

Trisomy 21 Research Society

Annual report 2014

A/ Foundation of 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.)
- To 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
- To 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
- To promote the **interaction between scientists and patient associations, foundations and pharmaceutical industries**

It has been created in April 2014 and statutes have been 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.

An Executive board has been designated for two years 2014-2015 and is composed of:

President:

Jean Maurice Delabar

Univ Paris-Diderot and ICM, Paris, France

Secretary:

Mara Dierssen

CRG, Systems Biology Program and Spanish Society for Neuroscience, Barcelona, Spain

Treasurer:

Tonnie Coppus

Radboud University Medical Center, Nijmegen, The Netherlands

6 Committees:**Program Committee:****Committee for Science & Society:****Committee for Sponsoring:****Committee for Fellowships, Education and Training:****Committee for Pre-clinical Research:****Committee for Clinical Research:****Webmaster:***Committee chairs:*

Jorge Busciglio

Peter De Deyn

Marie-Claude Potier

Renata Bartesaghi

Yann Hérault

André Strydom

Alain Dekker

A website has been created and can be found at www.t21rs.org (with the support of FRUTO internet, concepts & design, Amersfoort, The Netherlands).

A logo has been created (with the help of Sr. Brightside, Madrid, Spain).

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
- Roger Reeves
- 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

B/ Sponsoring:

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 .

1. Founding supporters are listed prominently on the home page of the T21RS website
2. The T21RS website display prominent links to the website of each Founding Supporter.
3. T21RS is a professional organization for researchers and the membership of the organization is intended for scientists. However, Founding Supporters receive 1 general assembly membership and 1 additional one per every 100 total members* or fraction thereof for whoever they deem appropriate.