Trisomy 21
Research Society

Annual report 2015

Includes:

The Trisomy 21 Research Society

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, scientific meetings, publications in journals and the two-yearly T21RS International Conference.
- To 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
- **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. 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.

In 2015 we held our first election of officers who replace the acting members of the Executive Board as of January 1, 2016. Two new positions were created at the General Meeting of the Society during the 2015 Paris meeting: “Past president” to serve two years following the term of office as president, and “President-elect” from the time of election until the individual assumes the office of president. In a small organization with minimal administrative infrastructure this will help to assure continuity and “corporate memory.”

The new officers are:

President:
Roger H. Reeves, Ph.D.
Johns Hopkins University, Baltimore, MD, USA
Past-President:
Jean Maurice Delabar, Ph.D.
Univ Paris-Diderot and ICM, Paris, France
Secretary:
Marie-Claude Potier, Ph.D.
CNRS, INSERM, UPMC, Paris, France
Treasurer:
Alain Dekker
University of Groningen, Groningen, The Netherlands

There are 6 Committees to carry out the work of the society**:**
Committee chairs:

Program Committee:	Mara Dierssen
Committee for Science & Society:	Peter De Deyn
Committee for Sponsoring:	Jean Maurice Delabar
Committee for Fellowships, Education and Training:	Renata Bartesaghi
Committee for Pre-clinical Research:	Yann Herault
Committee for Clinical Research:	André Strydom
Webmaster:	Alain Dekker

Advisory board
An advisory board has been recruited and members choice has been done by the Executive board with the objective to balance expertises and geographic origin.
USA

- Diana Bianchi
- George Capone
- William Mobley
- Michael Rafii
- Nicole Schupf
- Tom Blumenthal

Chile

- Pablo Caviedes

Canada - China

- Weihong Song

Europe

- Stylianos Antonarakis
- Andrea Contestabile
- Elizabeth Fisher
- John Hardy
- Rafael de la Torre
- Renaud Touraine

Europe - Singapore

- Dean Nizetic

Membership

The Society membership currently (May 2016) stands at 113. This includes 78 Academic-Faculty, 10 Postdoctoral Fellows, 11 Graduate Students, and 11 Associate members and 3 honorary members

Accomplishments, 2015

1st Meeting of the T21RS

A very successful first meeting of the T21RS was held June 4-7 2015 at the Brain and Spine Institute of Hôpital Pitié-Salpêtrière in Paris. The meeting, entitled "Changing paradigms in Down syndrome," attracted 230 participants from 20 countries including scientists, clinicians, students and postdocs, and members of associations and foundations. The meeting included a half day "Science and Society" session attracting international representation of parent/community associations. A report including the Official Programme and highlights of the sessions can be found on the society website, t21rs.org.

Founding sponsors

T21RS has recruited five non-profit organizations to be Founding Sponsors of T21RS, a society of scientists working on basic, translational and clinical research relevant to Down syndrome. Founding Supporters have committed themselves to 5 years of support at a level of €5000 per year. The Founding Sponsors are: Lumind-RDS Foundation; Trisomie 21 France; Matthew Foundation; Global Down syndrome; Jerome Lejeune Foundation. Founding Sposnors receive the following recognition:

1. Founding supporters are listed prominently on the home page of the T21RS website with links to the website of each Founding Supporter.
2. The Founding sponsors are displayed in Meeting materials and communications from the Society.
3. Each Founding Sponsor receives 1 general assembly membership and 1 additional one per every 100 total members or fraction thereof for whoever they deem appropriate.

Committee work
Our six core committees are the focus of much of the society's efforts. Some highlights of from 2015 include:

Committee for Science & Society: Held a half day workshop at the T21RS meeting in June attracting international representation of parent/community associations. See page 8.

Committee for Sponsoring: The committee has met telephonically to discuss fund-raising in support of the 2017 meeting and the society in general. Ideas for revamping of the logo/web page/ society marketing emerged from this group including idenitification of a professional firm that is providing this development pro bono.

Committee for Fellowships, Education and Training: This committee designed a new research award for the best dissertation related to DS with a small cash prize and a speaker's slot at the subsequent society meeting.

Committee for Pre-clinical Research: Substantial progress was made toward establishing a core set of behavioral characterizations for trisomic mouse models/ drug testing in models. Detailed protocols that can serve as a guideline to harmonize independent research efforts in this area are available on the Committee's pages of the website.

Committee for Clinical Research: The clinical committee has undertaken the difficult task of surveying the arena of clinical and pilot research to reach possible consensus on approaches to measures of cognitive abilities and their decline with age in DS.

Webmaster: Alain Dekker continues to support improvements/refinements to the website which is at the core of the society's internal copmmunications.

