Trisomy 21 Research Society
2025 Annual Report

Contents

Committee reports

General information

The Trisomy 21 Research Society (T21RS) is the first non-profit scientific organization of researchers studying Down syndrome. T21RS was founded to promote basic and applied research on Down syndrome, stimulate translational research, and apply new scientific knowledge to develop improved treatments and cures.

T21RS aims to:

- Facilitate the permanent interaction between researchers studying Down syndrome by means of our website, social media, scientific meetings, webinars, publications in journals and our biennial T21RS International Conference.
- Establish common protocols both for basic research (e.g. animal studies, stem cells studies) and translational research (e.g. for clinical trials with biomarkers, cognitive paradigms etc.).
- Support education and training of young researchers in all stages of their careers, including undergraduates, graduates and postdoctoral fellows that are interested in Down syndrome, by providing training programs and grants to young scientists to stimulate research on Down syndrome.
- Explain (recent) findings in Down syndrome studies to the general public and to inform legislators and other policymakers about new scientific knowledge and recent developments and their implications for public policy and society.
- Promote the interaction between scientists and patient associations, foundations, and pharmaceutical industries.

The society was created in April 2014 and statutes were registered on 17th April 2014 in Groningen, The Netherlands, under the auspices of Mr. Albert Kraster, civil-law notary practicing in Groningen and member of The Royal Dutch Association of Civil-law Notaries. These statutes were revised on 11th July 2017. The executive Board of T21RS produced a Governance document in line with these statutes to facilitate operation which will be revised every two years (most recently 2025). The society is a non-profit organization for the stimulation of scientific research on Down syndrome, operating under Dutch law. The original deed in Dutch and the English translation can be downloaded from the society website, t21rs.org, as well as the most up-to-date Governance document. In 2020, the executive Board of T21RS created a Policy of Conflict of Interest also available as Addendum 1 in the Governance. Finally, a privacy policy is available on the website according to EU General Data Protection Regulations. The Governance was revised and accepted by the executive board, and publicly posted in January 2025.

The society has organized five T21RS International Conferences:

1. 2015 edition in Paris, France (June 4-8, 2015)
2. 2017 edition in Chicago, USA (June 7-11, 2017)
3. 2019 edition in Barcelona, Spain (June 5-9, 2019)
4. 2022 edition in Long Beach, USA (June 9-12, 2022)
5. 2024 edition in Rome, Italy (June 5-8, 2024)

Due to COVID-19 pandemic constraints, the society organized in 2021 the first virtual T21RS International Conference (June 8-10, 2021). The sixth **T21RS International Conference** is planned for 2026 in Denver, Colorado, USA (June 17-20, 2026). A call to host the 7th T21RS International Conference in 2028 was launched in December 2025.

The **2025 T21RS General Assembly** was hosted online on June 30, 2025 by T21RS president, Marie Claude Potier, who presented the 2024 Annual Report and budget. An online survey was sent to active T21RS members who voted to approve both.

To comply with new European security and privacy laws, the secretariat of T21RS, BCO, transitioned T21RS documents from a Google Drive system to Microsoft 365, which requires two-factor authentication for access.

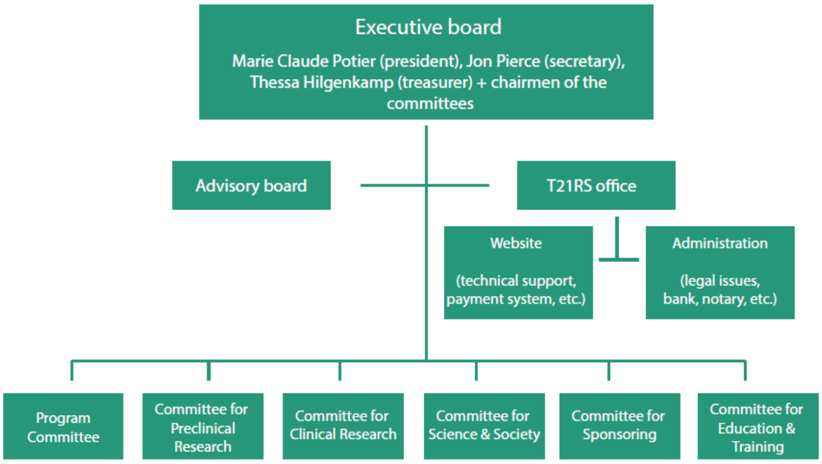
The Trisomy 21 Research Society awards prestigious biennial honors to recognize excellence in Down syndrome research. The society is grateful to the Catalan Down Syndrome Foundation for many years of support for the **Montserrat Trueta Outstanding Career Award**, which was discontinued in 2025.

T21RS Education and Training Committee continues to present the **Annette Karmiloff-Smith and Michael Harpold Dissertation Award** to recognize outstanding Ph.D. research. For 2024–2025, two young investigators were selected for this honor.

The National Down Syndrome Society (NDSS), based in the United States, proudly sponsors the **Charles J. Epstein Award for Early-Stage Investigators** in partnership with the Trisomy 21 Research Society. This award honors an outstanding early-stage independent researcher whose work shows exceptional promise for advancing Down syndrome research. Charles J. Epstein pioneered the gene-dosage hypothesis for Down syndrome and developed the first mouse models of trisomy 21, laying the foundation for understanding how extra copies of chromosome 21 genes affect development and cognition. Presented biennially, the award reflects the strong collaboration between NDSS and T21RS in supporting the next generation of researchers. Calls for nominations were issued to members in 2025, with awardees to be announced at the 6th T21RS International Conference in Denver, USA in June 2026.

Executive board of T21RS

The executive board is formed by the president, secretary, and treasurer of T21RS as well as the chairs of the committees.



President:
Marie Claude Potier, Paris Brain Institute ICM (France) until Dec 2025 followed by **Renata Bartesaghi,** University of Bologna (Italy)
Past President:
William Mobley, University of California (US) until Dec 2025
Secretary:
Jon Pierce, The University of Texas at Austin (US)
Treasurer:
Thessa Hilgenkamp, University of Nevada, Las Vegas (US)

Committee chairs:
Program Committee: **Kelly Sulivan**, Univ Colorado (US) from October 2024
Committee for Science & Society: **María Carmona-Iragui,** Hospital de la Santa Creu (Spain) and **Anne-Sophie Rebillat** (France), Institut Jérôme Lejeune, followed by **Floriana Costanzo** (Italy) and **Sujay Ghosh** (India) in September 2025
Committee for Sponsoring: **Eugenio Barone** and **Marzia Perluigi,** Sapienza University of Rome (Italy)
Committee for Education and Training: **Fiorenza Stagni** and **Marco Emili,** Bologna University (Italy)
Committee for Preclinical Research: **Frances Wiseman**, Dementia Research Institute (UK) and **Randall Roper,** Indiana University Indianapolis School of Science (US)
Committee for Clinical Research:
    Adult Sub Committee: **Shahid Zaman**, University of Cambridge (UK)
    Developmental Sub Committee: **Brian Skotko**, Massachusetts General Hospital (US)

Elections were for several positions in 2025 using electronic ballots. In July, 51 active members voted for the next co-chairs of the Science and Society Committee. **Dr. Floriana Costanzo** and **Dr. Sujay Ghosh** were elected with 76.5% of the votes. In December, 80 active members voted for the next president-elect. **Prof. Anita Bhattacharyya** was elected with 60% of the votes.

Report of the President

Dear Members, Colleagues, and Supporters,

As we reflect on 2025, I am proud to present this annual report on behalf of the Trisomy 21 Research Society (T21RS). This year, the Society's direction has focused on strengthening our mission to accelerate Down syndrome research through expanded support for early-career scientists, enhanced knowledge exchange, and stronger connections between laboratory research, clinical practice, individuals with Down syndrome and their families, and the Society as a whole.

I would like to take this opportunity to express my deep gratitude to the funding and supporting members of T21RS who have generously renewed their commitment through new agreements supporting the Society in the coming years. We are especially grateful to **Global Down Syndrome Foundation**, the **National Down Syndrome Society** (now merged with LuMind), the **Jérôme Lejeune Foundation**, **Trisomie 21 France**, **The Matthew Foundation**, **Down España**, and the **Association Française pour la Recherche sur la Trisomie 21 (AFRT)**.

In 2025, the Society continued to support the research and career development of T21RS members through three **Membership Initiatives**. These included **Early Investigator Awards**, **Knowledge Exchange Awards**, and **Scientific Exchange Awards**. Knowledge Exchange Awards enable basic and translational researchers to spend time in clinical settings, helping them better understand the real-world health needs of individuals with Down syndrome and bridge the longstanding gap between mechanistic research and clinical challenges. Scientific Exchange Awards support travel to other laboratories, where researchers can learn new techniques and build collaborations. This year's awardees included:

Name	Initiative Category
Emily Blackburn	Early Investigator Award
Paige Mumford	Early Investigator Award
Antonella Izzo	Early Investigator Award
Lisi Flores	Early Investigator Award
Antonella Di Paolo	Knowledge Exchange
Luis Miguel Echeverry Quiceno	Scientific Exchange
Julianne Clina	Scientific Exchange
Eric Rubenstein	Scientific Exchange

To support T21RS members travel to conferences during a year that we do not host our T21RS Conference, in January 2025 we launched a new initiative. Four young-stage T21RS members were awarded Off-Year Travel Fellowships to present their DS research at conferences:

- Victorine Artot, IGBMC, France
- Julia Atanasova, The Hospital for Sick Children, Toronto, Canada
- Sara Guerreiro, University of Minho, Campus de Gualtar, Portugal
- Bruna Zampieri, Hospital Israelita, Brazil

Support for scientific communication and dissemination expanded this year with two calls. The Society now assists members in organizing meetings and outreach events that raise awareness of Down syndrome research, reflecting a strong commitment to building global networks. This year, 18 awardees received Scientific Events Supporting DS Research fellowships to host events worldwide.

