Trisomy 21 Research Society
2022 Annual Report

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General information

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

The society aims to:

- Facilitate the permanent interaction between researchers studying Down syndrome by means of our website, social media, scientific meetings, publications in journals and the two-yearly T21RS International Conference.
- Establish common protocols both for basic research (mice studies, stem cells studies) and translational research (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 the 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 2 years. 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 Governance document. In 2020, the Executive Board of T21RS created a Policy of Conflict of Interest also available in the society website. Finally, a privacy policy is available on the website according to EU General Data Protection Regulations.

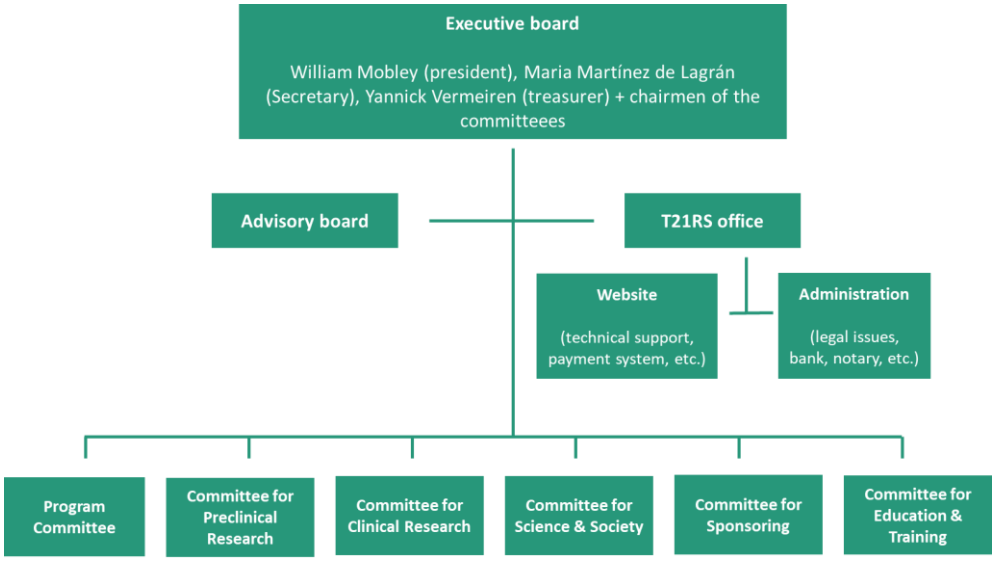
The society has organized four T21RS International Conferences:

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)

Due to COVID-19 pandemic constraints, the society organized in 2021 the first virtual T21RS International Conference (June 8-10 2021).

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:
William Mobley, University of California (US)

Secretary:
Maria Martinez de Lagran, Centre for Genomic Regulation (Spain)

Treasurer:
Yannick Vermeiren, Wageningen University & Research (the Netherlands)

Committee chairs:
Program Committee: **Elizabeth Head,** University of California Irvine (US)
Committee for Science & Society: **Maria Carmona,** Institut Jérôme Lejeune (France)
Committee for Sponsoring: **Eugenio Barone,** Sapienza University of Rome (Italy)
Committee for Education and Training: **Sandra Guidi,** Bologna University (Italy)
Committee for Preclinical Research: **Eugene Yu**, Roswell Park Comprehensive Cancer Center and State University of New York (US) until June 2022. **Frances Wiseman**, Dementia Research Institute (UK) from July 2022
Committee for Clinical Research: **Alberto Costa,** Case Western Reserve University School of Medicine (US)

An electronic ballot was organized on March for the election of the new chair of the Committee for Preclinical Research. Of the 173 active members, 28 (16%) voted. The candidacy of **Dr. Frances Wiseman** from Dementia Research Institute (UK) and **Dr. Randall Roper** from Indiana University-Purdue University Indianapolis (USA) were elected as joint chairs of the committee for Preclinical Research with 57% of the votes.

T21RS activities

T21RS launched two calls during 2022 for awards worth 500 EUR for the organization of scientific or dissemination events to contribute to increase the public visibility of Down syndrome research and of T21RS. Applicants were T21RS members. No application was received in the call launched in February. Executive board awarded 7 applications in the call launched in September.

The Education and Training Committee organized 5 webinars to support the dissemination of the latest research in Down syndrome (see Education and Training Committee section). In addition, the Committee granted two young investigators with the "Annette Karmiloff-Smith and Michael Harpold Dissertation Award", for recognizing an outstanding Ph.D. thesis.

The **Montserrat Trueta award** that recognizes outstanding scientists in the field of Down syndrome for their sustained and distinguished career, was awarded to Dr Ira Lott from National Down Syndrome Society of New York and University of California (US). The award was delivered in a ceremony during the 4th T21RS International Conference. This award is supported by the Catalan Down syndrome Foundation (Spain).

Report of the President

Another busy year for the Trisomy 21Research Society witnessed an outstanding meeting in Long Beach, continued work addressing COVID-19 in those with Down syndrome, and important new initiatives that promise to further enrich our members. In this brief report I will highlight the important events.

The 4th International Meeting of the Trisomy 21 Research Society was convened from June 9th through the 12th in Long Beach California at the Westin Long Beach Hotel. The meeting exceeded all expectations for excitement and active engagement of researchers from around the world. Our special and very sincere thanks to Dr Elizabeth Head and the Program committee she chaired for an outstanding program and to Dr Jorge Busciglio who chaired the Organizing Committee for a rich and rewarding experience for all those in attendance.

The meeting was attended by 510 people, including 73 students and postdoctoral fellows, from 16 countries. It explored 9 major research themes ranging from basic science topics to translation of research insights into potential treatment interventions. There were 4 satellite sessions, 20 symposia, 9 nanosymposia and 2 sessions designed for early-stage investigators. In addition, plenary sessions featured presentations by Drs Mara Dierssen, Evan Eichler, Elizabeth Fisher and Ira Lott. There was a total of 204 presentations: 88 oral, 69 posters, and 47 combination poster/oral presentations. The very popular Science and Society Symposium was highly informative and very well attended. New symposia were aimed at building bridges between the Society and our partners in industry and in the families of those with Down syndrome. One supported interaction of Society members with representatives from industry to focus on the status and challenges of translational initiatives. In another, families discussed with Society members the challenges faced by people with Down syndrome. Both were well received, pointing to the value of sustaining dialogues between the Society and its industry and family partners. Another highlight of the meeting was the Gala Dinner and Dance Party held on June 11th. I was impressed by the high spirits of all attendees and by the skilled dancing by Down syndrome advocates, their families and a large number of Society members.

The meeting was generously supported by a number of entities. Many thanks to the Lejeune Foundation and to the NIH for grants that made extremely important support without which the meeting would not have been possible. Thanks to the NIH INCLUDE Data Coordinating Center. Thanks also to foundations that have been so important to our ongoing work, including the Global Down Syndrome Foundation, Lumind/IDSC Down Syndrome Foundation, the National Down Syndrome Society, the Cure Alzheimer Fund, and the Company of Biologists. Support from Industry entities was greatly appreciated, including contributions from IQVIA, ProMIS Neurosciences, AELIA Farma, AC Immune, Alzheon, Annovis-Bio, Lilly, Bio Rad, and Merck.