Summary:
T21RS has made great strides in establishing itself as a presence in the T21 Clinical and Research communities. We have begun interactions with Family and Caregiver organizations to provide understandable interpretations of the latest scientific advances to the lay public. At the same time, our Core mission to support basic and clinical research is advancing as shown in the Committee reports. There are administrative issues to be dealt with as we refine the very lean structure of the young society, but these are proceeding well. Overall we are pleased with the groundwork laid for the Society in this first year of operation and are working hard to fulfill our mission to society.

Annual Financial Report 2015
Trisomy 21 Research Society

1. Treasury

T21RS is the first non-profit scientific research society (*Dutch:* vereniging) for the stimulation of scientific research on Down syndrome, operating under Dutch law. The official statutory address as well as the bank are located in Groningen, The Netherlands.

Address: T21RS Groningen Office
University Medical Center Groningen (UMCG)
attn. A.D.Dekker (AB51)
Hanzeplein 1, PO Box 30.001, 9700 RB Groningen
The Netherlands

Treasurer 2014-2015: Tonnie Coppus
Radboud University Medical Center Nijmegen, The Netherlands

Treasurer 2016-2017: Alain Dekker
University Medical Center Groningen, The Netherlands

2. Summary of 2015

In its second year, T21RS has matured as international research society, both as society itself, but also in a financial way. An increasing number of researchers and clinicians became a full member, and sponsor revenues have grown. Key fact in 2015 was the organization of the first T21RS International Conference in Paris, which dominates the 2015 balance (see below).

3. Revenues

T21RS main revenues consist of membership fees and sponsoring. We distinguish two types of membership: (1) full membership for researchers and clinicians, and (2) associate membership for those associations/foundations that are interested to be in contact with T21RS.

Full membership for researchers and clinicians

Master/PhD student	€ 40,-
Postdoctoral fellows	€ 80,-
Academic staff members / clinicians	€ 100,-

Association

Associate member	€ 50,-

After registration of an account on our website www.T21RS.org, people automatically proceed to the secured payment module, operated by the international payment operator Multisafepay.

Sponsors

T21RS has recruited five non-profit organizations interested in supporting the establishment of a society of scientists working on basic, translational and clinical research relevant to Down syndrome. Founding Supporters have committed themselves to 5 years of support at a level of € 5000,- per year.

- Lumind – Research Down Syndrome Foundation
- Fondation Jérome Lejeune
- Matthews Foundation
- Global Down Syndrome
- Trisomie21 France

In 2015, the Instituto Iberico Americano also provided 5000,- to T21RS.

In addition to the aforementioned donations, specific sponsoring was provided by Fondation Jérome Lejeune, Down syndrome UK, Lumind, Global Down Syndrome, IBRO, Roche and Elan Pharmaceuticals for the T21RS International Conference in Paris.

4. Expenses

In addition to the general ongoing expenses for maintenance of our website, banking fees and notary costs, the 2015 balance is dominated by costs for the T21RS International Conference in Paris. Apart from ongoing.

5. Balance

The 2015 balance is depicted on the next page. In short: the year 2015 is closed with a positive balance, providing a decent start for 2016.

INCOMES/REVENUES		EXPENSES/COSTS	
Balance 2014		FRUTO Internet design and modifications	
	7568,75		2932
Membership fees			828,8
Fees	9500		725,27
Sponsors		SR Brightside: Logo changes	
			150
Global Down syndrome	5000	Notary; de Haan	
Trisomie21 France	5000		1312,85
Trisomie21 Limoges	437,67	Bank fees	
Instituto Ibero americanc	5000		235,47
Lumind	4413,06	Paris meeting (including registration fees)	
Fondation J Lejeune	5000		38622,48
Sponsors, Paris meeting		Travel grants	
Fondation J Lejeune	11000		15599,26
Down syndrome UK	1500	Chicago Meeting 2017	
Lumind	871,99		1876,92
Global Down syndrome	18000		
IBRO	3000		
Roche	5000		
Elan Pharmaceuticals	5200,03		
Balance December 2015			
			24208,45

