

T21RS Science &
Society Symposium



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T21RS Committee for Science & Society

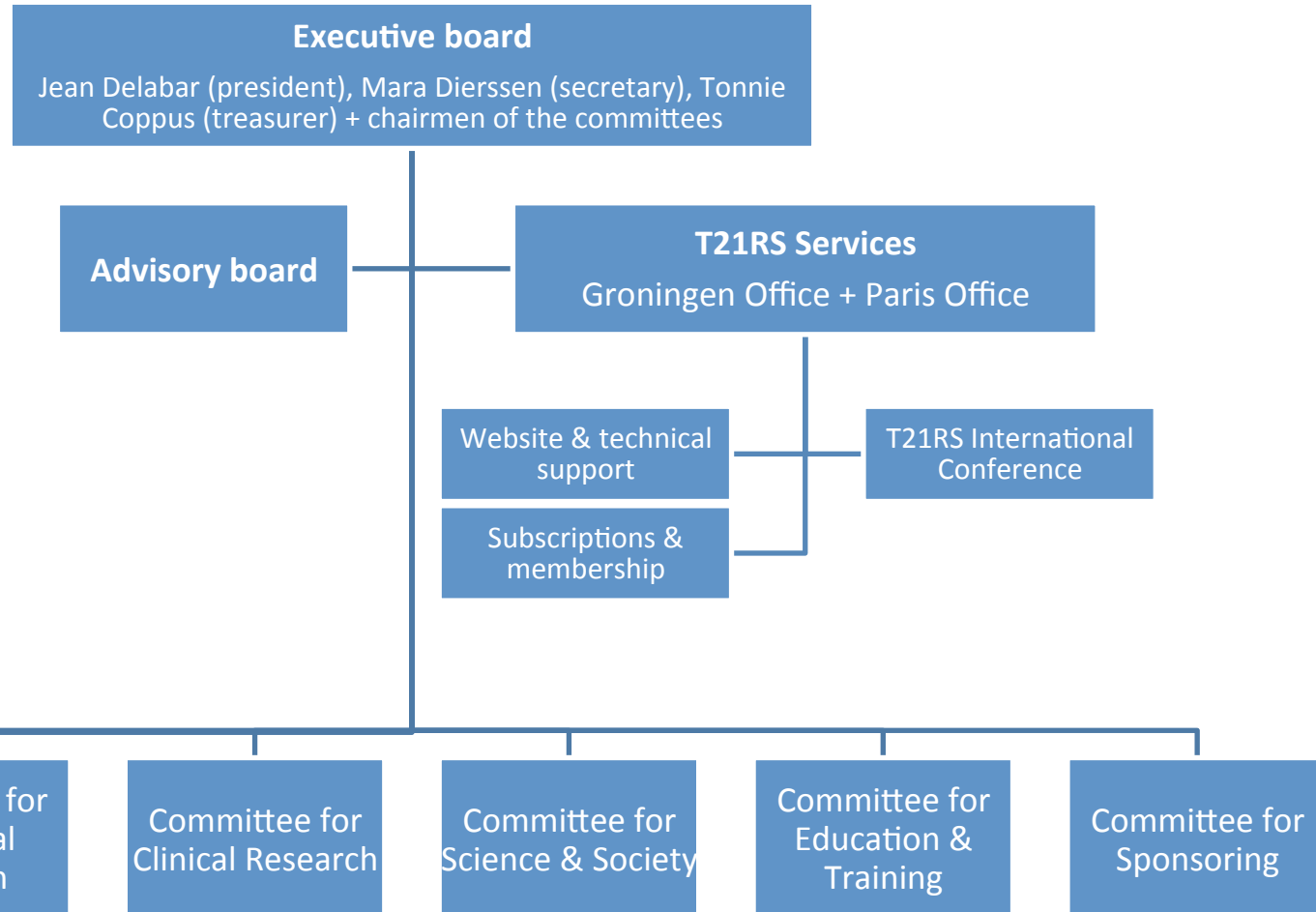
Prof. dr. Peter Paul De Deyn
(chairman)





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Committee for Science & Society