In summary, the Long Beach meeting demonstrated the extraordinary energy and momentum for research to understand and care for those with Down syndrome. It showed that we can partner effectively with both families and industry and that going forward will enable us to accomplish ever more to support the international Down syndrome community. We can't wait for the 5th International Meeting to be held in Rome in June of 2024.

Supporting and founding members

It gives me pleasure to once again express my gratitude for the support received from our founding and supporting members Lumind IDSC, Global DS, Lejeune Jerome Foundation, Trisomie 21, The Matthew Foundation, Down Spain and the Association Française pour la recherche sur la Trisomie 21 France (AFRT).

And I would like to acknowledge these organizations as well as many others for their expert input for addressing the concerns for people with Down syndrome and their families during the COVID-19 pandemic.

COVID-19 Taskforce

Last year, we updated progress under the COVID-19 Initiative launched by the Society in 2020 to inform the Down syndrome and larger research and clinical communities about the impact of COVID-19 on those with Down syndrome. During 2022 the T21RS COVID-19 initiative completed surveys of people with Down syndrome affected by COVID-19, and published several new reports, including:

1) An analysis of the impact on people with Down syndrome from India, compared to high income countries https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9356581/ ,
2) A report on COVID-19 vaccination safety, outcomes and factors associated with the decision to be vaccinated https://www.mdpi.com/2076-393X/10/4/530.
3) A combined analysis of factors related to vaccination serological efficacy - https://www.journalofinfection.com/article/S0163-4453(23)00090-7/fulltext.

The work of the T21RS COVID-19 initiative is now concluded. I wish to acknowledge with great thanks key leaders of the initiative. Drs Andre Strydom, Stephanie Sherman, Anke Huels and Alberto Costa are to be congratulated for their extraordinary efforts in support of those with Down syndrome and their families. And I wish also to thank all of the many collaborators, funders and stakeholders who worked to ensure data was available at a global level to inform a timely response to the pandemic. I have no doubt that working together, members of our Society saved the lives of many.

Welcome to…

Dr Marie-Claude who began her term as President Elect in January 2022. We look forward to her leadership in the years to come. Also welcome to Drs Randall Roper and Frances Wiseman, the new co-chairs of the preclinical committee. And I wish to express many thanks to Drs Eugene Yu and Elizabeth Fisher, the outgoing co-chairs of this committee. Their work was critical to the committee's success and its ability to add new value to the research community with the availability of increasingly useful mouse models as well as human model systems.

And saying goodbye…

We have been privileged to have had Dr Andre Strydom as our Past President. He will be leaving the Executive Committee after having contributed in so many ways to our deliberations and efforts over his tenure on the Committee. We valued greatly his counsel and wisdom. His careful work and wise counsel supported the Society's ability to maintain a strong financial position. We also express our deep thanks to Dr Yannick Vermeiren who able served as Treasurer during the last two years.

Looking forward

I see us entering an even more exciting time for research in Down syndrome. I look forward to continued growth and accomplishments. We are enacting new categories for membership, including lab memberships, with a view toward enhancing growth, especially among early-stage investigators and students. We will be discussing new initiatives to support young investigators through pilot projects, interlaboratory visits and

exposure to the work carried out in Down syndrome clinics. We see the possibility that these initiatives will not only serve our existing members but also help to attract new members. And we are eager to continue building the brides to families and to industry begun this year. Finally, I invite you to contact me directly with your suggestions as to how our Society can better serve your research goals.

And please remember to mark your calendars now for our meeting in Rome in 2024.

Committee reports

I –Program Committee

The Program Committee was formed in April 2020 to help craft the scientific content of the T21RS meeting that was initially proposed for Long Beach, California in 2021. Unfortunately, due to the COVID-19 pandemic, in person meetings were canceled and we moved to a virtual format, which we described in the report in 2021. The proceedings of the virtual symposium held in 2021 was published in July 2022 (https://www.karger.com/Article/PDF/526021). We were able to host the T21RS meeting in Long Beach, California on June 9-12, 2022. The proceedings of this conference are currently being completed for submission (Communications Committee). This report will be the final summary from this current Program Committee as new leadership has been elected (Dr. Shahid Zaman).

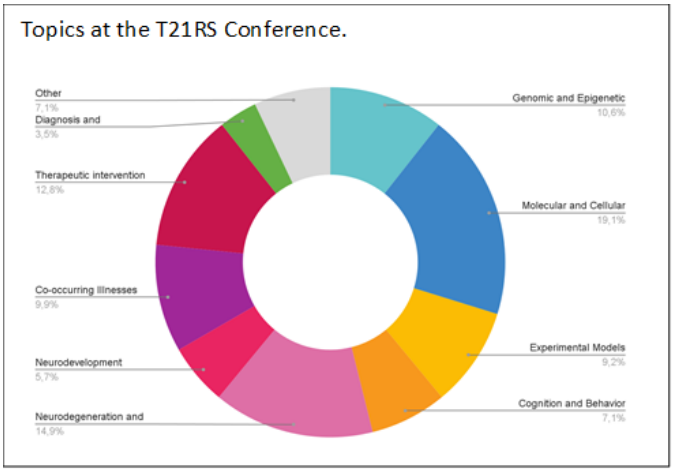
Program Committee members, location and area of research:

Title	Name	Location	Area of Research
Chair	Elizabeth Head	US	Aging and Alzheimer disease
Past Chair	Anita Bhattacharyya	US	IPSc/Molecular
Past President	Mara Dierssen	Spain	Preclinical
Member	Yann Herault	France	Mouse models/preclinical research
Member	Kelly Sullivan	US	Inflammation/biomarkers/leukemia
Member	Floriana Costanzo	Italy	Child and Adolescent Neuropsychiatry
Member	Brian Skotko	US	Clinician, medical geneticist
Member	Maria Carmona	Spain	Neuroimaging and biomarkers
Member	Tao Ma	US/China	Alzheimer's disease (AD) and Down syndrome/mouse models

The duties of this Committee included 1) coordination of submission of symposia proposals, 2) review and selection of symposia sessions, 3) providing feedback and suggestions for the schedule and for the plenary speakers, 4) selection of abstracts from junior investigators for a Data Blitz session. We successfully obtained an R13 conference grant from the NIH (R13HD108965 – Head/Busciglio/Mobley/Strydom) that supported USA junior investigator travel and child care costs to the meeting ($37,500). We were able to support 23 trainees with this funding mechanism for US domestic travel. Additional funds were raised through the LeJeune Foundation ($52K) and for 35 fellowships to trainees from Europe and Central and Latin America.