Annual report 2015
T21RS Committee for Science & Society

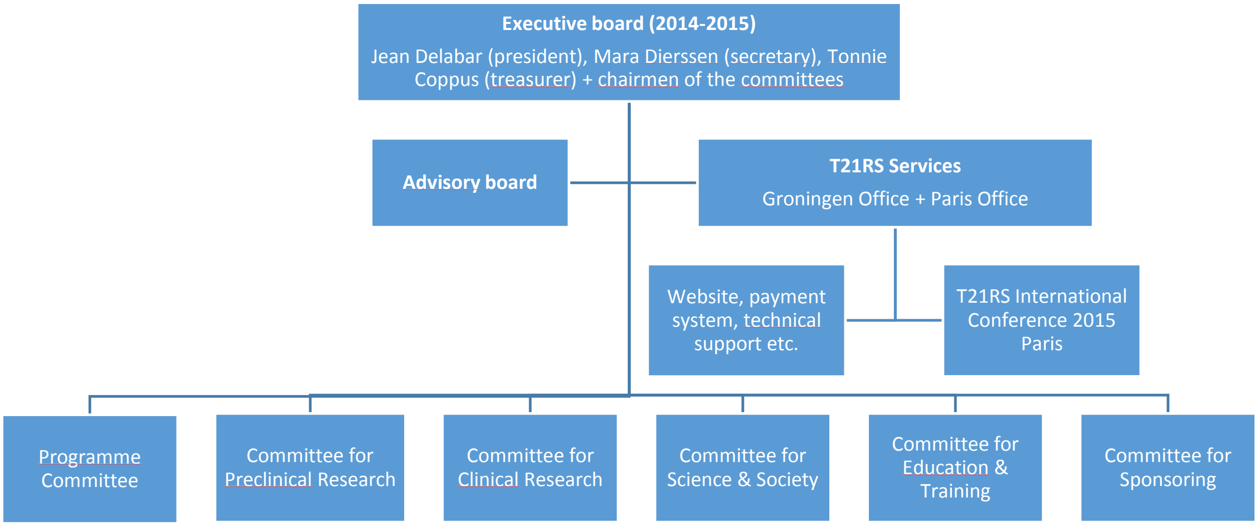
1. General information

Via the T21RS Committee for Science & Society, T21RS aims to be in contact with family members and caregivers of individuals with Down syndrome. To that end, the Committee for Science & Society, led by professor Peter Paul De Deyn, works together with local, national and international Down syndrome associations to disseminate and explain recent scientific findings in understandable language, and to encourage these associations to give feedback on key issues that you feel should be investigated.

Address: T21RS Groningen Office
University Medical Center Groningen (UMCG)
attn. prof. Peter Paul De Deyn (AB51)
Hanzeplein 1, PO Box 30.001, 9700 RB Groningen, The Netherlands

Chairman: Prof. Dr. Peter Paul De Deyn (Belgium)
Members in 2015: Alain Dekker (The Netherlands), Juan Fortea (Spain), Sebastián Videla (Spain), Hannah Wishnek (USA). *In 2016, Lotta Granholm and Cindy Lemere (USA) will join the committee.*

The Committee for Science & Society is one of the six committees of T21RS. As chairman of the Committee, Prof. Dr. Peter Paul De Deyn is also member of the Executive Board. The organizational structure of T21RS in 2015 is illustrated in the organization chart below.



2. Initiatives and achievements 2015

In the second year of T21RS (2015), the Committee concentrated its efforts on three major initiatives:

1) Publishing two T21RS Science & Society Bulletins

2) Organizing the T21RS Science & Society Symposium on Sunday 7th of June, as part of the T21RS International Conference in Paris (4-7 June 2015)
3) Contributing to The Dementia Table Initiative

As the T21RS International Conference approached, the Committee contacted a number of European and American associations in 2015 to invite them to join the Science & Society Symposium (see below), and to discuss potential avenues of collaborations. Currently, the collaborations comprise the following:

1. Presentation of the logo and link of the association our Science & Society page: http://www.t21rs.org/societal-partners, and vice versa (logo of T21RS on the website of the association).
2. Publication of the T21RS Science & Society Bulletin. The collaborating associations automatically receive the Bulletin via e-mail.
3. Bi-annual invitation to Science & Society Symposia (T21RS International Conference).

A list of the associations that collaborated with the Committee in 2015, most of which were present at the Science & Society Symposium, can be found on the T21RS website: http://www.t21rs.org/science-society/societal-partners

3.1. T21RS Science & Society Bulletin

Science-related issues, recent scientific findings, and overviews of key issues are published as special T21RS Science & Society Bulletins. This Bulletin is written by the Committee itself, or at the Committee's request, in understandable English. The Bulletin is not a scientific publication, but rather a non-specialist magazine article for parents, caregivers etc. Full T21RS members can download current and previous Bulletins in the protected T21RS Membership Environment. Collaborating associations receive the Bulletin via e-mail after signing up / requesting the Bulletin via the Committee. Local associations translate the Bulletin into their language (in case of non-English speaking countries) for publication on their website and in their magazines. The use of the Bulletin is free of charge, as long as the T21RS Committee for Science & Society is acknowledged and the content is not changed (apart from the translation).