Name	Event
Christy Hom	University of California, Irvine’s 3rd Annual Down Syndrome Showcase
Hannah Rea	“First Annual Down Syndrome Community Awareness, Resources, and Education Symposium” or “DS CARES”
Jean-Baptiste Oswald	JMT21 2025 – Journée mondiale de la trisomie 21
Jelena Hubrechts	scientific meeting on “Transition from pediatrics to adult medicine of Down patients”
Lucio Nitsch	IX National Scientific Conference “Down Syndrome: from Research to Therapy”
Mara Dierssen	World Down Syndrome Day: the science behind Down syndrome
Micaela Sartoretti	Symposium "Neuroscience through the lens of single cell genomics"
Shahid Zaman	World Down’s Syndrome Day hosted by the Cambridge Intellectual and Developmental Disability Research Group (CIDDRG) 2025
Jacqueline London	La Journée Mondiale de la Trisomie 21
Sigan Hartley	Genetically Determined Alzheimer’s Disease: ADAD-DSAD Conference 2nd edition
Luciene Covolan	I have Down syndrome—so what? - X Brazilian Congress on Down Syndrome and VII Ibero-American Congress on Down Syndrome
Randal Roper	Society for Neuroscience Social Event
Melanie Johnston	DSMIG-Aus Annual Scientific Meeting 2026: Health Across the Lifespan,
Agnish Ganguly	World Down Syndrome Day 2026 T21RS Indian Chapter
Cristina Fasolato	"Intellectual disability and neurodiversity, a challenge that concerns us" DADI Association Padua, Italy
Paige Mumford	World Down syndrome Day 2026 public engagement event
Tracie Rosser	Emory Down Syndrome Research and Caregiver Symposium Proposal
Jelena Hubrechts	Transit 21: On the way to adult life! - UZ Brussels

We have further reinforced our commitment to connecting research with real-world impact through an expanded program of online events. These include the 2025 **World Down Syndrome Day** webinar series, which covered topics such as genetics, cardiac phenotypes, Alzheimer-related mechanisms, and emerging areas of research. In April 2025, T21RS also published a Correspondence in *The Lancet Neurology* titled “Advocating for Increased Awareness and Research on Down Syndrome,” marking World Down Syndrome Day and highlighting the need for continued global research efforts.

Planning is already well underway for the sixth international **T21RS Conference**, scheduled for 17–20 June 2026 in Denver. The meeting will address lifespan health in Down syndrome, co-occurring medical conditions, translational therapeutics, biomarker development, clinical trials, and Alzheimer’s disease in Down syndrome. Submitted symposia and abstracts reflect a broad and multidisciplinary scientific agenda aimed at engaging both senior and early-career researchers.

I extend my deepest gratitude to our members, research teams, families, and supporters who continue to drive our mission forward. Together, we are making a meaningful impact, and I am confident that the years ahead will bring further breakthroughs and opportunities for individuals with Down syndrome.

We are also especially grateful to **Anita Bhattacharyya**, who was elected President-Elect; **Floriana Costanzo** and **Sujay Ghosh**, who were elected co-chairs of the Science and Society Committee, and **Mara Dierssen**, who was selected to serve as Chair of the Neuropathology Working Group.

As I now pass the leadership of T21RS to our new President, **Renata Bartesaghi**, I would like to thank all of you—especially Jon and Thessa, the chairs of our committees and working groups, and BCO—for your extraordinary dedication, commitment, and talent in supporting the growth and progress of T21RS.

With warm wishes,

I –Program Committee

Introduction

Below is an overview of the key activities and accomplishments of the committee for 2025. The committee was assembled with diverse expertise and has worked collaboratively to advance program objectives.

Committee Membership:

Title	**Name**	**Location**	**Career Stage**	**Professional Area of Research**	**Sex**
Chair	**Kelly Sullivan**	**US/CO**	**Mid-Career**	**Immune/Broad**	**M**
Past Chair	Shahid Zaman	UK	Senior	Neuro/AD	M
Past President	Bill Mobley	US/CA	Senior	Neuro/AD	M
Member	Larry Suva	US/TX	Senior	Bone Physiology	M
Member	Soula Danopolous	US/CA	Early Career	Lung Biology	F
Member	Bruna Zampieri	Brazil	Early Career	Immune/Broad	F
Member	Anna Esbensen	US/OH	Senior	Cognitive Development	F
Member	Eleanor Malloy	IRL	Senior	Immunity	F
Member	Patrick Lao	US/NY	Early Career	Neuro/AD	M

Major Activities and Accomplishments

1. BCO won a competitive bid to arrange 2026 conference which was approved by the executive committee.
2. Since May, the committee has convened bimonthly to discuss program design and strategy.
3. Two major grant applications for travel support were submitted: one to the NIH R13 program and another to the Jerome Lejeune Foundation.
4. A call for symposia was issued, resulting in more than 40 proposals received and 20 selected for inclusion.
5. Four plenary speakers have been identified and confirmed.
6. The committee collaborated with both the clinical and pre-clinical committees to initiate planning for the satellite meeting.
7. A call for poster submissions was released, and ~270 abstracts were received.
8. Abstract scoring is underway, with efforts focused on incorporating as many as possible into the program.
9. The abstracts will be used to select up to 36 speakers for the nanosymposia.

Conclusion

The committee has made strong progress in organizing the program and engaging the research community. Current efforts focus on reviewing abstracts and finalizing selections for symposia and nanosymposia speakers. These milestones reflect the effective collaboration and dedication of the committee members.

II - Committee for Science & Society

This committee works to explain recent scientific findings and promote access to research for people with Down syndrome (DS)

Chairs of the committee:
Maria Carmona-Iragui (Spain) & Anne-Sophie Rebillat (France), 2020-2025
Floriana Costanzo (Italy) & Sujay Gosh (India), 2025-onward
Committee members:
Lotta Granholm (USA, Sweden), temporarily resigned in 2025
Sebastián Videla (Spain)
Isabel Barroeta (Spain)
Hampus Hillerstrom (USA), resigned in 2025
Eric Rubenstein (USA)
Jacqueline London (France)
Michelle Maugham-Macan (Australia)
Asaad Baksh (UK), resigned in 2025
Floriana Constanzo (Italy)
Jelena Hubrechts (Belgium)
Sujay Gosh (India)
Maria Carmona-Iragui (Spain)
Anne-Sophie Rebillat (France)

Initiatives and achievements in 2025:

1) Election of the new chairs of the Science & Society Committee:
Maria Carmona-Iragui and Anne-Sophie Rebillat have completed their two-year term, which was renewed twice (for a total of nearly six years), in accordance with the T21RS bylaws.
A call for nominations was issued on May 23, 2025. Floriana Constanzo and Sujoy Gosh were elected as the new chairs on July 28, 2025, by a 76.47 % vote of the T21RS members.

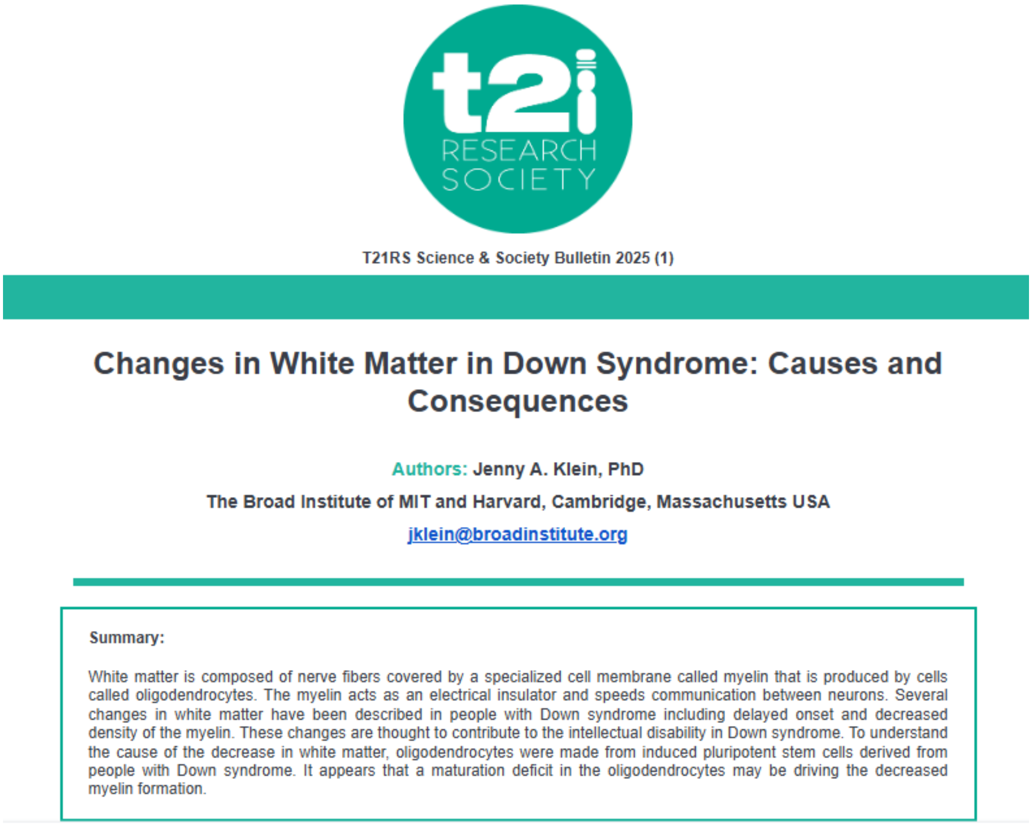
2) Call for new members:
A call for applications to recruit new members (in the fields of basic science and advocacy) was issued on December 4, 2025.
Carmona-Iragui and Rebillat will remain on the committee to support the transition.