The Program Committee selected and invited 4 outstanding plenary lecturers. The first was Dr. Ira Lott (USA), who was the winner of the Montserrat Trueta award. Dr. Mara Dierssen (Spain) was invited to be the Presidential Lecture. Dr. Elizabeth Fisher (UK) was nominated for an EMBO supported speaker and also provided a lecture. Dr. Evan Eichler (USA) was invited as a speaker outside of research in Down syndrome to bring in new concepts to our conference. Four satellite meetings were held on June 8, 2022.

Symposia were solicited (February 2022) and peer reviewed in March 2022. We selected 20 submitted symposia proposals. The symposia were selected to include diversity in terms of sex, geography and junior/senior investigators. The Program Committee also dedicated time for a T21Rs General Assembly in which, each Committee was given an opportunity to update the T21RS community on the accomplishments and future directions from each of their teams. We also enjoyed an exciting Science and Society session. Given our overwhelming positive responses to our conference, we added 9 nanosymposia to accommodate proposals that we could not implement within the symposium format. Last, we included 2 special sessions for junior investigators that were well attended. Thus in total, the program committee established 35 conference events related to satellite meetings, plenary speakers, symposia, nanosymposia and junior investigator sessions.



Abstracts were solicited and we received 140 contributions that were either given orally (88) or as a poster (69) and in some cases both were presented (47). Thus, in total, we had 204 presentations (posters and orals). There was an excellent breadth of topics presented at the meeting, suggesting that the efforts of the committee to diversify topics was accomplished.

In total, 483 people registered for and attended our conference (14.3% were trainees/students). Attendees were from 17 countries internationally (see the Table below).

Geographical distribution of attendees

Registration by country	Number	%
United States	259	53,62
Canada	4	0,83
Spain	54	11,18
France	72	14,91
Italy	15	3,11
India	8	1,66
United Kingdom	40	8,28
Mexico	8	1,66
Germany	1	0,21
Ireland	1	0,21
Netherlands	1	0,21
Sweden	3	0,62
Switzerland	1	0,21
Argentina	6	1,24
Brazil	3	0,62
Chile	3	0,62
Israel	4	0,83
Total	**483**	**100,00%**

Our agenda is provided below:

Thursday June 9, 2022			
8:00 am - 5:00 pm	Registration - Centennial Foyer		
8:00-9:00	Poster Setup		
9:00-10:00	T21 General Assembly - Salon AB		
XXXXX		Opening Ceremony and Honorary Member presentation	
10:00-10:30	Coffee Break - Salon A Terrace & Ocean Terrace West		
10:30-12:00	Session 1		
	Session 1A - Salon AB	Session 1B - Salon C	Session 1C - Salon D
	Title	Title	Title
	Chairs	Chairs	Chairs
12:00-1:00	Lunch with Posters (Poster Judging Group 1) - Salon A Terrace & Ocean Terrace West/ Selected Nansymposia		
1:00-2:00	Plenary Lecture #1 - Salon AB Montserrat Trueta Award (Ira Lott)		
2:00-3:00	INCLUDE/NIH Funding Discussion (Diana Bianchi, Melissa Parisi, Laurie Ryan, DCC)	European Funding Opportunities Discussion	The Down syndrome Research Roadmap (Trisomy 21 EBRA cluster)
3:00-3:30	Coffee Break - Salon A Terrace & Ocean Terrace West		
3:30-5:00	Session 2A		
	Session 2A Salon AB	Session 2B - Salon C	Session 2C - Salon D
	Title	Title	Title
	Chairs	Chairs	Chairs
5:30-9:00	Welcome Reception		

Friday June 10, 2022			
8:00 am - 5:00 pm	Registration - Centennial Foyer		
9:00-10:00	Plenary Lecture #2 - Salon AB Presidential Lecture. Mara Dierssen		
10:00-10:30	Coffee Break - Salon A Terrace & Ocean Terrace West		
10:30-12:00	Scientific Session 3		
	Session 3A - Salon AB	Session 3B - Salon C	Session 3C - Salon D
	Title	Title	Title
	Chairs	Chairs	Chairs
12:00-1:00	Lunch among the Posters (Poster Judging Group 2) - Salon A Terrace & Ocean Terrace West and selected Nanosymposia		
1:00-2:00	Annette Karmiloff-Smith and Michael Harpold Thesis Awards Ceremony		
2:00-3:00	Blitz presentations (junior investigators)		

3:00-3:30	Coffee Break - Salon A Terrace & Ocean Terrace West		
3:30-5:00	Scientific Session 4		
	Session 4A - Salon AB	Session 4B - Salon C	Session 4C - Salon D
	Title	Title	Title
	Chairs	Chairs	Chairs
5:00	Dinner on your own		

Saturday June 11, 2022			
8:00 am - 5:00 pm	Registration - Centennial Foyer		
8:30-10:00	Science and Society		
10:00-10:30	Coffee Break - Salon A Terrace & Ocean Terrace West		
10:30-12:00	Science and Society		
12:00-1:00	Lunch Event Science and Society - Salon A Terrace & Ocean Terrace West		
1:00-2:00	Mouse models of Down syndrome - the Latest and Greatest (Reeves/Yu)/ parallel session : Congress highlights for Families?		
2:00-3:00	Plenary Lecture #3 - Salon AB Jerome Lejeune Lecture. Evan Eichler		
3:00-3:30	Coffee Break - Salon A Terrace & Ocean Terrace West/		
3:30-5:00	Scientific Session 5		
	Session 5A - Salon AB	Session 5B - Salon C	Session 5C - Salon D
	Title	Title	Title
	Chairs	Chairs	Chairs
6:00-10:00	Gala Dinner and Awards		

Sunday June 12, 2022			
8:00 am - 5:00 pm	Registration - Centennial Foyer		
8:00 am - 5:00 pm	Posters Removal		
9:00-10:00	Plenary Lecture #4 - Salon AB: EMBO Lecture Lizzy Fisher		
10:00-10:30	Coffee Break - Salon A Terrace & Ocean Terrace West		
10:30-12:00	Scientific Session 6		
	Session 6A - Salon AB	Session 6B - Salon C	Session 6C - Salon D
	Title	Title	Title
	Chairs	Chairs	Chairs
12:00-1:00	Lunch		
1:00-2:00	T21RS Committee Presentations		
2:00-3:00	Education Committee session		
3:00-3:30	Coffee Break - Salon A Terrace & Ocean Terrace West		
3:30-4:00	Going from Preclinical to Clinical - Challenges and Opportunities (Fisher/Yu/Costa)		
4:00-5:00	Closing Ceremonies - announcement of location of next meeting		

II - Committee for Science & Society

Science & Society Committee Members

Chair of the committee:
Maria Carmona-Iragui (Spain)

Co-chair of the committee:
Anne-Sophie Rebillat (France)

Members:
Peter De Deyn (The Netherlands), past chair of the committee
Lotta Granholm (US, Sweden)
Sebastián Videla (Spain)
Isabel Barroeta (Spain)
Hampus Hillerstrom (US)
Eric Rubenstein (US)
Jacqueline London (France)

NB: Maria Carmona-Iragui and Anne-Sophie Rebillat are also members of the Executive Board, of the Covid-19 DS task force and respectively of the Program Committee (Maria) and of the Clinical Committee (Anne-Sophie)

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

Initiatives and achievements in 2022

The main activity of the committee in 2022 was the organization of the symposium held in Los Angeles during the T21RS conference

1) **T21RS International Conference 2022 in LA - Science & Society Symposium – 11/06/22 – program in the attached flyer**

   To encourage the participation of people with Down syndrome and their families, the symposium was hybrid and presentations, in English, translated simultaneously in French and Spanish by professional interpreters.
   180 people could attend virtually the symposium, at the same time as all the conference attendees in the room.
   The symposium was recorded in order to be available online on the T21RS website but unfortunately not achieved for technical reasons. We especially shot 2 short videos summarizing the highlights of the conference and testimonials from research participants.
   The symposium was partly facilitated by people with Down syndrome: Theresa Mabie (opening), a panel of actors with Down syndrome from Hollywood (testimonials), a panel of persons with Down syndrome and their families about research participation (testimonials), Sujet Desai (music show and closing).

