21RS for at least two years before the prize is awarded. Candidates should attend the award ceremony held at the biennial T21RS International Conference, and should write an article about their work for the T21RS bulletin no later than six months after the award ceremony. Registration fees are waived.

10.5 Jérôme Lejeune lecture

- The Jérôme Lejeune Keynote lecture is supported by the Jérôme Lejeune Foundation as part of their biennial meeting 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.

10.6 T21RS grants to support Scientific Events

- T21RS provides funding to T21RS members for the organization of scientific and

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dissemination events, such as scientific meetings and other events, which will

contribute to increase the public visibility of Down syndrome research and of T21RS.

- The activities have to be targeting 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 Euro 500, with two calls per year. Foundations/ supporting or associate members cannot be awarded funding, but they can be co-applicants with 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 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 labs focused on Down syndrome research. Under this initiative, a young investigator and, if applicable their mentor, would propose a visit to another lab to gain expertise, launch a collaboration or some other activity that would enhance the young investigator's work in Down syndrome.
- Only T21RS members can apply to this grant.
- Young investigators are considered to be: 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 report of progress made during the visit will be required.

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 be T21RS members and would 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 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 report of progress is required at the time of project completion.

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) confirm that each of those named are active members of T21RS; 4) speak to 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) outline 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 and organize events regularly: 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 conferences) for dissemination of scientific results and programs.
- Help members broaden their knowledge by hosting scientific lectures, poster sessions, and workshops.
- Announcement of local grant opportunities, announcement of local funded scientific programs, scientific reports for these funded programs, local clinical trials.
- 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 neuroscientists to educate and inform the public about Down syndrome research.

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- Contact scientists that are new in the field.

11.2 Funding:

- Local chapters may apply for funding from T21RS to organize specific events (typically through the scientific events grant programme); they can also apply for local funding supports.

11.3 Executive board attendance

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

12. Industry membership

- 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 associate industry members of the society, and be sponsors of the T21RS international conference.
- An important benefit for industry members is that their contribution/ associate membership will be recognised 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 advertisement of products or services to members are not allowed other than via conference sponsorship where industry can have the option of manned stands, if approved by the Executive board.
- Benefits and expectations associated with Industry membership are explained in an addendum.
- In addition, individuals from companies may become ordinary members of the T21RS, and contribute to workgroups (with the exception of 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. Conflict of interest policy
2. Associate and industry membership 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 minimise 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 persons covered by this policy, as defined in paragraph 1a), must declare any disclosable existing or arising external interest on their appointment to T21RS, and during the whole period of service. A register of interests will be kept up to date by the chair of each committee, who will update the Executive boards annually.
- b. Interests that should be disclosed by T21RS officers include:

Equity interests (if worth USD 5,000 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 organisations (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

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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 finalised annual reports, or newsletters) and should not be discussed with persons outside the T21RS.
- b. Committee member(s) and chairs should report potential breaches of confidential information to the Executive board.

3) Managing conflicts of interests

- a. Where a committee member, or chair, identifies or 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 the relevant decision; this includes for 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

4) Resolution conflicts of interest

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- a. The T21RS recognises that the majority of 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.

5) Updating the policy

- a. The society will endeavour to review this policy, if necessary, every two years.



Addendum 2: T21RS INDUSTRY ASSOCIATE MEMBERSHIP

Companies, and corporations that have an interest in Down syndrome research and comorbidities may apply to the T21RS for Industry Associate Membership

An official request for Industry Associate Membership should be sent to the T21RS Office. The decision and vote on membership is made by the Executive board of T21RS.

Automatic Benefits:

All Industry Associate Members receive robust benefits.

Publicity and Exposure

- A listing in our bi-annual meeting's *Program*
- Your logo and website link featured in our [Member Directory](#)

Annual Meeting Perks

- Fifty-percent reduction in registration fee for one representative to attend the T21RS conference
- Priority housing for one representative

Extra benefits for Platinum affiliate member

€ 750 Annually

- Advertisement in two issues of *T21RS newsletter*
- An enhanced listing on the biannual meeting's exhibitor page

Extra benefits for Gold affiliate member

€ 500 Annually

- Advertisement in one issue of *T21RS newsletter*
- An enhanced listing on the biannual meeting's exhibitor page