Annual report T21RS Committee for Science & Society

1. T21RS Committee for Science & Society

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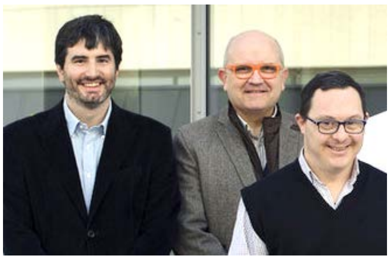

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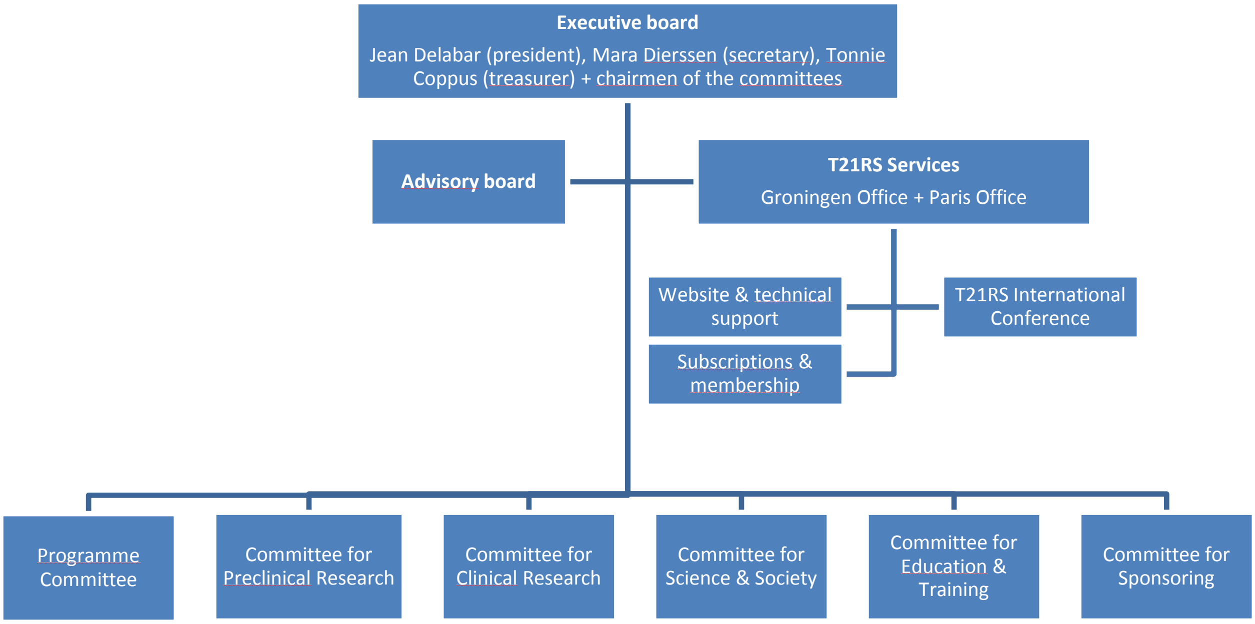
The Committee for Science & Society is one of the six committees of T21RS. As chairman of the Committee, Prof. Dr. Peter Paul De Deyn is also member of the Executive Board. The organizational structure of T21RS is illustrated in the organization chart below.



2. General introduction

The Trisomy 21 Research Society (T21RS) is the first non-profit scientific organization of researchers studying Down syndrome. However, T21RS is not only for scientists. Through the Committee of Science & Society, we aim to be in contact with family members and caregivers of individuals with Down syndrome via Down syndrome organizations. Besides being the scientific network for the Down syndrome community, T21RS aims to be a source of scientifically-founded information for the general public. We realize that scientific results are often difficult to follow and that the English scientific journals are unnecessarily complex to read. The Committee for Science & Society, led by professor Peter Paul De Deyn, will work 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.

3. Initiatives and achievements 2014-2015

In the first start-up year (2014-2015), the Committee has initiated four major initiatives: 1) contacting a first group of Down syndrome associations, 2) developing the T21RS Science & Society Bulletin, 3) organizing the T21RS Science & Society Symposium on Sunday 7th of June, as part of the T21RS International Conference in Paris (4-7 June 2015), and 4) contributing to The Dementia Table Initiative.

3.1. Down syndrome associations

In the first year, the Committee has decided to contact a limited number of European and American associations in order to discuss potential avenues of collaborations and to make an inventory of their ideas and wishes. Based on contact with seven associations (mentioned below), a first blueprint for the upcoming year has been established that will be used to continue the existing collaborations and guide new collaborations with other associations. 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. Question & Answer: questions from members of the collaborating associations can be asked to the Committee via info@T21RS.org. The Committee will subsequently forward the question to the most appropriate researcher within T21RS. If multiple questions on a similar topic are received, the Committee may decide to dedicate a special T21RS Science & Society Bulletin to it.
3. Quarterly publication of T21RS Science & Society Bulletin. The collaborating associations automatically receive the Bulletin via e-mail.
4. Bi-annual invitation to Science & Society Symposia (T21RS International Conference).

In 2014-2015, the Committee has established collaboration with Stichting downsyndroom (The Netherlands), Deutsches Down-Syndrom Infocenter (Germany), Trisomie 21 Lëtzebuerg (Luxemburg), Fundació Catalana Síndrome de Down (Spain), Down Syndrome International (international, United Kingdom-based), Down Syndrome Connection of the Bay Area (California, USA) and the Down Syndrome Center for Research and Treatment (California, USA).

3.2. 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. that is published every quarter. Full T21RS members can download current and previous Bulletins in the protected T21RS Membership Environment. Collaborating associations automatically receive the Bulletin via e-mail. Currently, 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 the period 2014-2015, three T21RS Science & Society Bulletins have been published:

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

3.3. T21RS Science & Society Symposium

During the first T21RS International Conference from 4-7 June 2015, at the Brain and Spine Institute of the famous 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.

3.4. The Dementia Table Initiative

In The Netherlands, the Committee is contributing to the organization of The Dementia Table Initiative: sharing & improving knowledge about ageing and dementia in people with intellectual disabilities. This initiative is presented at the T21RS Science & Society Symposium, and extensive information is available via the Committee and The Dementia Table organization to introduce similar initiatives in other countries around the world.

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