The symposium also involved 4 scientists who presented their results to the public. The topics discussed have been chosen for their interest in improving the health of people with Down syndrome: COVID-19, regression, physical activity and sleep apnea.

2) T21RS Science & Society Bulletins

No bulletins have been published in 2022.
We have been in contact with the winners of the PhD thesis award but they have not followed up. There may be confusion between the T21RS newsletter and the Science and Society bulletin.

3) T21RS website

We still hope that the videos shot for the Science and Society symposium can be seen on the website.

4) Regular meetings

Approximately every 3 months.

5) New members

The committee would like to organize a new call, especially to recruit colleagues from Italy in order to organize the next symposium to be held during the T21RS conference in Rome in 2024.

4th International Conference
9-12 June 2022
Long Beach California

Science and Society Symposium
Saturday June 11 | Hybrid format

8h30- 8h35 | Introduction

Anne-Sophie Rebillat and María Carmona-Iragui,
co-chairs S&S Committee T21RS

8h35- 8h40 | Opening

Theresa Mabie 

8h40- 9h10 | Presentations

DS and Covid-19, including psychosocial impact
Dr. Sujay Ghosh, *University of Calcutta, India*

Therapeutics: IVIG treatment for regression
Dr. Jonathan Santoro, *Childrens Hospital Los Angeles, USA*

9h10- 10h00 | Panel discussion on research participation: Why families' participation in Down syndrome research is key and how you can get involved

On the importance of research participation
Hampus Hillerstrom, *President & CEO, LuMind IDSC* 

Introduction of the clinical trial networks
Hampus Hillerstrom, *President & CEO, LuMind IDSC*
Dr. Andre Strydom, *King's College, London, UK*
Dr. Michael Rafii, *University Southern California, USA* 

Importance of Brain Biobank and how it works
Dr. Lotta Granholm, *University of Colorado, USA* 

EBRA T21 cluster (European Brain Research Area)
Dr. Mara Dierssen, *Centre for Genomic Regulation- CRG, Barcelona, Spain*
Dr. Marie-Claude Potier, *ICM, Paris, France* 

Testimonials from research participants in Europe and the US
Coordinated by Dr. Isabel Barroeta,
Hospital Sant Pau, Barcelona, Spain 

Panel discussion with all the speakers
Moderated by Hampus Hillerstrom and Isabel Barroeta 

10h00- 10h30 | Coffee break

10h30- 11h00 | Presentations

Physical activity and impact of exercise on cognition
Dr. Sarah Pape, *King's College, London, UK*

Innovative treatments for sleep apnea disease. Presentation of DSC2U
Dr. Brian Skotko, *Massachusetts General Hospital*

11h00- 11h30 | Hollywood panel




Moderated by Eric Rubenstein
Guests: Cole Sibus, *actor, Los Angeles, CA, USA*
Blair Williamson, *actor, Los Angeles, CA, USA*
Gail Williamson, *talent agent, Los Angeles, CA, USA*

11h30- 11h40 | Cultural program

Music show
Sujeet Desai, *Musician & Motivational speaker, Williamsville, NY, USA*

11h40- 11h55 | Video with highlights of the conference

11h55 - 12h00 | Closing

Anne-Sophie Rebillat and María Carmona-Iragui,
co-chairs S&S Committee T21RS

Registration

Registration for in-person attendance:
10 USD

Registration Form for in-person attendance

Registration for virtual attendance:
Free of charge

Registration Form for virtual attendance

www.t21rs2022.com

III - Committee for Sponsoring

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)

An active communication between members was maintained through conference calls and emails

Sponsoring activities

During 2021 research of sponsors had the objective of maintaining the functioning of the society to cover basic expenses (web, technical secretariat)

T21RS sponsors include 4 groups:

1) LuMind IDSC Down Syndrome Foundation, Global Down syndrome, Lejeune Foundation, Matthews Foundation, Trisomie 21 France, Down Espana, Association Française pour la Recherche Sur la Trisomie 21 (AFRT).
2) foundations that give specific support for meetings and travel grants.
3) institutional granting agencies
4) Pharmas with interest in developing treatments for Down syndrome: Aelis Pharma, Fontup

Membership activities

The committee was active in reviewing membership categories.

Starting from 2023, in addition to existing categories, new options will be given for renewal for members that are not students.

-Multiyear renewal. You can renew for two or three years; in so doing paying a rate discounted relative to that if paying year by year.

-Lab memberships. You can renew as the PI of a laboratory. 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 at a rate that does not differ between predoctoral or post-doctoral students. This option is only available on a year-by-year basis. Members viewed this option as increasing student engagement in the Society. While PIs will pay more there will be an overall saving on the cost of membership for their team.

The committee continued the update of a contact list of more than 1000 names of researchers, clinicians and associations.

IV - Committee for Education and Training

Education and Training Committee Members

Chair of the committee:

Sandra Guidi (University of Bologna, Italy)

Members:

Renata Bartesaghi (University of Bologna, Italy)
Carmen Martinez-Cué (University of Cantabria, Spain)
Fiorenza Stagni (University of Bologna, Italy)

The T21RS Committee for Educational and Training worked on:

- establishing a network of host laboratories working on Down syndrome, where visiting young scientists may expand knowledge in different methodological and conceptual issues regarding Down syndrome
- providing grants to students to enable them to attend scientific conferences regarding Down syndrome
- issuing thesis prizes in order to stimulate research on Down syndrome

Initiatives and activities in 2022

In the year 2022, the Committee for Fellowships, Education and Training announced at the 4th International Conference of Trisomy 21 Research Society (Long Beach,CA) the winners of the "Annette Karmiloff-Smith Thesis Award Program", for outstanding Ph.D. thesis launched in 2021: Dr. Anna Joyce Moyer and Dr. Tomer Illouz. They won €1000 each one.

During the 4th International Conference of T21RS the Education Committee in agreement with Program Committee organized a symposium titled "T21RS Society Awards, Annette Karmiloff-Smith, and Michael Harpold Dissertation Award" in which the winners have made a talk on the results showed in their thesis of Ph.D.