3) Regular meetings by videoconference (60 minutes)
13/02/2025
04/09/2025
07/10/2025
11/11/2025
18/12/2025

4) T21RS Science & Society Bulletins
Two bulletins were published in 2025:

Bulletin 1 (11/03/2025):
Changes in white matter in Down syndrome : causes and consequences by Jenny KLEIN
Bulletin 2 (01/07/2025):
Is screening for obstructive sleep apnea between 3 and 4 years of age in childen with Down syndrome too

late by Hervé WALTI.



T21RS Science & Society Bulletin 2025 (1)

Changes in White Matter in Down Syndrome: Causes and Consequences

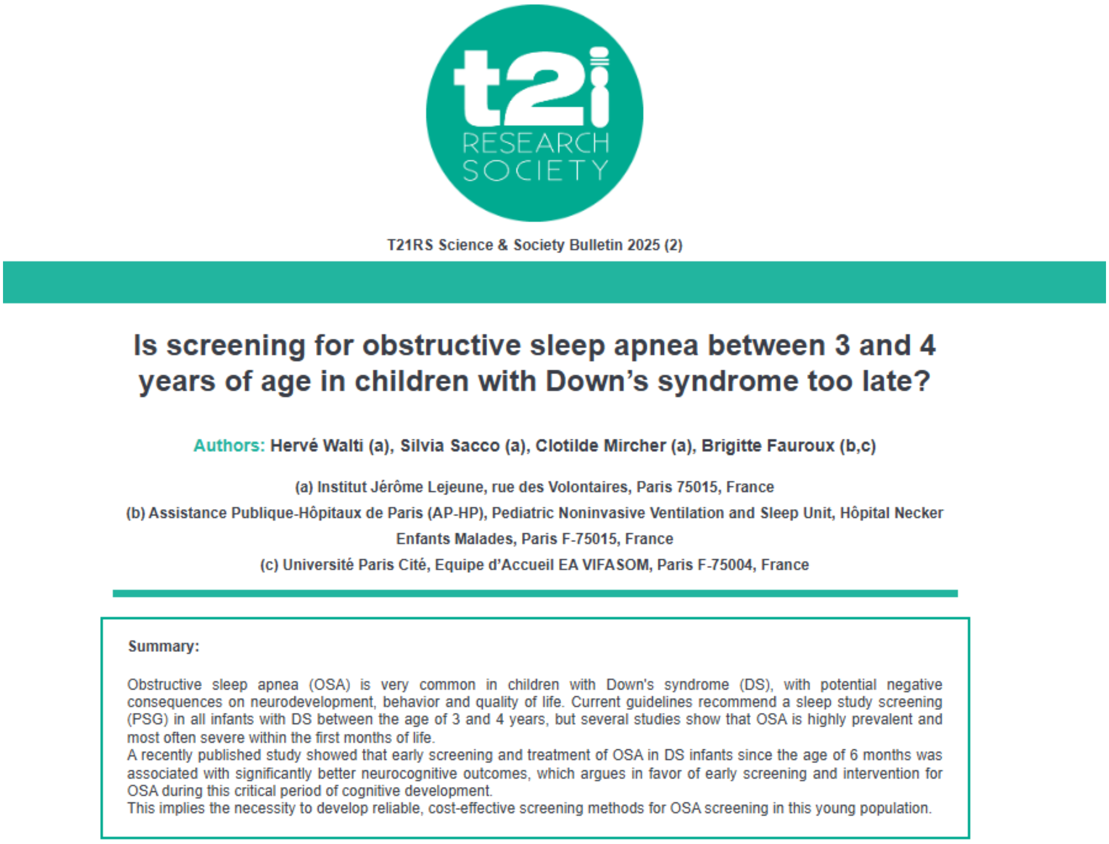
Authors: Jenny A. Klein, PhD

The Broad Institute of MIT and Harvard, Cambridge, Massachusetts USA

jklein@broadinstitute.org

Summary:

White matter is composed of nerve fibers covered by a specialized cell membrane called myelin that is produced by cells called oligodendrocytes. The myelin acts as an electrical insulator and speeds communication between neurons. Several changes in white matter have been described in people with Down syndrome including delayed onset and decreased density of the myelin. These changes are thought to contribute to the intellectual disability in Down syndrome. To understand the cause of the decrease in white matter, oligodendrocytes were made from induced pluripotent stem cells derived from people with Down syndrome. It appears that a maturation deficit in the oligodendrocytes may be driving the decreased myelin formation.



T21RS Science & Society Bulletin 2025 (2)

Is screening for obstructive sleep apnea between 3 and 4 years of age in children with Down's syndrome too late?

Authors: Hervé Walti (a), Silvia Sacco (a), Clotilde Mircher (a), Brigitte Fauroux (b,c)

(a) Institut Jérôme Lejeune, rue des Volontaires, Paris 75015, France
(b) Assistance Publique-Hôpitaux de Paris (AP-HP), Pediatric Noninvasive Ventilation and Sleep Unit, Hôpital Necker Enfants Malades, Paris F-75015, France
(c) Université Paris Cité, Equipe d'Accueil EA VIFASOM, Paris F-75004, France

Summary:

Obstructive sleep apnea (OSA) is very common in children with Down's syndrome (DS), with potential negative consequences on neurodevelopment, behavior and quality of life. Current guidelines recommend a sleep study screening (PSG) in all infants with DS between the age of 3 and 4 years, but several studies show that OSA is highly prevalent and most often severe within the first months of life.
A recently published study showed that early screening and treatment of OSA in DS infants since the age of 6 months was associated with significantly better neurocognitive outcomes, which argues in favor of early screening and intervention for OSA during this critical period of cognitive development.
This implies the necessity to develop reliable, cost-effective screening methods for OSA screening in this young population.

5) T21RS International Conference 2026 in Denver - Science & Society Symposium

As with every conference, the committee is working hard to organize the symposium, which will be held on June 20, 2026, and will consist of two 2-hour sessions.

III - Committee for Sponsoring

Committee Members

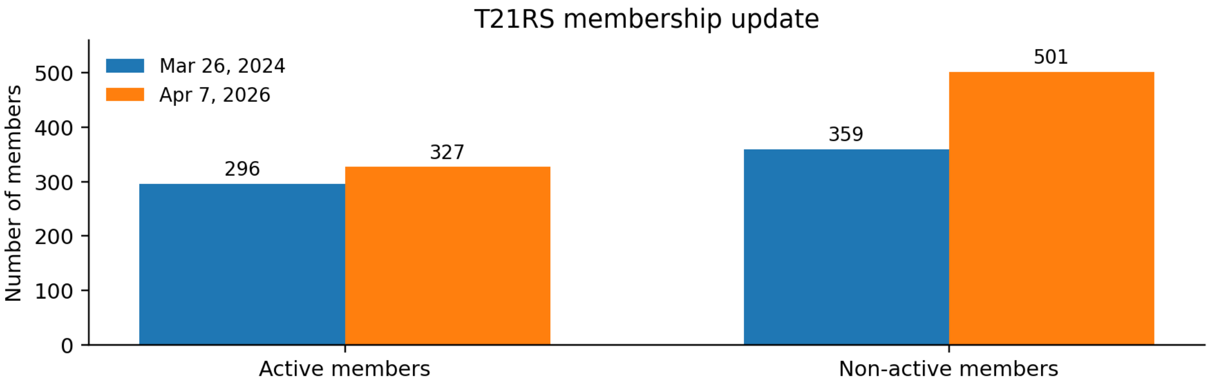
Chair of the committee: **Eugenio Barone** (Italy)
Co-chair of the committee: **Marzia Perluigi** (Italy)
Members:
Yong Dai (China)
Pablo Helguera (Argentina) **Hampus Hillerstrom** (US) **Sujay Ghosh** (India)
Marie-Claude Potier (France) **Carmen Martinez-Cue** (Spain) **Michelle Whitten** (GDSF, US)

Members of the Committee should be reviewed, considering that we lost contact with many of them. The committee regrettably did not convene over the past year(s). Our priority remains to reconnect with all members to ascertain their availability and interest in continuing their involvement. Furthermore, we are actively seeking new members to bolster our efforts.

