



t21
RESEARCH
SOCIETY

T21RS General introduction

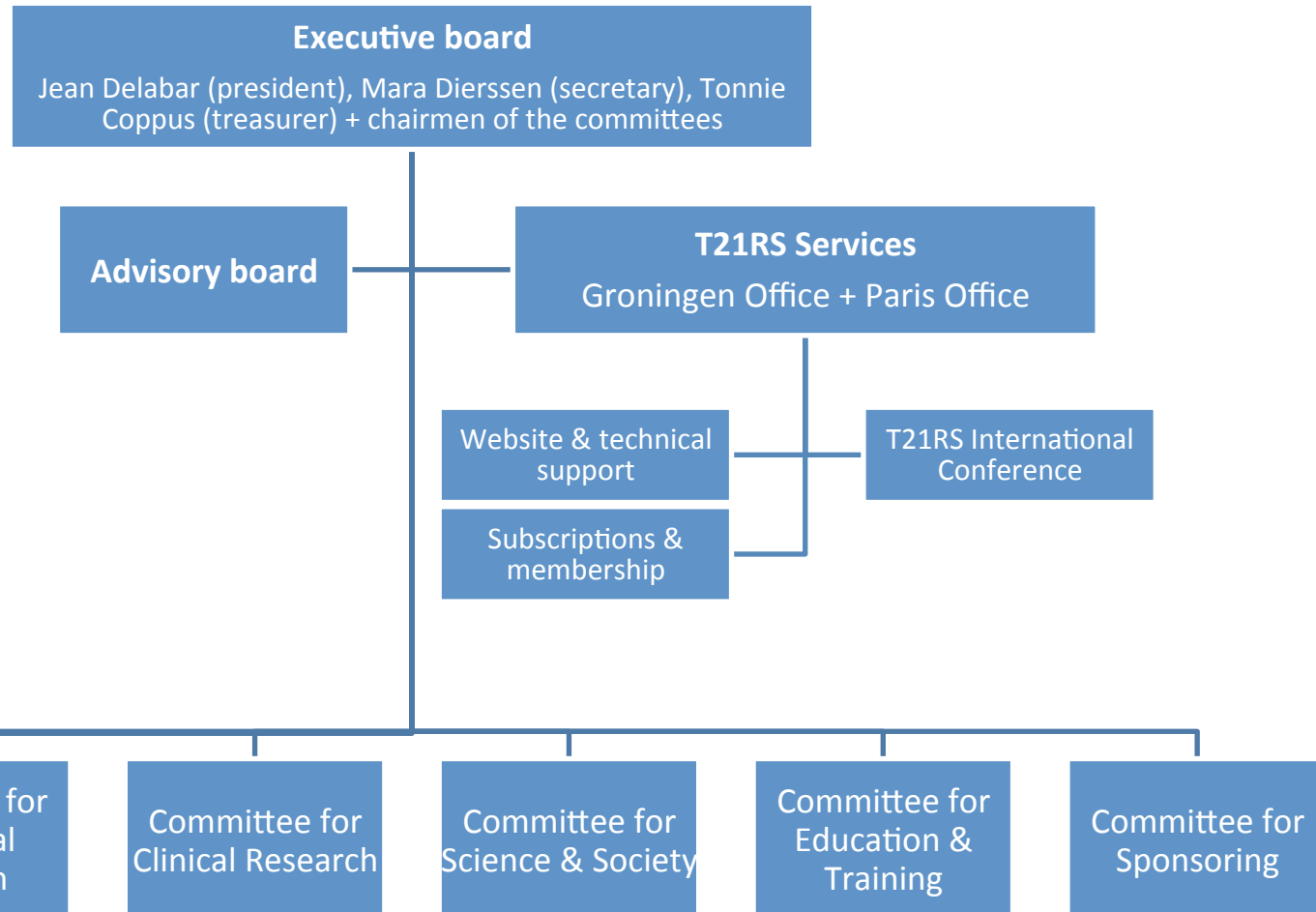
Alain Dekker
(webmaster, treasurer-elect)