During the 4th International Conference of T21RS, the Education Committee in agreement with Program Committee organized a symposium titled "Education Committee World Down Syndrome Day Junior Investigator Talks" in which we invited as speaker the young scientists involved in the Word Down Syndrome Day webinar made on line during the week of WDSD 2022.

During the 4th International Conference of T21RS, the Education Committee in agreement with Program Committee organized a judging committee for the evaluation of best poster shown during the conference. The committee was formed by 12 colleagues that evaluated 7 posters each one. The winners have been Dr. Daniella Balduino Victorino (ICM, Paris, France) and Dr. Agnish Ganguly (University of Calcutta, India). They are nominees during the social dinner at the Conference, and they won a free membership to the next Conference of Trisomy 21 Research Society in Rome in 2024.

During the last year, the Education and Training Committee organized a series of webinars aimed to give our young members the opportunity to take part in an exclusive discussion. We hosted leaders of several specific research fields to discuss together the most recent results in clinical and preclinical Down syndrome research. The webinars are hosted on Zoom platform and lasted about one hour; 45 minutes of presentation and 20 minutes for the discussion with the attendances. Generally, the attendances were about 70 people each webinar from all over the world.

In 2022 the following webinars have been organized:

- November 9th, 2022: title of webinar: “Neural substrates of memory rescue mediated by postnatal environmental enrichment in trisomic mice”; speaker: Maria Victoria Puig (ICN2 e INc-UAB, Spain);

- September 21st, 2022: title of webinar: “GnRH replacement rescues cognition in Down syndrome”; speaker: Dr. Vincent Prevot (Inserm, University of Lille, France);

- May 30th, 2022: title of webinar: “A randomized, double-blind, placebo controlled phase II trial to explore the effects of a GABAA-α5 NAM (basmisanil) on intellectual disability associated with Down syndrome”; speakers: Dr. Xavier Liogier d’Ardhuy (chief of Transaltional Science, Loulou Foundation) and Dr. Celia Goeldner (Senior Principal Clinical Scientist, Roche PRED);

- May 2nd, 2022: title of webinar: “Young scientists speak about their research”; speakers: Dr. Sandra Gimenez-Badia: “Is obstructive sleep apnea treatment with continuous positive airway pressure (CPAP), a long term feasible treatment in adults with Down syndrome?”; Dr. Javier Zorrilla de San Martin: “Alterations of specific cortical GABAergic circuits underlie abnormal network activity in a mouse model of Down syndrome”; Dr. Asaad Baksh: “Susceptibility to COVID-19 diagnosis in people with Down syndrome compared to the general population”;

- March 24th, 2022: title of webinar: “Young scientists speak about their research to support people with Down syndrome”. Speakers: Dr. Jonathan D. Santoro: “The Down syndrome regression disorder”; Dr. Jeanhee Chung: “Down Syndrome Clinic to You (DSC2U), a novel online health tool”; Dr. Lisi Flores-Aguilar: “Evolution of neuroinflammation across the lifespan of individuals with Down syndrome”; Dr. Abi Fukami-Gartner: “Early brain MRI imaging in newborns with DS”.

V - Committee for Pre-clinical Research

Preclinical Committee Members:

Chairs of the committee:

Eugene Yu (US), until June 2022
Frances Wiseman (UK), from July 2022

Co- Chairs of the committee:

Elizabeth Fisher (UK), until June 2022
Randall Roper (US), from July 2022

Members:

Antonarakis, Stylianos (Switzerland)
Bhattacharyya, Anita (US), stepped down July 2022
Delabar, Jean-Maurice (France)
Dierssen, Mara (Spain)
Fisher, Elizabeth (UK)
Haydar, Tarik (US)
Herault, Yann (France)
Mobley, William (US)
Potier, Marie-Claude (France)
Puig, Vicky (Spain)
Reeves, Roger (US)
Yu, Eugene (US)

Junior fellows:

Florencia Iulita (Spain) 2021-2022
Hiruy Meharena (USA) 2021-

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 2022

1. **Our committee promotes research in Down syndrome by extensive involvement in various scientific meetings**: Members presented their data in 2022 in the usual range of international meetings such as FENS, ECNP, AAIC and at SfN in San Diego, CA. Our committee was also successful in a bid to host a "Down Syndrome Social" at SfN 2022, to promote networking of scientists working in DS or interested in joining T21RS; this event attracted a significant number of researchers, including some researchers new to the field. Our committee was also successful in hosting a Satellite Meeting on

Animal and Cell Models at the T21RS International Conference in June 2022, in Long Beach, CA. The Satellite Session allowed researchers to present and discuss technical aspects, pros and cons and the way forward with the models for studying Down syndrome, looking ultimately to improve translational research. The sub-sessions included (1) Animal models: new models/ how we work with them; (2) Human models iPSC/organoids/tissues; (3) Specific problems with cognition? Working across platforms; and (4) a general panel discussion, overall, a wide range of models and techniques were reviewed.

2. **Our committee members promote research in Down syndrome by serving as Editors for Down syndrome-focused special issues.** This included a Frontiers Current Advances in the Study of Down Syndrome: from Development to Aging, (Editors Y. Hérault and W. Mobley).

3. **Our committee members promote research in Down syndrome by undertaking public communication activities.** This included Dr. Wiseman (UK Dementia Research Institute "Diversity in dementia research" and Pint of Science "Down syndrome - 1% extra" talks for a general public audience).

4. **Training the next generation of DS researchers:** We continued to commit our efforts to be inclusive for new investigators. We have now had four early career stage scientists to join our committee and join in all the roles of committee members. During 2022, Drs. Florencia Iulita, and Hiruy Meharena, served as junior members.

5. **Promoting the interactions between the clinical and preclinical committees.** We organized two meetings joined by the preclinical and clinical committees, and we continue to explore efforts to enhance communication between preclinical and clinical scientists, and this remains a key goal for T21RS across the committees.

6. **Broadening preclinical research experience of the committee.** Much trisomy 21 preclinical research has focused on the use of rodent model systems but recent developments in alternative preclinical models (iPSC and invertebrate model systems) provide new opportunities to further understanding of mechanisms underlying phenotypes associated with Down syndrome and for proof-of-principal testing of potential interventions. The committee advertised for new members in 2022 with an emphasis on encouraging researchers who use a diverse range of preclinical models to join the committee.

7. **Our committee explored better ways to identify sources of Down syndrome patient-derived iPS cells and fibroblasts/lymphoblastoids and to facilitate the deposit and distribution of these cells at public domain to increase availability of cells to all researchers**. In an initiative led by Lisi Flores Aguilar (University of California, San Diego), the preclinical committee has helped to investigate how T21RS can facilitate researchers' access to human tissues and biosamples. In 2023 we propose to align this work with the new T21RS Neuropathology Working Group (Chaired by Lotta Granholm), this will include shared committee members and presentations of planned work by the respective committee chairs twice per year.

8. **Drs. Randall Roper and Yann Hérault in our committee are working with the Jackson Laboratory to update the list of mouse models for Down syndrome in Mouse Genome Informatics**.