Membership activities

As of April 7, 2026, T21RS had 327 active members, 501 non-active members, and 12 honorary members. For comparison, on March 26, 2024, the Society had 296 active members and 359 non-active members. These updated figures are reported here to support the 2025 annual report.

The figure below summarizes the updated membership counts, comparing the most recent snapshot available (April 7, 2026) with the figures reported on March 26, 2024.



Honorary members (Apr 7, 2026): 12

Overall, the updated data indicate a modest increase in active members (from 296 to 327) together with a marked expansion of the broader contact base classified as non-active members (from 359 to 501). Honorary membership currently includes 12 individuals. These figures confirm continued interest in the Society while also underscoring the importance of strengthening renewal and re-engagement strategies to convert non-active members into active members.

IV - Committee for Education and Training

Education and Training Committee Members

Chair of the committee:
Fiorenza Stagni (University of Bologna, Italy)

Co-Chair of the committee:
Marco Emili (University of Bologna, Italy)

Member:
Jennifer Bruno (Stanford University, CA, USA)
Renata Bartesaghi (University of Bologna, Italy)

The activity of the T21RS Committee for Education and Training is aimed at:

- Organizing Webinars to promote the dissemination of the latest research advancements in the field of Down syndrome and to provide young members of the Society with the opportunity to interact and exchange ideas with leading international experts in both preclinical and clinical Down syndrome research;
- Recognizing the high quality of research carried out by young investigators of the Society through the awarding of various prizes;
- Encouraging the professional and scientific development of early-career researchers by supporting initiatives that facilitate collaboration, knowledge exchange, and access to pilot funding opportunities.

Initiatives and activities in 2025

Throughout the course of 2025, the Education and Training Committee hosted the following webinars, in which recognized scientists in the preclinical and clinical fields of Down syndrome research presented their latest findings to the T21RS community:

January 29th, 2025 “**NKCC1 inhibition: the long journey from basic research to clinical studies**". Speaker: **Dr. Laura Cancedda**, Brain Development and Disease Laboratory, Istituto Italiano di Tecnologia, Genova, Italy;

March 3rd, 2025: “**Spatial multi-omics in DS-AD identifies shared changes with sporadic AD**”.
Speaker: **Prof. Vivek Swarup**, Institute for Memory Impairments and Neurological Disorders, Department of Neurobiology and Behavior, University of California, Irvine;

July 17th, 2025: “**A dynamic in vitro model of Down syndrome neurogenesis with trisomy 21 gene dosage correction**”. Speaker: **Prof. Stefan F. Pinter**, Department of Genetics and Genome Sciences, UCONN Health, University of Connecticut, Farmington, CT, USA;

September 30th, 2025: "**Comorbidities and quality of life in trisomy 21: clinical and molecular evidence from an Italian cohort**". Speaker: **Prof. Maria Chiara Pelleri**, Department of Biomedical and Neuromotor Sciences, University of Bologna, Bologna, Italy;

December 15th, 2025: "**Non-invasive brain stimulation as a new therapeutic strategy for cognitive and behavioural improvement in Down syndrome**". Speakers: **Dr. Floriana Costanzo**, Unit of Child and Adolescent Neuropsychiatry, Bambino Gesù Pediatric Hospital (IRCCS), Rome, Italy and **Dr. Marco Cambiaghi**, Department of Neurosciences, Biomedicine and Movement Sciences, University of Verona, Italy

In February 2025, the Education and Training Committee launched the Call for the World Down Syndrome Day Webinar, dedicated to young members of the Society. This initiative gave PhD students and postdoctoral fellows the opportunity to present and discuss their latest research findings with a broad audience of researchers, associations, and families.

Based on the number of applications received, the Education and Training Committee hosted two editions of the **World Down Syndrome Day Webinar**.

On April 3rd, 2025 the following young investigators presented their data:
First talk – **Elysabeth D. Otte**, Indiana University, Indianapolis, USA: "Characterization of behavioral phenotypes in the TcMAC21 mouse model of Down syndrome";
Second talk – **Md Rezaul Islam**, Picower Institute for Learning and Memory, Massachusetts Institute of Technology, Cambridge, MA, USA: "Multisensory gamma stimulation enhances adult neurogenesis and improves cognitive function in male mice with Down syndrome";
Third talk – Abbas Raza, Department of Biology, University of Dayton, Ohio, USA: "Cerebellar circuit deficits in Down syndrome";
Fourth talk – **Maria Franquesa Mullerat**, Sant Pau Memory Unit – Department of Neurology, Institut de Recerca Sant Pau - Centre CERCA, Barcelona, Spain: "Study of brain blood flow changes in Down syndrome";
Fifth talk – **Cliona Farrell**, UK Dementia Research Institute and UCL Institute of Neurology, UK: "Studying Alzheimer's disease and Down syndrome using brain tissue"

On May 5th, 2025 the following young investigators presented their data:
First talk – **Maria Caracausi**, Department of Biomedical and Neuromotor Sciences, University of Bologna, Bologna, Italy: "Deletions of human chromosome 21 regions in fibroblasts with trisomy 21";
Second talk – **Sophie Sanchez**, University of Texas, Austin, USA: "Identifying key genetic drivers of Down syndrome traits and shedding light on other duplication disorders";
Third talk – **Leah Borden**, Department of Biology, Massachusetts Institute of Technology, Cambridge, USA: "Investigating the role of extracellular matrix in mechano-genomic regulation of trisomy 21 associated cardiac phenotype";
Fourth talk – **Edward Evans Jr.**, Anschutz Medical Campus, University of Colorado, Aurora, USA: "Understanding the Mutational Landscape of the Blood in People with Down Syndrome";
Fifth talk – **Dong Shin Park**, Picower Institute for Learning and Memory, Massachusetts Institute of Technology, Cambridge, USA: "Prenatal GENUS treatment supports brain development in a mouse model of Down syndrome";
Sixth talk – **Christopher David Ozeroff**, Crnic Institute Boulder Branch, BioFrontiers Institute, University of Colorado Boulder, USA: "Insights into Down syndrome comorbidity and gene associations using AREA (Attribute Rank Enrichment Analysis);
Seventh talk – **Charlotte Jacob**, Department of Biomedical Science, University of Antwerp, Belgium: "Can behavioral changes predict an Alzheimer's diagnosis in Down Syndrome"

In November 2025, the Education and Training Committee launched a call to recruit new members, offering early career researchers the opportunity to apply for joining the Committee.

In November 2025, the Education and Training Committee launched a call for the **Annette Karmiloff-Smith and Michael Harpold Dissertation Award Program** for outstanding PhD theses in the Down syndrome research field. This initiative was limited to candidates who obtained the PhD during the period January 1, 2024 to December 31, 2025. Eight candidates were reviewed and the winners will present the main findings of their PhD thesis at the 2026 T21RS Conference.

V - Committee for Preclinical Research

Preclinical Committee Members:

Chairs of the committee:
Randall Roper (US)
Frances Wiseman (UK)

Members:
Antonarakis, Stylianos (Switzerland)
Balduino, Danella (France)
Dierssen, Mara (Spain)
Fisher, Elizabeth (UK)
Haydar, Tarik (USA)
Herault, Yann (France)
Khor, Bernard (USA)
Meharena, Hiruy (USA)
Mobley, William (USA)
Okun, Eitan (Israel)
Pinter, Stefan USA
Potier, Marie-Claude (France)
Nizetic, Dean (UK)
Maugham-Macan Michelle, (Australia)
Reeves, Roger (USA)
Roper, Randall J (USA)
Sathyanesan, Aaron (USA)
Sousa, Andre (USA)
Thyme, Summer (USA)
Tramutola, Antonella (Italy)
Welshhans, Kristy (USA)
Wiseman, Frances K (UK)
Yu, Y. Eugene (USA)
Zampieri, Bruna (Brazil)
Zeldich, Ella (USA)

Junior fellows: served in 2025

Daniella Victorino (animal models subcommittee)
Leah Borden (cellular models subcommittee)
Kaoru Takasaki (cellular models subcommittee)

The Committee is pursuing its objectives to help standardize high quality preclinical research into Down syndrome, including by facilitating access to important resources, and helping provide essential robust data for those resources including controls.

Initiatives and achievements in 2025

1. **Reorganization of the Committee: to facilitate effectiveness:** The Preclinical Committee has grown in size and in 2025 this permitted the establishment of three subcommittees each with specific aims outlined below. Each committee elected a nominated chair to lead their activities Translational subcommittee: Chair Bernard Khor, Cellular subcommittee: Chair Kristy Welshhans, Animal Models subcommittee: Chair Aaron Sathyanesan.