In 2015, two T21RS Science & Society Bulletins have been published:

1. T21RS Science & Society Bulletin, 2015 (1): Depression in Down syndrome: a big problem?
2. T21RS Science & Society Bulletin, 2015 (2): Alzheimer's disease in adults with Down syndrome: a challenge

3.2. T21RS Science & Society Symposium

During the first T21RS International Conference from 4-7 June 2015, at the Brain and Spine Institute of the Salpêtrière hospital in the heart of Paris, the Committee organized a special Science & Society Symposium on Sunday the 7th of June. This Symposium, dedicated to Down syndrome associations, aimed to (1) more extensively introduce T21RS, its goals and committees, especially the Committee for Science & Society, (2) get acquainted with each other, (3) share thoughts and ideas and discuss about future directions and collaborations.

One of the key sessions within the symposium was the association introduction round, in which thirteen associations from Europe and the USA presented themselves in three minutes ecah.

1. Alzheimer's Association ISTAART PIA: DS-AD (USA, international), represented by: Cindy Lemere
2. LuMind RDS Foundation (USA), represented by: Michael Harpold
3. The Matthew Foundation (USA), represented by: John Blascovich and Maddalena Adorno

4. Global Down Syndrome Foundation (USA), represented by: Michelle Sie Whitten
5. Fondation Jérome Lejeune (France), represented by: Thierry de la Villejegu
6. Trisomie 21 France (France), represented by: Cécile Dupas
7. Down Syndrome International (UK, international), represented by: Andrew Boys
8. Down España (Spain), represented by: Manuel Velázquez López
9. European Down Syndrome Association (Europe), represented by: Manuel Velázquez López
10. Fondation AMIPI-Bernard Vendre (France), represented by: Remi Cornubert, Marie-Laure Blandin
11. Catalan Down Syndrome Foundation (Catalonia, Spain), represented by: Sebastián Videla
12. Association Française pour la Recherche sur la Trisomie 21 (France), represented by: Agnes Duguet
13. Hungarian Down Association (Hungary)

The symposium programme, as well as the PDFs of various presentations listed above, can be found on the T21RS website: http://www.t21rs.org/science-society/t21rs-science-society-symposium

A second major topic at the T21RS Science & Society Symposium concerned The Dementia Table Initiative: sharing & improving knowledge about ageing and dementia in people with intellectual disabilities. In The Netherlands, the Committee is contributing to the organization of The Dementia Table Initiative. **The Committee asked** Sandra Overbeek and Charlotte Thoolen, founders of the The Dementia Table Initiative, to present their work on how to involve caregivers and family members. Such an initiative is a great example of how science/professional care and society (family members, daily caregivers) can interact in an easy-accessible way and in a pleasant ambiance. Various of the aforementioned associations were very positive about the initiative and consider to adopt a similar set-up as well. The presentation about The Dementia Table Initiative can be downloaded on the T21RS website: http://www.t21rs.org/science-society/t21rs-science-society-symposium

Prof. Dr. Peter Paul De Deyn
Chairman T21RS Committee for Science & Society
p.p.de.deyn@umcg.nl

Full professor in neurology, University of Groningen and University of Antwerp
Director Alzheimer Research Center, Groningen, The Netherlands; Scientific director Institute Born-Bunge, Antwerp, Belgium
Department of Neurology and Alzheimer Research Center, University Medical Center Groningen, Groningen, The Netherlands
Laboratory of Neurochemistry and Behaviour, Institute Born-Bunge, University of Antwerp, Wilrijk, Antwerp, Belgium

T21RS Annual Report 2015 (incl. Financial Report)
Executive Board – signatures

J. Delabar
President T21RS

A.M.W. Coppus
Treasurer T21RS

M. Dierssen
Secretary T21RS

Jorge

J. Busciglio
Chair Program Committee

P.P. De Deyn
Chair Committee for Science & Society

Y. Herault
Chair Committee for Preclinical Research

R. Bartesaghi
Chair Committee for Education

M-C. Potier
Chair Committee for Sponsoring

A. Strydom
Chair Committee for Clinical Research

t21
RESEARCH
SOCIETY

T21RS Governing Council (General Assembly) meeting

Saturday 10th of June 2017, Chicago, Illinois, USA
during T21RS International Conference 2017

Venue

Date: Saturday 10th of June 2017

Time: 13:30 – 14:30 (Chicago time)

Location: Feinberg Conference Center
Feinberg Pavilion, Northwestern Memorial Hospital
251 E. Huron Street
Chicago, Illinois 60611
United States of America

main meeting room

Program

1. Welcome and opening of the General Assembly (13:30)
2. Presentation and Approval of Annual Reports 2015/2016 (incl. Financial Reports 2015/2016) (discharge)
3. Discussion and Approval of revised T21RS Statute
4. Society announcements and discussion
5. Closing (meeting adjourned/ended at 14:25)

Membership

Members present: **105 full members with voting rights**

Voting on annual report 2015:
Against: 0 members
Abstain: 0 members
In favor: 105 members

Voting on annual report 2016:
Against: 0 members
Abstain: 0 members
In favor: 105 members