9. **Drs. Randall Roper, Haydar and Meharena serve on the Cytogenetics Resource External Advisory Board at The Jackson Laboratory, which helps to coordinate the maintenance and distribution of mouse models of Down syndrome to researchers throughout the world**

VI - Committee for Clinical Research

Clinical Adult Committee Members:

Chair of the committee:

Alberto Costa (US)

Members:

Juan Fortea (Spain)
Tonnie Coppus (The Netherlands)
Benjamin Handen (US)
Elizabeth Head (USA)
Sharon Krinsky-McHale (US)
Andrew Nowalk (US)
Huntington Potter (US),
Michael Rafii (US)
Anne-Shopie Revillat (France)
Stephanie Sherman (US)
Weihong Song (Canada)
Andre Strydom (UK)
Shahid Zaman (UK)

Tonnie Coppus, MD (NL); Tonnie.Coppus@radboudumc.nl

Dr. Coppus is a researcher at the Department for Primary and Community Care, Radboud University Medical Center, Nijmegen, The Netherlands. Her research focuses on dementia and aging in people with intellectual disabilities, especially Down syndrome.

Alberto Costa, MD, PhD (US); alberto.costa@case.edu

Dr. Costa is Professor at the Departments Psychiatry and Macromolecular Science and Engineering at Case Western Reserve University. For over two decades, Dr. Costa has been investigating the pathophysiology and potential pharmacotherapeutic approaches to Down syndrome using both preclinical and clinical strategies. He is the principal investigator of a recently-concluded phase II 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.

Elizabeth Head, PhD (US); heade@hs.uci.edu

Dr. Head is Professor at the University of California at Irvine in the Department of Pathology & Laboratory Medicine. She is actively engaged in longitudinal studies of aging and Alzheimer disease in people with Down syndrome that includes cognitive, clinical, fluid biomarker and neuroimaging outcome measures. Her lab is focused on the study of anatomical and molecular changes in the brains of people with Down syndrome at the University of California Irvine.

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; Parent training in autism spectrum disorder.

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.

Andrew Nowalk, MD (US); Andrew.Nowalk@chp.edu

Dr. Nowalk is Associate Professor in the Department of Pediatrics at the University of Pittsburgh School of Medicine. He has served as a pediatric infectious disease consultant at UPMC Children's Hospital of Pittsburgh for 15 years, with special interest in hospital acquired infections and the care of infectious complications of Down syndrome in the pediatric population.

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

Dr. Potter is a Professor of Neurology, a 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-Shopie 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.

Stephanie Sherman, PhD (US); ssherma@emory.edu

Dr. Sherman is a genetic epidemiologist in the Department of Human Genetics at Emory University, Atlanta GA. Her research focus is to identify genetic and environmental risk factors that are associated with the causes and clinical consequences of trisomy 21.

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

Dr. Song is the Canada Research Chair in Alzheimer's Disease and a Full Professor with tenure at Department of Psychiatry 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 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 world-leading 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 Affiliated Lecturer at the Cambridge Intellectual and Developmental Disabilities Research Group, Department of Psychiatry, University of Cambridge. He is a consultant psychiatrist 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. He is currently involved in research in dementia in Down's syndrome. He also has plans to explore the role of sleep on memory and learning in this population.

Initiatives and achievements in 2022

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 frequency of meetings of the Adult Clinical Committee has increased from quarterly meetings to one meeting every two months. This change occurred in order to make the Adult Clinical Committee more responsive to issues, ideas, and concerns raised during monthly Executive Committee meetings. In 2022, members of the committee have contributed articles to the T21RS Newsletter. Additionally, our committee accomplished the following:

1. Together with the Clinical Child Developmental Committee, several members of the Adult Clinical Committee continued using their expertise to provide input to COVID-19 related projects that were ongoing through the T21RS COVID Taskforce. This effort has resulted in four peer-reviewed publications

and might continue through a new international surveys on the long-term effects of COVID-19 and COVID-19 vaccination in individuals with Down syndrome.

2. The Adult Clinical Committee has discussed many issues related to clinical research in Down syndrome (e.g., the potential usefulness and challenges of using anti amyloid antibody therapies in the treatment of Alzheimer's disease in individuals with Down syndrome, and the results of the phase 2 memantine clinical trial). Members of the committee have shared the results of these discussions through their contacts with clinical organizations.

3. The Adult Clinical Committee sponsored and contributed speakers to a symposium at the T21RS Forth International Conference (held in Long Beach, CA, USA on June 9-12, 2022), which was titled: "New Data, Resources, Challenges, and Opportunities at The Interface Between Translational and Clinical Research." Dr. Costa was the chair and one of the speakers in the symposium and Dr. Raffi was one of the speakers. Dr. Ann-Charlotte (Lotta) Granholm (USA) was the third speaker of the symposium.

4. Many members of the Adult and Child Developmental Committees joined members of the Preclinical Committee in contributing to preparation of a letter to the journal Science in response to the paper by Manfredi-Lozano et al., titled: "GnRH replacement rescues cognition in Down syndrome" (DOI: 10.1126/science.abq4515). The resulting letter was published as an E-letter at https://www.science.org/doi/10.1126/science.abq4515.

Developmental Clinical Research Subcommittee Members

Chair of the subcommittee:

Brian Skotko (US)

Members:

Cécile Cieuta-Walti (CA; FR)
Floriana Costanzo (IT)
Jessica Hunter (US)
Silvia Sacco (FR)
Stephanie Santoro (US)
Stephanie Sherman (US)
Rafael de la Torre (ES)
Stefano Vicari (IT)

Cécile Cieuta-Walti, MD (CA; FR); cecile.cieuta@usherbrooke.ca
Dr. Cieuta-Walti is a Pediatric Neurologist, working in Medical University of Sherbrooke, QC, Canada. She is involved in Clinical Trial in Down Syndrome People (in collaboration with Jerome Lejeune Institute) and is a member of the scientific committee of the Jerome Lejeune Foundation.

Floriana Costanzo, PhD (IT); floriana.costanzo@opbg.net
Dr. Costanzo is a Psychologist in the Child and Adolescent Neuropsychiatry Unit of the Bambino Gesù Children's Hospital in Rome and Assistant Professor of Developmental Neuroscience at the European University of Rome. Her research interests include the neuropsychological and psychopathological characterization as well as the development of clinical trials for improving cognition and psychopathology in children and adolescents with Down syndrome.

Jessica Hunter, PhD (US); Jessica.E.Hunter@kpchr.org
Dr. Hunter is a genetic epidemiologist in the Department of Translational and Applied Genomics at the Center for Health Research of Kaiser Permanente Northwest. Her research interests include the characterization of risk factors and associated with chromosome 21 nondisjunction as well as clinical outcomes and healthcare needs in Down syndrome.