   Translational Subcommittee Aims
   Maximise translational relevance of preclinical studies
   Maximise preclinical potential of clinical work/studies (e.g. clinical metadata)
   Communicate potential translational leads to clinical colleagues
   Hear emerging/critical needs from clinical colleagues and self/family advocates
   Cellular models Subcommittee Aims
   Create a spreadsheet of T21 and control induced pluripotent stem cells (iPSCs)
   Create a spreadsheet T21 Somatic Cells
   Dissemination of resources and best practice
   Animal models Subcommittee Aims
   Pharmacological interventions in T21 animal models spreadsheet/database
   Resource to facilitate current animal model researchers to use other methods
   Dissemination of resources and best practice

2. **Our committee promotes research in Down syndrome by extensive involvement in various scientific meetings:** Our committee has proposed to co-host a Satellite Meeting in collaboration with the Clinical Committee with three sessions “Vaccine Safety and Efficacy for persons who have Down syndrome”, “Congenital Heart Defects in persons who have Down syndrome” and “Infantile spasms in persons who have Down syndrome” ” at Trisomy 21 at T21RS International Conference in June 2026, in Colorado, USA. The Satellite Meeting will be led and delivered by Early Year Career (Postdoctoral and Junior Faculty) and focus on specific themes of interest to both the Preclinical and Clinical research communities (in coordination with the Programme Committee).
3. Co-chair of our committee (Randall Roper) proposed and was awarded a Society for Neuroscience Social “Preclinical Researchers and Clinicians Improving Lives in Individuals with Down Syndrome.” The event successfully brought together a diverse group of preclinical and clinical researchers. Attendees included long-standing T21RS members as well as scientists not yet affiliated with the society, providing an excellent opportunity for recruitment and outreach. Members of the T21RS Preclinical Committee also presented their data at, Winter Conference on Brain Research, Lake Tahoe, California, 2025 (A. Sathyanesan), Indian Academy of Neuroscience Annual International Conference, Thiruvananthapuram, India, 2025 (A. Sathyanesan), The International Mammalian Genome Society Conference, Glasgow, Scotland (R. Roper).

4. **Our committee members promote excellence in Down syndrome research using animal models by sitting on National Committees.** This includes the Medical Research Councils National Mouse Genetics Network, UK (F. Wiseman), and the Cytogenetic Resource - External Advisory Board of the NIH and Jackson Laboratory, USA (R. Roper, H Meharena, T. Haydar, and B. Khor). Through this Advisory Board, we have worked to continue to provide essential information and a broader access to the TcMAC21 DS mouse model, and access to the Ts66Yah mouse model in 2025.

5. **Our committee members provide information on the use of Down syndrome animal models.** Members of the T21RS Preclinical Committee including Daniella B. Victorino, Leah K. Borden, Marie-Claude Potier, William Mobley, Mara Dierssen, Kristy Welshhans, Michelle Maugham-Macan, Antonella Tramutola, Eitan

Okun, Roger Reeves, Randall Roper, Y. Eugene Yu, Yann Hérault, Elizabeth M.C. Fisher, and Aaron Sathyanesan worked to submit a *STAR Protocols* primer entitled "A Researcher's Guide to Rodent Models of Down Syndrome: Recent Insights and Translational Perspective". Members of the T21RS Preclinical Committee including Aaron Sathyanesan, Michelle Maugham-Macan, Daniella Balduino Victorino, Summer Thyme, Antonella Tramutola, Randall Roper, and Frances Wiseman have worked to review and create a database of pharmacological interventions in animal models of Down syndrome with an accompanying review for submission to *Molecular Pharmacology* entitled "A curated resource of intervention evidence summaries in preclinical animal models of Down syndrome" to highlight this resource to the community.

6. **Our committee members promote research in Down syndrome by undertaking public and key stakeholder communication activities.** This included the 2025 World Down Syndrome Day celebration of science (Francis Crick Institute, London) (F. Wiseman, E. Fisher), AFRT21, Le Mans March 20-21st (Y. Herault), 2025 Science Night at Indiana University Indianapolis (R. Roper), (DS-CARES and DSMIG Vaccine sub-group, B. Khor).

7. **Training the next generation of DS researchers:** We continued to commit our efforts to be inclusive for new investigators, both early career and new to the field, by inviting applications from early career investigators to join the T21RS Preclinical Committee. Drs. Daniella Victorino, Leah Borden, and Kaoru Takasaki will be junior members of the T21RS Preclinical Committee for 2025, and Drs. Rene Crans and Eva Lana-Elola will be junior members of the T21RS Preclinical Committee for 2026.

8. **Our committee continued to update a list of Down syndrome patient-derived iPS cells and fibroblasts/lymphoblastoids and to increase availability of cells to all researchers.** Drs. Kristy Welshhans and Bruna Zampieri led this effort and hired an additional person using funds from T21RS to assist in gathering this information. This information is available on the T21RS website (https://www.t21rs.org/).

9. **Broadening the usage and understanding of Down syndrome mouse models in the society and larger community.** Drs. Randall Roper, Yann Hérault, Roger Reeves, Lizzy Fisher, Victor Tybulewicz, and Eugene Yu updated a list of currently available Down syndrome mouse models that will be freely available to all on the T21RS website (https://www.t21rs.org/).

VI - Committee for Clinical Research

Clinical Adult Committee Members:

Chair of the committee:
Shahid Zaman (Current Chair)

Members:
Angelo Carfi (Italy)
Alberto Costa (US)-past-chair
Juan Fortea (Spain)
Benjamin Handen (US)
Sigan Hartley (US)
Sharon Krinsky-McHale (US)
Huntington Potter (US)
Michael Rafii (US)
Anne-Shopie Rebillat (France)
Weihong Song (China/Canada)
Andre Strydom (UK)

Angelo Carfi, MD (IT); angelo.carfi@policlinicogemelli.it
Dr. Carfi is a geriatrician at the Centre for Continuing Healthcare and Frailty Fondazione Policlinico Universitario A. Gemelli IRCCS, Rome. His top areas of expertise are Down Syndrome, COVID-19, Long Haul COVID, and Severe Acute Respiratory Syndrome (SARS).

Alberto Costa, MD, PhD (US); alberto.costa@case.edu
Dr. Costa is Clinical Professor at the Departments Psychiatry at Case Western Reserve University. For over two decades, Dr. Costa has been investigating the pathophysiology and potential pharmacological therapeutic approaches to Down syndrome using both preclinical and clinical strategies. He has been the principal investigator of a clinical trial of the effects of memantine on the cognitive abilities of adolescents and young adults with Down syndrome.

Juan Fortea, MD (ES); jfortea@santpau.cat
Dr. Fortea combines his research and clinical activities at the Hospital of Sant Pau in Barcelona and the Catalan Foundation for Down Syndrome in Barcelona, Spain, where he leads the neuroimaging laboratory and directs the Alzheimer’s Disease and Down Syndrome Unit. He has extensive experience in clinical practice and in medical research. Dr. Fortea is the coordinator of a worldwide pioneering population based health plan for adults with Down syndrome in Catalonia. This program is the foundation for the Down Alzheimer Barcelona Neuroimaging Initiative (DABNI), one of the largest cohorts of adults with Down syndrome with multimodal biomarker studies.

Benjamin Handen, PhD (US); HandenBL@upmc.edu
Dr. Handen is Professor of Psychiatry, Pediatrics, Psychology and Instruction and Learning (Education) at the University of Pittsburgh. His research interests are Down syndrome and dementia; ADHD in autism spectrum disorder; and parent training in autism spectrum disorder.

Sigan Hartley, PhD; slhartley@wisc.edu

Dr. Hartley is 100 Women Distinguished Chair in Human Ecology and Professor of Human Development and Family Studies at the School of Human Ecology and Waisman Center Investigator, UW-Madison. Her research takes a biopsychosocial approach to understand the mechanisms that shape development in people with neurodevelopmental conditions such as Down syndrome, autism, and fragile x syndrome.

Sharon Krinsky-McHale, PhD (US); Sharon.Krinsky-McHale@opwdd.ny.gov

Dr. Krinsky-McHale is a Research Scientist at the New York State Institute for Basic Research in Developmental Disabilities – IBR, Department of Psychology. Her research interests are Down syndrome and dementia.

Huntington Potter, PhD (US); HUNTINGTON.POTTER@ucdenver.edu

Dr. Potter is Professor of Neurology, member of the Linda Crnic Institute for Down Syndrome, and the founder and director of the University of Colorado Alzheimer’s and Cognition Center. His research focuses on the mechanistic relationship between Alzheimer’s disease and Down syndrome and on the development of novel therapeutics and their testing in animal models and human trials. He is a Fellow of the American Association for the Advancement of Science and a Founding Fellow of the National Academy of Inventors.

Mike Rafii, MD, PhD (US); mrafii@usc.edu

Dr. Rafii is Associate Professor of Neurology at the Keck School of Medicine of the University of Southern California and Medical Director of the Alzheimer’s Therapeutic Research Institute (ATRI). He is Principal Investigator of the NIH-funded Alzheimer’s Clinical Trial Consortium for Down syndrome (ACTC-DS).

Anne-Sophie Rebillat, MD (FR); annesophie.rebillat@institutlejeune.org

Dr. Rebillat is a geriatrician. Within the Jérôme Lejeune Institute in Paris, she runs a clinic specialized in the management of age-related diseases for patients with Down syndrome. Her research interest is mainly focused on comorbidities of cognitive functioning with aging in people with Down syndrome, e.g. Alzheimer’s disease and Obstructive Sleep Apnea.