Members

“Unpaid voluntary membership in addition to their regular jobs in academia, hospital or institute”



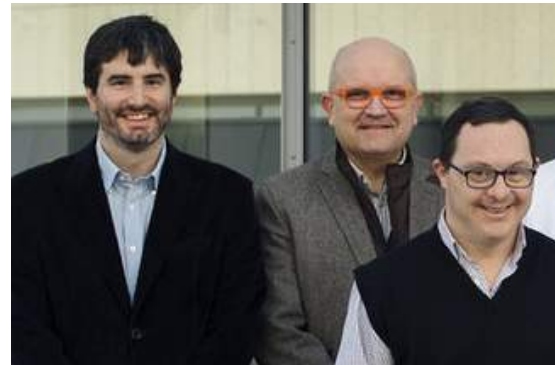
Peter Paul De Deyn
(chairman, Belgium)

University of Antwerp, Institute
Born-Bunge and UMCG



Alain Dekker
(Netherlands)

University Medical
Center Groningen



Juan Fortea & Sebastián Videla
(Spain)

Sant Pau Hospital Barcelona and Catalan
Down Syndrome Foundation



Hannah Wishnek
(USA)

Univ. California San Diego
Down Syndrome Center



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Goal

Parents/caregivers: “We do not know what is going on in the ivory tower, but would like to know more about it.”

Besides being the scientific network, T21RS aims to be a source of scientifically-founded information in understandable language **to bridge the gap between science/academia and society**



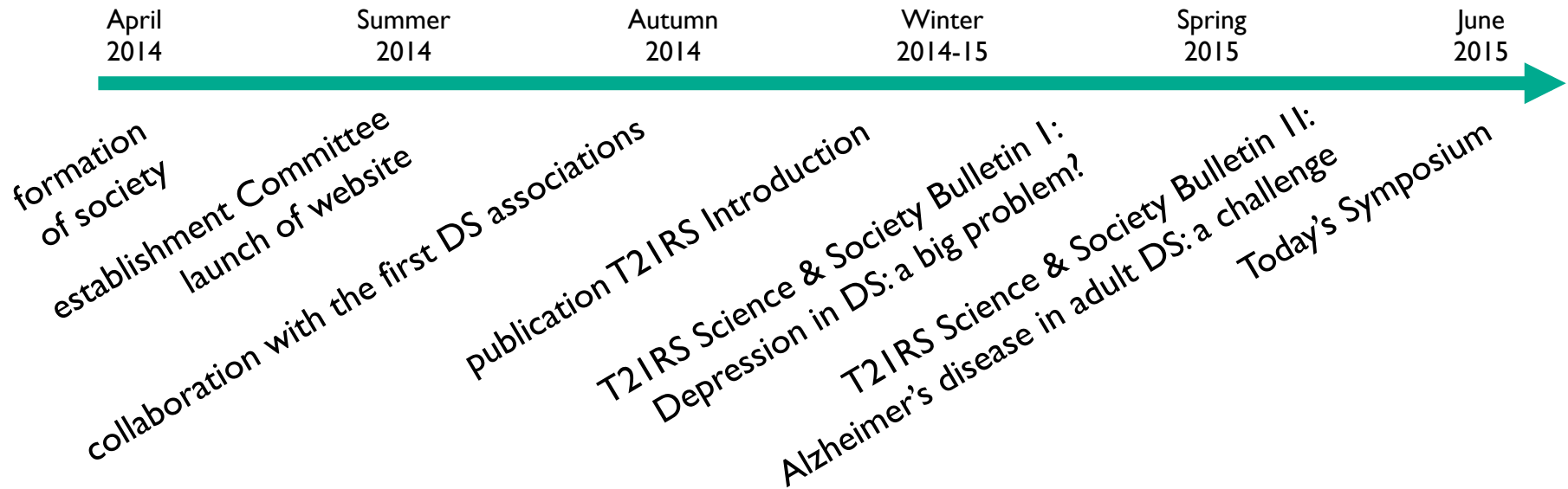


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Timeline 2014-2015





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collaborates with
regional and (inter)national
DS associations/foundations