Silvia Sacco, PhD (FR); silvia.sacco@institutlejeune.org
Dr. Sacco is licensed as developmental psychologist and neuropsychologist. She is working at the Institut Jérôme Lejeune in Paris. She is involved clinical and research programs. Her interest is to support and develop research programs for people with Down Syndrome for a better understanding of issues related to development and cognitive decline in Down Syndrome. **Dr. Sacco retired this last year and we thank her for your work on this committee.**

Stephanie Santoro, MD (US): ssantoro3@mgh.harvard.edu
Dr. Santoro is a clinical geneticist at Massachusetts General Hospital and the Director of Quality Improvement Research at the Mass General Hospital Down Syndrome Program. Her research interest includes the study of health, the use of quality improvement to maximize health outcomes for individuals with Down syndrome, development and implementation health care guidelines, and collaboration to study unique aspects of Down syndrome such as Unexplained Regression in Down Syndrome.

Stephanie Sherman, PhD (US); ssherma@emory.edu

Dr. Sherman is a genetic epidemiologist in the Department of Human Genetics at Emory University, Atlanta GA. Her research focus is to identify genetic and environmental risk factors that are associated with the causes and clinical consequences of trisomy 21. **Dr. Sherman retired this last year and we thank her for your work on this committee.**

Brian Skotko, MD, MPP (US); BSKOTKO@mgh.harvard.edu

A Board-certified medical geneticist, Dr. Skotko is the Emma Campbell Endowed Chair on Down Syndrome at Massachusetts General Hospital. As the Director of the hospital's Down Syndrome Program, he has dedicated his professional energies toward children with cognitive and development disabilities. **Dr. Skotko has replaced Dr. Sherman as the Chair of the Clinical Child Developmental Committee since January 2022.**

Rafael de la Torre, PhD (SP); rtorre2@imim.es

Dr. Rafael de la Torre is a pharmacologist in the Neurosciences Research Program at the Hospital del Mar Medical Research Institute, Barcelona, Spain. His research is mainly focused in the clinical development of pharmacological and non-pharmacological approaches for improving cognitive performance and adaptive functionality in individuals having Down syndrome

Initiatives and achievements in 2022

The goal of this subcommittee of the T21RS Clinical Committee is to increase our knowledge of the cognitive and behavioral trajectory of children and adolescents with Down syndrome (DS) and deepen our understanding of the effect of various comorbid disorders on these trajectories and on the quality of life.

In 2022, we accomplished the following:

1. Based on the efforts of Dr. Hunter, a survey was developed to capture data describing existing cohorts and their inclusion of genotype and phenotype data. The Committee then developed a "use case" to show the value of using the existing cohorts for collaboration. The focus will be on KBIT-2, an instrument widely used to assess cognitive level among children with DS. The goal is to describe the distribution of scores (standardized and raw scores) across the ages and identify associated covariates. Currently, data from five of the eight cohorts (n=~461 cases of the possible 789) have been centralized. Hurdles to obtain the other cohorts primarily relate to lack of resources (e.g., time or personnel available to pull the data) and Data Transfer Agreements, but these are being addressed. In 2021, Dr. Hunter was able to secure funding from NIH to support the analyses related to this use case and exploration of next steps. The goal for 2023 is to analyzed and publish the results from the use case.
2. The committee continues to focus on ways increase outreach to all people with Down syndrome to provide research opportunities. Drs. de la Torre and Costanza are currently working with LuMIND IDSC to enhance their catalog of ongoing clinical studies and trials (https://www.lumindidsc.org/s/1914/20/filter.aspx?sid=1914&gid=2&pgid=512) by adding information about international clinical studies. This committee will continue to collaborate with LuMIND IDSC on expansions once this first step is accomplished.
3. The committee has written and submitted its chart to the T21RS Executive Committee.

4. The committee has made its available as a resource for clinical connections and collaborations for T21RS Researchers. On a regular basis, the following message was sent to T21RS members:

Looking for clinical ideas, resources, or collaborators for your research?

The T21RS Clinical Child Development subcommittee (add link to committee) is willing to help you. This subcommittee is composed of Down syndrome clinician-researchers, who are happy to assist you with questions such as

- Where can I find some blood or tissue samples for a research project?
- I'm looking for a clinical expert to weigh in on a research proposal or to serve as a co-investigator. Can you help me find the right person?
- Our lab would like to bounce some ideas off of practicing clinical experts in Down syndrome. Can you help us find someone?
- I am looking to recruit patients to one of my research studies. Can you help me out?

Send your question to info@t21rs.org and our committee will do our best to answer your questions.

5. The committee helps broker opportunities for T21RS researchers to observe in Down syndrome specialty clinics. The following message has been created:

Many benchtop researchers have shared that they would like to observe a Down syndrome specialty clinic, giving them an opportunity to observe the clinical care of patients with Down syndrome.

The T21RS Clinical Child Development subcommittee is willing to help benchtop researchers make a connection to a local Down syndrome specialty clinic. The main objectives for this experience would be to (a) meet patients with Down syndrome and their families and (b) witness a clinical encounter. If you are interested in this facilitated matchmaking, please e-mail info@t21rs.org. If travel is necessitated for the observation, researchers would be expected to cover their own costs at this time.

Budget justification for Yr2022: given the uncertainty associated to in-person meeting until very recently, neither the Adult Clinical Committee nor the Developmental Clinical Committee requested any budget distribution for 2022.

VIII- Communication Workgroup

Communication workgroup members:

Chair of the workgroup:

Michael Yaeger (USA), until July 2022
Lisi Flores Aguilar (USA), from July 2022

Members:

Sujay Ghosh (India)
Eric Hamlett (USA)
James Hendrix (USA), until May 2022
Blandine Ponroy (Canada)
Ilias Ziogas (Italy)
Natalia Valle Tamayo (Spain)
Hannah Saternos (USA)
Lorena Sordo (USA)

Activities in 2022

1. We generate content for the T21RS **monthly Newsletter.** The Newsletter is distributed to the T21RS members who signed up to receive it and among a list of interested persons who subscribed through our website.

2. We **update the website** with news, events, and job offers when solicited. The Communication workgroup made suggestions to improve the website and will work with a web developer to improve the website.

3. We worked on promoting **the 4th T21RS International Conference** in June 2022.

4. We have developed a **strategic plan** to improve the communication and dissemination of the Society.

5. Finally, we acted as **Community Managers of the T21RS Twitter and Facebook accounts.**

FINANCIAL REPORT

01-01-2022 – 31-12-2022

1. Treasury

The Trisomy 21 Research Society (T21RS) is a non-profit society (in Dutch: *vereniging*) established under the laws of the Netherlands, having its registered statutory seat in the municipality of Groningen, and its principal place of business at the Wageningen University & Research, Stippeneng 4, 6708 WE Wageningen, listed in the trade register under number 60501162 (Chamber of Commerce).
T21RS is recognized by the Dutch Tax Administration as a Public Benefit Organization (in Dutch: *Algemeen Nut Beogende Instelling*, ANBI).