Weihong Song, MD, PhD (CA); weihong@mail.ubc.ca

Vice President – Academic Director, Institute of Aging and Dean, Alberta Institute, Wenzhou Medical University. Director, Oujiang Laboratory (Zhejiang Lab for Regenerative Medicine, Vision and Brain Health), and Professor at The University of British Columbia. Over the past 30 years, his lab has made significant contributions to define the mechanisms underlying Alzheimer’s disease and the molecular pathways contributing to the development of Alzheimer’s disease in persons with Down syndrome. Dr. Song was elected to Fellowship in the Canadian Academy of Health Sciences (CAHS) in 2012, one of the highest honors for members of the Canadian health sciences community.

Andre Strydom, MRCPsych, MSc, PhD (UK); andre.strydom@kcl.ac.uk

Dr. Strydom is a Professor in Intellectual Disabilities at the Institute of Psychiatry, Psychology and Neuroscience at King’s College London, where his research is focused on mental disorders in adults with neurodevelopmental conditions, including Down syndrome and other genetic disorders. Dr. Strydom is particularly interested in ageing-related conditions such as dementia in adults with Intellectual Disability and Down syndrome. He is the chief investigator of the LonDownS consortium http://www.ucl.ac.uk/london-downsyndrome-consortium which consists of several research groups from prominent London universities (KCL, UCL, QMUoL, Birkbeck and the Crick Institute) collaborating on various aspects of Alzheimer’s disease in Down syndrome. One of the important aims of the consortium is to deliver the knowledge, tools and expertise that is necessary to enable clinical trials of treatment to prevent or delay the onset of dementia in individuals with Down syndrome. Professor Strydom works as a Consultant

Psychiatrist in Intellectual Disabilities at the South London and the Maudsley NHS Foundation Trust.

Shahid Zaman, MD (UK); shz10@medschl.cam.ac.uk
Dr. Zaman is an Assistant Professor and Director of the Cambridge Intellectual and Developmental Disabilities Research Group, Department of Psychiatry, University of Cambridge. He is an honorary consultant psychiatrist in psychiatry of intellectual disability and a neuroscientist who has published in the following areas: the molecular pharmacology of GABAA receptors, neurosteroids, hippocampal synaptic plasticity (long-term potentiation), familial Alzheimer's disease (presenilin) and female autism. He is interested in understanding the neuronal mechanisms that underlie deficits in learning and memory in people with intellectual disabilities and exploring ways of ameliorating or treating these conditions. He is currently involved in research in dementia in Down syndrome and PI at the University of Cambridge clinical site for ABC-DS.

Initiatives and achievements in 2025/6

The T21RS Clinical Committee is a platform to encourage the development, discussion, and dissemination of translational research efforts across the T21 research community, families of individuals with Down syndrome and self-advocates, and clinicians serving patients with Down syndrome. The Adult Clinical Committee held six on-line meetings in 2025 and have made contributions to the T21RS Newsletter. Below is a list of the main events and accomplishments of the Adult Clinical Subcommittee in 2025:

1. Some committee members have engaged in putting together featured research sessions contributions for the annual 2025 AAIC meeting. Jaun Fortea gave a plenary to the AAIC at the meeting which was very well received.

2. The committee discussed the value of linking with national Down syndrome medical interest groups who often have useful resources for clinicians on their websites. We did not come to a consensus.

3. Contributions were made to help to shape the satellite meeting at the next T21RS conference in June 2026. Although many excellent suggestions were made, we had to keep in line with the vision of the organizers of the conference, "Insights from across the lifespan," and an emphasis on the translational and reverence translational aspect of research in this field. Together with members of the pre-clinical committee, an exciting plan evolved that proposes a dialogue between fundamental scientist and clinical researcher.

4. The committee had a request to answer queries from the Down Espana Group regarding several points including the availability of clinical guidelines for individuals with Down syndrome between the age of 40 and 45 years old and about recommendations for vaccinating against herpes zoster.

5. Andre Strydom and Juan Fortea were invited to present their work on Horizon21 (the European consortium for Down syndrome and dementia) at the celebration of the ABC-DS meeting as 2026 is the end of ABC-DS and it is expected that there will be a continuation into ABC-DS-2.

6. Shahid Zaman was elected as member of the steering committee of the Down Syndrome Medical Interest Group (UK) representing adults with Down syndrome as the Group consists predominantly of pediatricians.

Developmental Clinical Research Subcommittee Members

Chair of the subcommittee:
Brian Skotko (US)

Members:
Cécile Cieuta-Walti (CA; FR)
Hannah Rea (US)
Elizabeth Will (US)
Ana Claudia Brandao (Brazil)
Dannah Raz (US)
Floriana Costanzo (IT)
Jessica Hunter (US)
Stephanie Santoro (US)
Anna Esbensen (US)
Ella Rachamim (UK) (Joined July 2025)
Pierre-Yves Maillard (FR) (Joined Sept 2025)

Member Biographies

- **Brian Skotko, MD, MPP (US)**: Dr. Skotko is a physician-researcher at Massachusetts General Hospital in Boston, USA. He serves as the committee chair, and his first term is scheduled to end in January 2026.

- **Cécile Cieuta-Walti, MD (FR)**: Dr. Cieuta-Walti is affiliated with the Lejeune Institute in France. Her first term on the committee ends in January 2026.

- **Hannah Rea (US)**: Dr. Rea is based at West Virginia university. Her first term on the subcommittee concludes in January 2027.

- **Stephanie Santoro, MD (US)**: Dr. Santoro is a clinician-researcher at Massachusetts General Hospital, USA. She is currently serving her second term, which ends in January 2028.

- **Elizabeth Will (US)**: Dr. Will is affiliated with the University of South Carolina. Her first term of service ends in January 2027.

- **Ana Claudia Brandao (Brazil)**: Dr. Brandao is affiliated with Hospital Israelita Albert Einstein. She serves as a site lead for the DS-4C longitudinal study in Brazil, and her first term ends in January 2027.

- **Dannah Raz (US)**: Dr. Raz is based at the Barrow Neurological Institute at Phoenix Children's. Her first term on the committee runs through January 2027.

- **Floriana Costanzo, PhD (IT)**: Dr. Costanzo is a researcher at Bambino Gesù Children's Hospital in Italy. Her second term ends in January 2028.

- **Jessica Hunter, PhD (US)**: Dr. Hunter is affiliated with the Center for Health Research of Kaiser Permanente Northwest in Portland, USA. She serves as the main PI for the NIH-funded DS-4C longitudinal study, and her first term ends in January 2026.

- **Anna Esbensen, PhD (US)**: Dr. Esbensen is the Research Director at the Jane and Richard Thomas Center for Down Syndrome. She also serves on the program committee for the T21RS Biennial Meeting, and her first term ends in January 2026.

- **Ella Rachamim, MBBS BSc. (UK)**: Dr. Rachamim is a Specialist Doctor in Community pediatrics based in London. She joined the committee in July 2025, and her first term ends in January 2029.

Pierre-Yves Maillard (FR): Dr. Maillard is a geneticist with the Jerome Lejeune Institute in Paris, France. He joined the subcommittee in September 2025 with a term ending in January 2029.

Initiatives and achievements in 2025

The goal of this subcommittee is to increase knowledge of the cognitive and behavioral trajectory of children with Down syndrome and the effects of co-occurring disorders on their quality of life.

The T21RS Clinical Child Development Committee's meetings in 2025 focused on several key areas:

- **Membership & Charter**: The committee reached its maximum capacity of 12 members. Formal term schedules were established, and the Committee Charter was submitted to the Executive Committee.

- **DS-4C Study**: Members provided regular updates on this NIH-funded longitudinal study. Progress included establishing a common protocol with recruitment at U.S. and Latin American sites anticipated soon.

- **T21RS Biennial Meeting (Denver 2026)**: Planning commenced for the June 2026 conference.. Discussions included creating "accessible" presentations and pairing bench researchers with clinicians to foster cross-disciplinary dialogue..

- **Clinical Trial Finder**: The committee continued collaborating with LuMind IDSC (now National Down Syndrome Society) regarding the migration of their Clinical Trial Finder. Efforts focused on ensuring European-based trials are included in the global database.

- **Research Outreach**: The committee maintained a recurring "communication blurb" in the T21RS newsletter to connect researchers with clinical experts and resources.

Key accomplishments included:

- Recruited two new international members to enhance committee diversity.
- Finalized and submitted the formal Committee Charter.
- Connected benchtop researchers with clinical experts to facilitate cross-disciplinary dialogue.
- Initiated cross-disciplinary symposia planning for the 2026 Biennial Meeting.

VII - Communication Workgroup

Communication workgroup members:

Chair of the workgroup:
Esteban J Rozen (USA)

Members:
Paula B. Hernández (USA)
Sujay Ghosh (India)
Eric Hamlett (USA)
Natalia Valle Tamayo (Spain)
Nancy Raitano Lee (USA; since October 2024)
Sara F Ramalhosa Guerreiro (Portugal; since October 2024)
Véronique Brault (France; since March 2025)
Oscar M. Lazo (Chile; since November 2025)

Activities in 2025

1. **T21RS Monthly Newsletter**

- Provided two summaries of recently published scientific articles each month, including both technical and lay audience summaries for each.
- A monthly feature highlighting early career researchers (ECRs).
- Special content provided upon request, including materials for World Down Syndrome Day, Christmas/Holidays Celebrations, webinar announcements, technical notes, and job opportunities.