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General structure



Executive board 2014-2016

Presidency



Jean Delabar
president

Université Paris-Diderot, France



Mara Dierssen
secretary

CRG-Center for Genomic
Regulation, Barcelona, Spain



Tonnie Coppus
treasurer

Radboud University Medical
Center Nijmegen, The Netherlands

Executive board 2014-2016

Committee presidents



Yann Hérault
*Committee for
Preclinical Research*



André Strydom
*Committee for
Clinical Research*



Peter Paul De Deyn
*Committee for
Science & Society*



Renata Bartesaghi
*Committee for
Education & Training*



Jorge Busciglio
*Programm Committee
(T2IRS Int. Conference)*



Marie-Claude Potier
Committee for Sponsoring



Committee for Science & Society



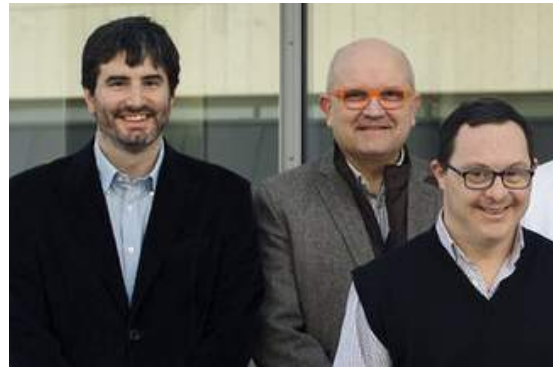
Peter Paul De Deyn
(chairman, Belgium)

University of Antwerp, Institute
Born-Bunge and UMCG



Alain Dekker
(The 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



Timeline 2014-2015

April
2014

Summer
2014

Autumn
2014

Winter
2014-15

Spring
2015

formation
of society

launch logo + website

establishment committees

start membership registrations

start organization T2IRS International Conference

Programme committee

Today's Symposium

Our main goals

- To stimulate Down syndrome research
- To facilitate interaction and collaboration between researchers
e.g. *two-yearly T2IRS International Conference*
- To harmonize protocols for (pre)clinical research
- To support education and training of young researchers
- To explain findings to the general public
- To promote the interaction between scientists, DS associations/foundations and companies





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Deed of incorporation



T2IRS was founded on 17th April 2014 in Groningen, The Netherlands, under the auspices of Mr. A. Kraster, member of The Royal Dutch Association of Civil-law Notaries.

The society (*Dutch*: vereniging) is a non-profit organization for the stimulation of scientific research on Down syndrome, operating under Dutch law.

Original deed

+ translation (English):

<http://www.t21rs.org/about-us/statutes>



AKTE HOUDENDE
OPRICHTING
VERENIGING
AKN/bg
2014.001119.01
rep.nr :
AFSCHRIFT

Heden, zeventien april tweeduizend veertien, verscheen voor mij, mr. Albert Kraster, notaris te --
Groningen:-----

de heer mr. Albert Johannes Gunnink, werkzaam en te deze zaak domicilie kiezende ten -----
kantore van mij, notaris, geboren te Haren op achtentwintig februari negentienhonderd -----
vijfentachtig;-----

te dezen handelende als schriftelijk gevolmachtigde, waarvan blijkt uit de aan de akte te -----
hechten volmachten, van:-----

1. de heer Jean Maurice Delabar, wonende te Le Kremlin-Bicetre, 17 Rue Pasteur (94270) ---
(Frankrijk), geboren te Parijs (Frankrijk) op twaalf april negentienhonderd achtenveertig, ---
gehuwd, zich legitimerende met een Frans paspoort nummer: 11AK46977; en-----
2. mevrouw Antonia Maria Wilhelmina Coppus, wonende te Deurne, Suezlaan 8 (5752 BG), --
geboren te Vierlingsbeek op éénentwintig november negentienhonderd vijftien, -----
gehuwd, zich legitimerende met een paspoort nummer: NMB114H01.-----

De comparant verklaarde namens de volmachtgevers, bij deze akte een vereniging op te -----
richten, welke zal worden geregeerd door de volgende:-----

STATUTEN-----

Naam en zetel-----

Artikel 1-----

1. De vereniging draagt de naam: **Trisomy 21 Research Society**.-----
2. Zij heeft haar zetel in Nederland, in de gemeente Groningen.-----