Statutory seat:	Groningen, The Netherlands
Registered office/place of business:	Wageningen University & Research (WUR) Helix 124, Stippeneng 4 6708 WE Wageningen (The Netherlands)
RSIN identification number (NL):	853938283
KvK Chamber of Commerce number (NL):	60501162
Current treasurer (2021-present):	Dr. Y.P.Y. (Yannick) Vermeiren Wageningen University & Research, Wageningen, The Netherlands
Past-treasurer (2014-2021):	Dr. A.D. (Alain) Dekker (2016-2021) University Medical Center Groningen, The Netherlands Dr. A.M.W. (Tonnie) Coppus (2014-2016) 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. General summary of 2022

Even though 2022 started off pretty uncertain with, again, an almost worldwide lockdown due to the COVID19 pandemic, our organizing and program committees decided to take the risk and to organize the two yearly *in person* International Conference of our society in Long Beach (California) from 9-12 June 2022. In the end, this paid off and showed to be a great success. Moreover, income in 2022 was primarily sustained via our membership fees in addition to the yearly Founding and Supporting member fees, which are guaranteed at least up and until the end of 2024 or 2025 via mutually signed agreements. The balance sheet (**Figure 2**) also shows that the cash asset at the banking account has been steadily maintained throughout the last few years. We also decided to grant more Travel Awards in the end than originally foreseen via the financial sponsors, so that more junior researchers could join the conference. This led 2022 to be closed with a small net loss on our T21RS banking account but for a good reason (**Figure 1**). Nevertheless, the financial support from numerous sponsors for organizing the conference finally resulted into a small profit (conference revenue), if only looked at "financial sponsorship + conference registration fee incomes – (minus) the organization expenses". Moreover, more Science Event Awards, and, again, Thesis Awards have been granted in 2022.

3. Revenues

Revenue in 2022 primarily consisted of 1) membership fees, 2) general financial support for the society by Founding and Supporting members, and, 3) financial sponsorship + conference revenue related to the organization of the T21RS Conference in Long Beach (California; June 9-12, 2022).

1) Membership[1]

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,-

[1] As mentioned above in this year report, the membership categories and accompanying fees will change from 2023 onwards. For 2022, the categories have remained the same as it was previous years.

2) Founding and Supporting Members 2022

T21RS is very grateful to a number of non-profit organizations that financially support the continuation of the society and its aims. In 2022, this concerned:

• Fondation Jérôme-Lejeune (France):	€ 5.000,-	Founding Member
• Global Down Syndrome Foundation (USA)	€ 5.000,-	Founding Member
• Lumind-IDSC Foundation (USA):	€ 5.000,-	Founding Member
• Trisomie 21 France (France):	€ 5.000,-	Founding Member
• The Matthew Foundation (USA):	€ 2.500,-	Founding Member
• Down España (Spain):	€ 5.000,-	Supporting Member
• Association Française pour la Recherche sur la Trisomie 21 (AFRT) (France)	€ 2.500,-	Supporting Member

3) Financial sponsorship + conference revenue related to the (organization of the) T21RS Conference in Long Beach

Our society is very grateful to have received financial support from numerous sponsors for organizing the T21RS International Conference at Long Beach, California (June 9-12 2022). These sponsors, were: Global Down Syndrome Foundation, Lumind-IDSC Foundation, IQVIA, AC Immune, National Down Syndrome Society (NDSS), ProMIS Neurosciences Inc., Fondation Jérôme-Lejeune, Annovis Bio, Alzheon, Merck, Cure Alzheimer's Fund, Aelis Farma, Lilly, The Company of Biologists, Bio-Rad Laboratories, Include DCC and Embo. Not all financial contributions were directly received on the T21RS banking account. BCO Congresos also, in part, received some of the abovementioned sponsorships.
The conference revenue in total amounted to a small net profit of € 8.648,15 (this is, financial sponsorship + registration fee incomes – (*minus*) organization expenses).

4. Expenses

As can be retrieved from **Figure 1** below, expenses in 2022 were primarily related to the conference organization in addition to the allocation of many Travel Awards for that conference, as well as the usual operational/running costs (website maintenance, BCO secretariat of the society, payment operator Mollie), monthly banking costs, and, T21RS Thesis and Science Event Awards granted.

The society also decided to invest more via its own means into extra granted Travel Awards for junior researchers. This is, in addition to the received grant from Fondation Jérôme-Lejeune (France) of a total amount of € 43.000 dedicated to grant Travel Awards to a total of 32 junior researchers.

Some fair amount of open access fees related to the publication of Down syndrome's research articles in which T21RS was a co-author was also spent in 2022. In part, latter expense of the open access fees was covered by a LuMind-IDSC coordinated grant of € 8650,- provided in 2020 to T21RS, for sponsorship of a COVID-19 & Down syndrome's research project.

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 2022.

Figure 1. Profit and Loss Statement (Euro (€))

Trisomy 21 Research Society (T21RS)

Profit and Loss Statement

For the period from 01/01/2022 to 31/12/2022

Accrual basis

	31/12/2022
Income	
Conference revenue	**8 648,15**
Financial support (conference)	**99 042,14**
Financial support (founding/supporting members)	**29 980,00**
Interest	**9,92**
Membership fees	**16 471,77**
Total — Income	**154 151,98**
Less: Expenses	
Conference organization (via T21RS account)	**111 135,74**
Open Access Fee APC of joint T21RS publications - Lumind-IDSC Down & COVID19 Taskforce allocated project expense (in part)	**4 099,26**
Operational costs	**2 089,37**
Other	**400,00**
T21RS Event Awards	**2 500,00**
T21RS Thesis Awards	**2 000,00**
T21RS Travel Award	**47 805,11**
Total — Expenses	**170 029,48**
Net profit (loss)	**(15 877,50)**

6. Total Balance

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

Trisomy 21 Research Society (T21RS)

Balance Sheet

As at 31/12/2022

Accrual basis

	31/12/2022	31/12/2021	31/12/2020	31/12/2019	31/12/2018
Assets					
Cash at bank	**352 030,51**	367 908,01	327 866,69	301 335,19	161 139,65

7. Conclusion

The year 2022 has been closed with **a net loss of € 15.877,50**. The final balance amounts into **a total (positive) cash asset of € 352.030,51** on the T21RS banking account.

8. Discussion and outlook

Luckily, we had a relatively stable financial year given the high-risk organization of the conference with the COVID19 pandemic just lurking around, especially at the beginning of 2022, when also the financial organization of the conference took place. In the end, this paid off well, with even a small conference revenue. There was more investment again compared to 2021 in Science Event-, Travel-, and Thesis Awards, all of which stimulated the scientific research within the T21RS community. As can be derived from **Figure 2**, the steady financial growth of the society has now come to an overall equilibrium, and we expect things to remain more or less stable for the in-between year 2023, in which no international conference is organized. The plan is, however, to invest more into member initiatives in the near future, as already discussed in the Executive Board, such as scientific exchanges and/or financial support for early investigators. This will increase again the financial cash flow and is a proper investment of the financial means of our society of Down syndrome researchers. In addition, we will also still have a financial buffer that protects the society from financially harsh times, given the guaranteed membership fee incomes and yearly sustained support from the founding and supporting members mentioned above.