The Newsletter is distributed to signed up T21RS members and to a list of interested persons who subscribed through our website.

2. **T21RS Website Redesign**

   In collaboration with the General Secretary, the Technical Secretariat (BCO Congresos), and Tapp Network (tappnetwork.com), the Communication Workgroup has been critically involved in the design and development of a new, modernized T21RS website**.**

3. **Social Media Strategy**

   Efforts are underway to enhance T21RS's visibility and engagement across social media platforms. The Communication Workgroup evaluated current practices and implemented improvements for managing the society's X (formerly Twitter), Facebook, and YouTube accounts. Additionally, we have expanded our social media presence through the creation of accounts in other platforms such as Instagram, LinkedIn and Bluesky.

4. **Outreach and Public Image**

   To strengthen the Society’s public presence, the Communication Workgroup has taken the lead on several outreach initiatives, including the development of a new T21RS informational flyer and support for other visibility-related projects.

VIII – T21RS Indian Chapter

Outreach Activities

September 2025 – December 2025

Eye Care Clinic and Ophthalmologic Study for Persons with Down Syndrome

The T21RS Indian Chapter, in collaboration with Disha Eye Hospitals, successfully organized a series of free eye check-up camps for individuals with Down syndrome across Kolkata. These camps were conducted in both North Kolkata (Girish Park) and South Kolkata (Gariahat) with the aim of promoting early detection and management of visual impairments, which are commonly associated with Down syndrome. A total of five camps were held between 13th September 2025 and 20th December 2025, collectively benefiting around 75 participants with Down syndrome, along with guidance and support extended to their families.

The initiative was coordinated by Dr. Santanu Mandal, an eminent ophthalmologist at Dish Eye Hospitals, who served as the clinician coordinator and ensured smooth execution of the camps with a multidisciplinary approach. Comprehensive eye examinations were conducted, and necessary recommendations for corrective measures and follow-up care were provided. This outreach program not only improved access to specialized eye care but also highlighted the importance of regular ophthalmological screening in enhancing the quality of life and overall well-being of individuals with Down syndrome.

October 2026

The T21RS Indian Chapter commemorated Down Syndrome Awareness Month with a special event held on 29th October 2025 at the Department of Zoology, University of Calcutta. The program was attended by faculties, scientists and postgraduate students, as well as individuals with Down syndrome and their parents. The program was designed as a platform to amplify the voices of individuals with Down syndrome, who shared their personal journeys, daily challenges, and experiences of self-advocacy. Their speeches highlighted not only the barriers they face in everyday life but also their determination, achievements, and growing independence, making the session both insightful and inspiring for all attendees.

An equally moving segment featured parents who spoke about their journeys of raising children with Down syndrome, reflecting on their struggles, resilience, and evolving perspectives. The highlight of the event was a vibrant cultural showcase performed by individuals with Down syndrome, including dance, recitation, and instrumental music. These performances beautifully celebrated their talents and creativity, reinforcing the core message of inclusion, dignity, and the importance of recognizing abilities beyond limitations.

March 2026

Celebrating Abilities: A Two-Day International Symposium–cum–Workshop for Empowerment, Inclusion, and Well-Being of Persons with Down Syndrome

The two-day international symposium *"Celebrating Abilities 2026"* was held on 28th and 29th March 2026 at Kennedy Hall, University of Calcutta. Organized jointly by the T21RS Indian Chapter, the Down Syndrome Research Unit, University of Calcutta, NIEPID Regional Centre Kolkata, and the AbleFable Foundation, the event brought together over 200 participants including researchers, clinicians, educators, caregivers, and self-advocates. The symposium began with an inaugural session and featured expert lectures on early diagnosis, neurodevelopment, communication, and behavioral aspects of Down syndrome. Sessions emphasized the importance of early intervention and evidence-based practices, while post-lunch discussions focused on social inclusion, employment pathways, and self-advocacy. Notable scientific sessions explored emerging therapies such as transcranial direct current stimulation, alongside parallel academic presentations that highlighted ongoing research.

The second day included discussions on hematological aspects, psychological support for families, and early onset Alzheimer's disease, followed by sessions on education, inclusion, and parental roles. Afternoon sessions addressed residential care, legal provisions, and personal narratives of resilience, including a panel featuring individuals with Down syndrome sharing their experiences and aspirations. Additional highlights included discussions on Special Olympics, recreational therapy, and a concluding cultural performance. Parallel scientific sessions further explored advanced research topics, including leukemogenesis. The event concluded with a valedictory session and award recognition, reinforcing the symposium's success in integrating research, practice, and advocacy to promote inclusion and improved quality of life for individuals with Down syndrome.

Financial Report 2025

01-01-2025 – 31-12-2025

1. Treasury

T21RS is the first non-profit scientific society (*Dutch:* vereniging) for Down syndrome research. T21RS is officially established in Groningen (NL), and operates under Dutch law.

Statutory seat:	Groningen, The Netherlands
Registered office/place of business:	T21RS Rotterdam Office Erasmus MC University Medical Center Department of General Practice attn Thessa Hilgenkamp – GVG Dr. Molewaterplein 40 3015 GD Rotterdam, the Netherlands
RSIN identification number (NL):	853938283
KvK Chamber of Commerce number (NL):	60501162
Current treasurer:	Dr T.I.M. (Thessa) Hilgenkamp (2023-present), affiliated with Erasmus MC University Medical Center, Rotterdam, The Netherlands and employed by University of Nevada, Las Vegas, USA
Past-treasurers:	Dr. Y.P.Y (Yannick) Vermeiren (2021-2023) Wageningen University & Research, Wageningen, The Netherlands Dr. A.D. (Alain) Dekker (2016-2021) University Medical Center Groningen, The Netherlands Dr. A.M.W. (Tonnie) Coppus (2014-2015) Radboud University Medical Center Nijmegen, The Netherlands
Operational currency:	Euro (€)
Number format:	Continental European Example: 40.000,25 *(forty thousand and twenty-five cents)*

2. Summary of 2025

After the conference in Rome in 2024, the year 2025 was the off-year without a conference. Income in 2025 was primarily sustained via our membership fees in addition to the annual contributions of our Founding Members and Supporting Members. For all Founding and Supporting Members, new memberships agreements were signed in 2025, guaranteeing their support for the next 5 years, from 2025-2029. Shown in the Profit and Loss Statement (figure 1) the Founding and Supporting Member Fees for 2025 also included the delayed fees from 2024 for the

Matthew Foundation and LuMind/IDSC as shown in the annual report of 2024. As expected in the off-year in between conferences, the membership fees were slightly lower than in 2024, but still slightly higher than the previous off-year in 2023. Note that LuMind merged with National Down Syndrome Society (NDSS) in October 2025.

On the expense side, the Scientific Event Awards, Early Investigator Awards, Scientific Exchange Awards and Conference Travel Awards demonstrate T21RS' commitment to promote research on Down syndrome and stimulate dissemination of knowledge to improve quality of life for individuals with Down syndrome. Another large expense was expenses for the upcoming conference in Denver, Colorado in 2026, which mainly consists of the costs for securing the conference venues. The combination of these sources of income and expenses resulted in a net loss on our T21RS bank account of €104.078,25. The balance sheet (**Figure 2**) shows that the cash asset at the banking account has been steadily maintained throughout the last few years, but is lower at the end of 2025, mostly due to these advance payments for the conference venue.

3. Revenues

Sources of revenue in 2025 consisted of 1) membership fees, 2) general financial support for the society by Founding and Supporting members, 3) donations, and 4) interest. Membership fees were significantly decreased from 2024 (€ 31.189) due to 2025 being a year without a conference, but were still slightly higher than the previous off-year (2023: € 22.704). With regards to the support from the Founding and Supporting members, the overall amount is slightly higher than usual (€ 30.000), as the 2024 contributions from LuMind/IDSC and The Matthew Foundation were received in 2025, as well as all the 2025 fees. Additionally, we received € 3201 in donations.

1) Membership

T21RS distinguishes two types of membership: a) full membership for researchers and clinicians, and (b) associate membership for DS associations/foundations.
A 50% reduced membership fee applies to individuals living and working in countries with low-, low-middle and upper-middle income economies (as defined by the Worldbank).