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Founding
supporters



**GLOBAL
DOWN SYNDROME
FOUNDATION®**



FONDATION
Jérôme Lejeune
chercher, soigner, défendre

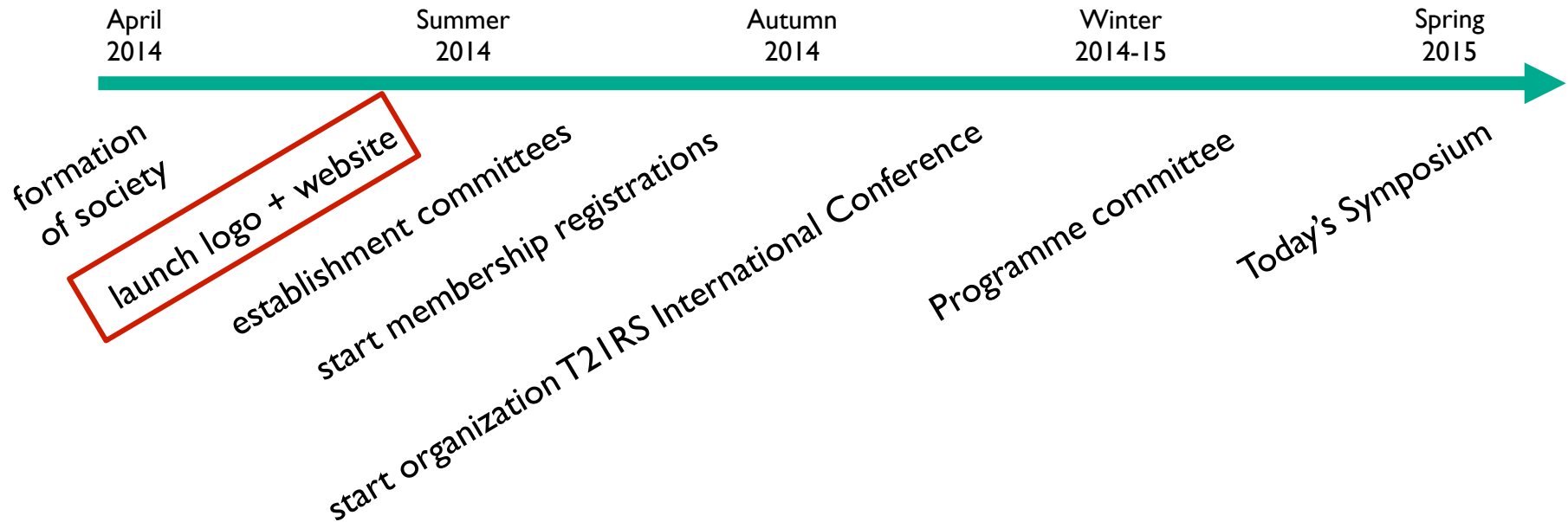
Research Down Syndrome™
Lumind
FOUNDATION

t21somie
FRANCE

**THE MATTHEW
FOUNDATION INC.**



Timeline 2014-2015

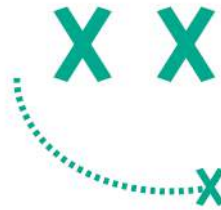




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Logo

The T21RS logo has been designed by
Sr. Brightside, Madrid, Spain
www.srbrightside.com



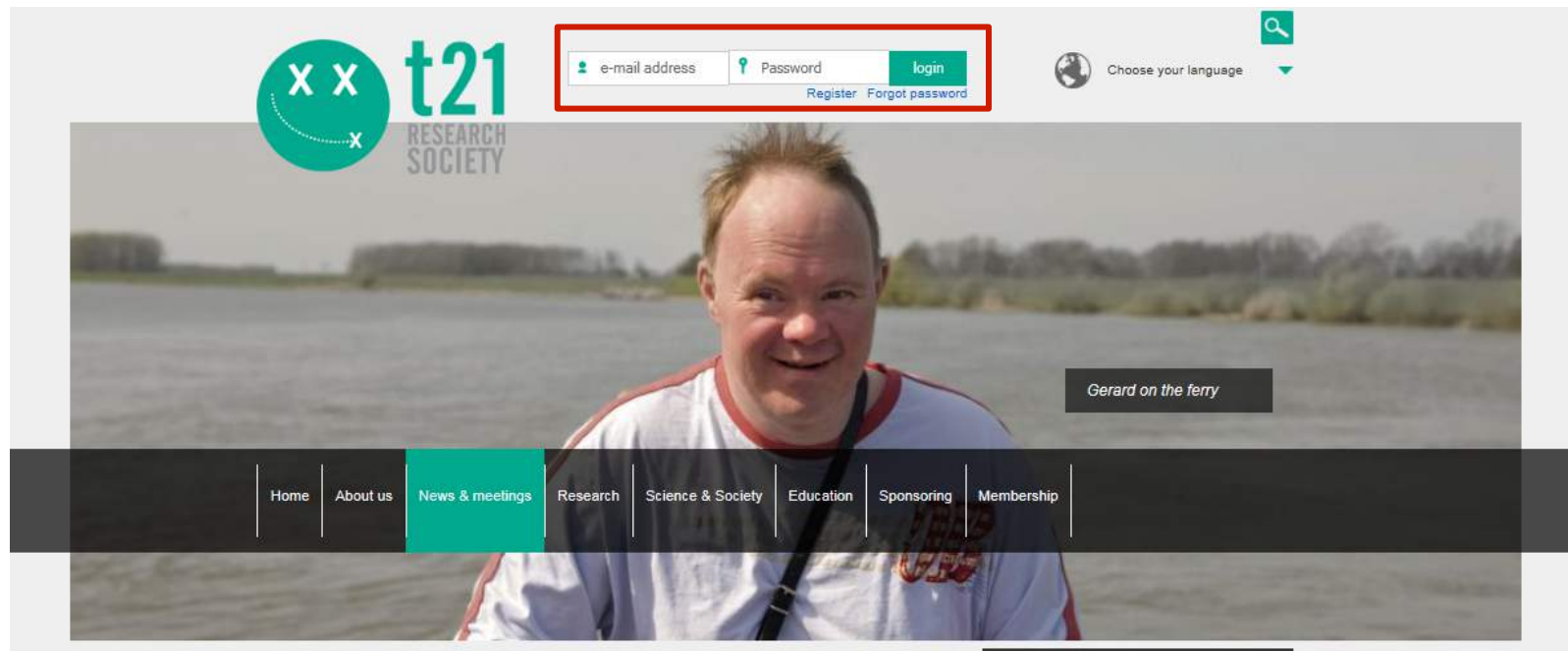
Positive approach: looking at possibilities
rather than the deficits/impairments.