Down Syndrome Center
for Research and Treatment
USA California



Down Syndrome Connection
OF THE BAY AREA
USA California



FUNDACIÓ CATALANA
SÍNDROME DE DOWN
Spain

TRISOMIE 21 Lëtzebuerg
Luxemburg

DSi **Down Syndrome**
International
Worldwide



deutsches
down-syndrom
infocenter

Germany

STICHTING **Down** syndroom
The Netherlands

TO BE
EXPANDED





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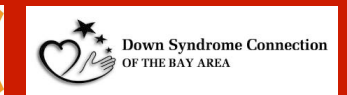
Collaboration



Question & Answer

T2IRS Science & Society
Bulletin (*quarterly*)

T2IRS Science & Society
Symposium (*bi-annual*)



DS associations & foundations

T2IRS provides understandable information in easy English.
Question & Answer via info@T2IRS.org

T21RS Science & Society Bulletin, 2015 (1)

Depression in Down syndrome: a big problem?

The Committee for Science & Society of the Trisomy 21 Research Society (T21RS) regularly addresses issues raised by parents and Down syndrome associations through summarizing the state-of-the-art knowledge from a scientific perspective. The Committee for Science & Society* is strongly committed to introduce scientific research and explain recent findings in an understandable way. Today, the first edition of the T21RS Science & Society Bulletin: key issues on depression in Down syndrome.



FAQ on depression in Down syndrome

- Are changes in mood normal with aging?
- How does depression manifest itself in adults with Down syndrome? Is it different from depression in adults without Down syndrome?
- Is there anything we can do to prevent mood changes?
- How do you know when to seek help?
- What needs to be ruled out when assessing depression?
- What kind of therapeutic options are there?

While the transition from the teenage years to adulthood brings many new challenges for individuals with Down syndrome, one of the most common concerns expressed by caregivers regards changes in mood. 'When we see adults with Down syndrome in the clinic, they are typically brought in for the emergence of new symptoms,' says Dr. Michael Rafii from the Down Syndrome Research and Treatment Center of the University of California in San Diego, United States. 'In younger adults aged 20-40, there is usually a report of depression, anxiety, increased self-talk and rarely psychosis'. Rafii stresses that in many cases there is a change in social situation 'that precipitates the behaviors'. This concerns, among others, 'change in staff at day program, change in daily routine, moving to a new home, or loss of a

T21RS Science & Society Bulletin

- Explains recent scientific findings or reviews current issues
- Send to associated partners
(~ every 3 months)
- In understandable English.
- Can be translated in the local language and published online or in magazines.

Online Bulletin Archive:

<http://www.t21rs.org/science-society>



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Collaboration



Input & suggestions
(themes, topics, etc.)

Local translation and
publication of T21RS
Science & Society
Bulletin (quarterly)



DS associations &
foundations

Mutual publication of logo and website links



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Committee for Science & Society

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Science & Society

We strongly believe that scientific research will aid the understanding of Down syndrome. Every day, our members are working all around the globe in universities, academic hospitals, research institutes or health care centers to bring our ultimate goal a little closer: to unravel the details of Down syndrome with the final aim to better help people with Down, their families and caretakers.

We realize that scientific results are often difficult to grasp and that those English journals are unnecessarily complex to read. That is why the Committee for Science & Society has been established. Led by prof. dr. Peter Paul De Deyn (University Medical Center Groningen, The Netherlands; University of Antwerp, Belgium), this committee will work together with local Down syndrome associations and explain recent scientific findings on our website.



Science & Society

What is Down syndrome?

Why scientific research?

T21RS Science & Society Bulletin

Societal partners

Join us!



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Choose your language

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Fluorescent neurons

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Multi-language approach in collaboration with local partners.

Online platform for scientific DS-related news in English, Dutch, French or Spanish, e.g. newspaper articles, interviews



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New initiatives

- Intensifying our collaborations with the aforementioned DS associations
 - based on joint discussions and input (also today!)
 - will serve as blueprint for collaborations with other associations
- Expanding our network of collaborations in Europe, USA, and the rest of the world
- “The Dementia Table Initiative” (next talk)





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- Administrative issues
- Question & Answer
- T2IRS Science & Society Bulletin