1a) Full member (for researchers and clinicians)	
● Master/PhD student	€ 40,-
● Postdoctoral fellows	€ 80,-
● Academic staff members / clinicians	€ 100,-
1b) Associate member	€ 50,-

2) Founding members and Supporting members 2025

T21RS is very grateful to a number of non-profit organizations that financially support the continuation of the society and its aims. In 2025, this concerned:

• Fondation Jérome Lejeune (France) 2025	€ 5000,-	Founding Member
• GLOBAL Down Syndrome 2025	€ 5000,-	Founding Member
• LuMind-IDSC Foundation (USA) 2024	€ 5000,-	Founding Member
• LuMind-IDSC Foundation (USA) 2025	€ 5000,-	Founding Member
• Trisomy 21 France (France) 2025	€ 5000,-	Founding Member
• The Matthew Foundation (USA) 2024	€ 2500,-	Founding Member
• The Matthew Foundation (USA) 2025	€ 2500,-	Founding Member
• Down España (Spain) 2025	€ 5000,-	Supporting Member
• L'Association Francaise pour la Recherche sur la Trisomie 21 (AFRT) (France) 2025	€ 2500,-	Supporting Member

4. Expenses

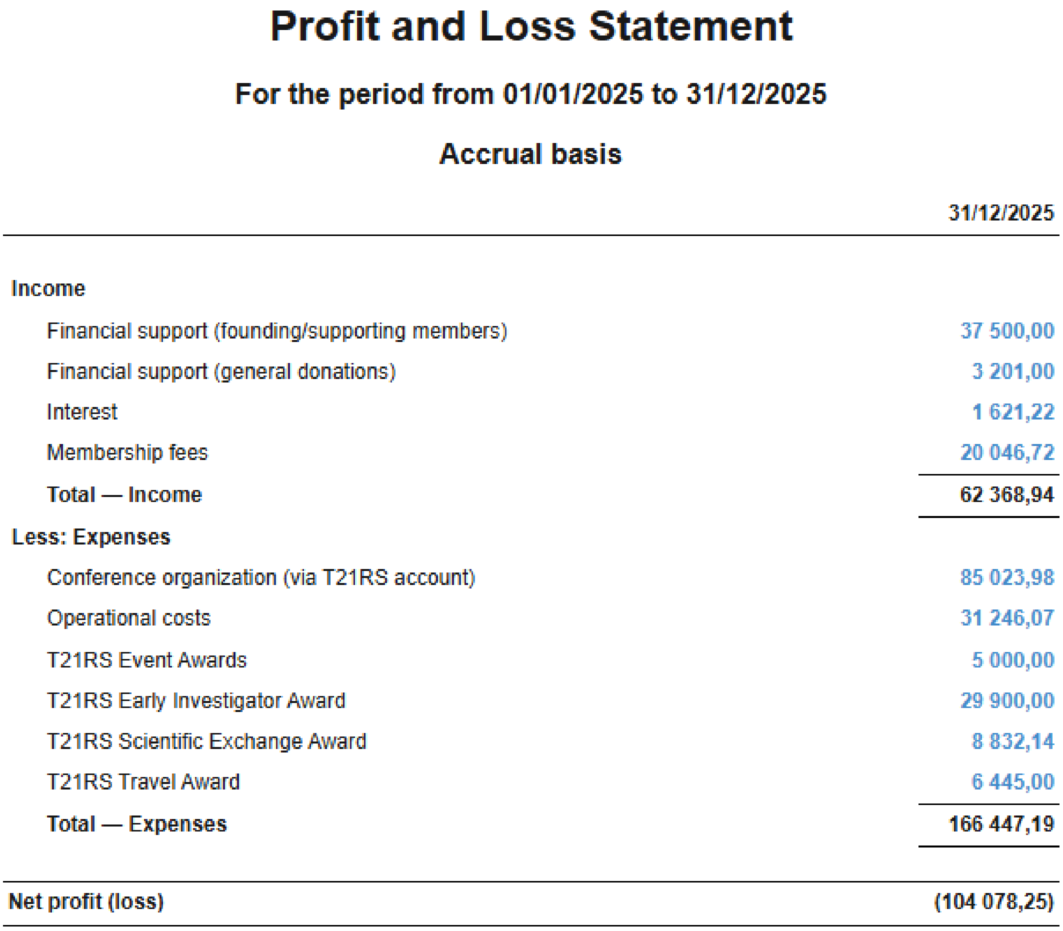
A total of € 50.177,14 was awarded in 2025 to Scientific Event Awards (n=10), Early Investigator Awards (n=3), Scientific Exchange Awards (n=2) and Conference Travel Awards (n=3). All members are eligible for these awards and they demonstrate T21RS' commitment to promote research on Down syndrome and stimulate dissemination of knowledge to improve quality of life for individuals with Down syndrome.

A little over half of the expenses was due to the advance payments for the conference venue, to be held in 2026. Operational costs included the redesign of the website (€ 26.697,18), our regular banking fees, and support for a database project of the Preclinical Committee. Note that the support from the technical secretariat of the society (BCO) was not included in 2025 as the invoice was received in 2026.

5. Profit and loss statement

The statement visualized below (**Figure 1**) provides a clear overview of income (Dutch: *baten*) and expenses (Dutch: *lasten*) directly through the T21RS Banking Account (RaboBank NL) for the year 2025.

Figure 1 Profit and Loss Statement 2025 (in Euro (€))



Profit and Loss Statement

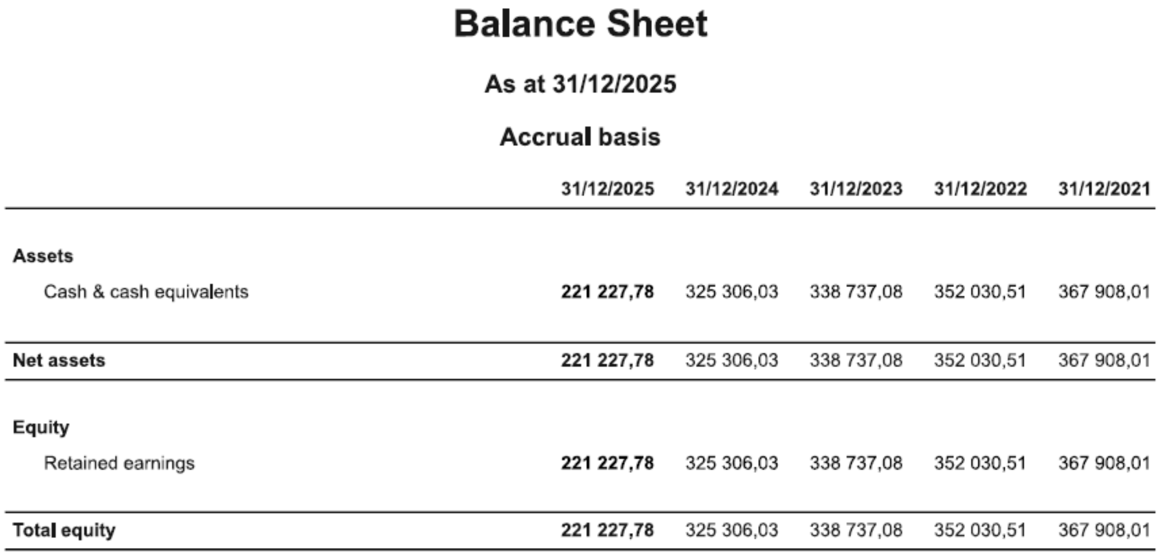
For the period from 01/01/2025 to 31/12/2025

Accrual basis

	31/12/2025
Income	
Financial support (founding/supporting members)	37 500,00
Financial support (general donations)	3 201,00
Interest	1 621,22
Membership fees	20 046,72
Total — Income	**62 368,94**
Less: Expenses	
Conference organization (via T21RS account)	85 023,98
Operational costs	31 246,07
T21RS Event Awards	5 000,00
T21RS Early Investigator Award	29 900,00
T21RS Scientific Exchange Award	8 832,14
T21RS Travel Award	6 445,00
Total — Expenses	**166 447,19**
Net profit (loss)	**(104 078,25)**

6. Balance

Figure 2. Balance sheet throughout the years (in Euro (€))



Balance Sheet

As at 31/12/2025

Accrual basis

	31/12/2025	**31/12/2024**	**31/12/2023**	**31/12/2022**	**31/12/2021**
Assets					
Cash & cash equivalents	**221 227,78**	325 306,03	338 737,08	352 030,51	367 908,01
Net assets	**221 227,78**	325 306,03	338 737,08	352 030,51	367 908,01
Equity					
Retained earnings	**221 227,78**	325 306,03	338 737,08	352 030,51	367 908,01
Total equity	**221 227,78**	325 306,03	338 737,08	352 030,51	367 908,01

7. Conclusion

The year 2025 has been closed with **a <u>net loss</u> of € 104.078,25**. The final balance amounts into **a total (positive) cash asset of € 221.227,78** on the T21RS banking account.

8. Discussion and outlook

As mentioned in the annual report of 2024, we were expecting higher expenses in 2025 for the conference organization and the redesign of the website for T21RS. Those costs were made and are the main reason for the larger net loss of 2025. As 2026 will be the year of the next T21RS Conference, in Denver, Colorado, we are expecting 2026 to be seeing more of the revenue of the conference to compensate these costs. The large amount of membership initiatives shows increased engagement of our members with T21RS, which is a positive development especially in a year with no conference. The continued support from our Founding and Supporting Members, and we are incredibly grateful for their continued commitment to supporting T21RS, as shown by their signed agreements until the end of 2029. Due to their support and the continued growing number of members, we continue to maintain a financial buffer that allows the society to organize large international conferences and promote our mission for individuals with Down syndrome, even though the net loss was larger in 2025.

For 2026 we are expecting to see an increase in the number of individual members and revenue due to the 2026 conference in Denver, Colorado.