Research: trying to diminish negative effects
due to the third copy of chromosome 21

1.- TEXT AND SYMBOL ARE
CLEARLY DIFFERENTIATED
AND CAN EVEN WORK
SEPARATELY.

2.- IT WORKS IN A WIDE RANGE
OF COLORS, BOTH POSITIVE
AND ON A COLOR BACKGROUND.

3.- THIS LOGO REFLECTS
POSITIVISM WITH WHICH
BOTH THE FAMILIES AND PEOPLE
WITH DOWN SYNDROME FACE AND
THE CHALLENGE OF RESEARCH IN
THIS FIELD.



T21RS International Conference 2015: Changing paradigms in Down Syndrome

Paris, June 4 - 7, 2015

Sponsored by The Lumind Foundation, The Fondation Jerome Lejeune, The Matthews Foundation, Trisomie 21 France, Hoffman- LaRoche, The Global Down Syndrome Foundation



News & meetings

News

Meetings



Responsive site
for use on
computer, tablet
and smartphone

T2IRS Membership Environment

Welcome Mr. Dekker

Your account is valid till : 06 July 2015

Members

Announcements

Downloads

Photo database

Edit your account

Change password

Logout

Members

Finding researchers: e-mail + phone numbers

Name	Affiliation	Phone
Ms. MA (Maddalena) Adorno <i>Instructor - Postdoc</i>	Stanford University	+1 6507141723
Ms. NA (Nidhi) Aggarwal <i>Student</i>	University College London	+44 (0) 7459062419
Ms. Z (Ahmad) Ahmad <i>Consultant Pediatrician</i>	Sheikh Khalifa Medical City	+971506539740
Ms. J (Tamara) al Janabi <i>LonDownS Study Co-ordinator</i>	UCL	07462889708
Ms. c (Christelle) ALBAC <i>Engineer</i>	Institut du Cerveau et de la Moelle épinière	+33627507886
Ms. MML (Bernadette) Allinquant <i>Research Director, PhD</i>	INSERM	33-648982516
Mr. KG (Göran) Annerén <i>Professor</i>	Uppsala University	+46 705502295
Mr. A (Alejandro) Avila <i>Student</i>	UNAM	
Mr. CB (Carlo) Baccichetti <i>President of Fondazione Baccichetti per la sindrome down</i>	Fondazione Baccichetti per la Sindrome down	+393477217760
Mr. G W (George) Ball <i>MSc student</i>	Centre for Brain and Cognitive Development, Birkbeck, University of London	447877702552

Members
only

T2IRS Membership Environment

Welcome Mr. Dekker

Your account is valid till : 06 July 2015

Members

Announcements

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Photo database

Edit your account

Change password

Logout

Downloads

Downloads Committee for Science & Society


T2IRS Folder Science & Society

Through the Committee of Science & Society, T2IRS aims to be in contact with Down syndrome organizations, family members and caregivers, and other interested persons. The aims and background of this committee are described in the folder.

 [Click here to start the download](#)

T2IRS Science & Society Bulletin 2015 (1)

The T2IRS Committee for Science & Society 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. The first edition of the T2IRS Science & Society Bulletin: key issues on depression in Down syndrome.

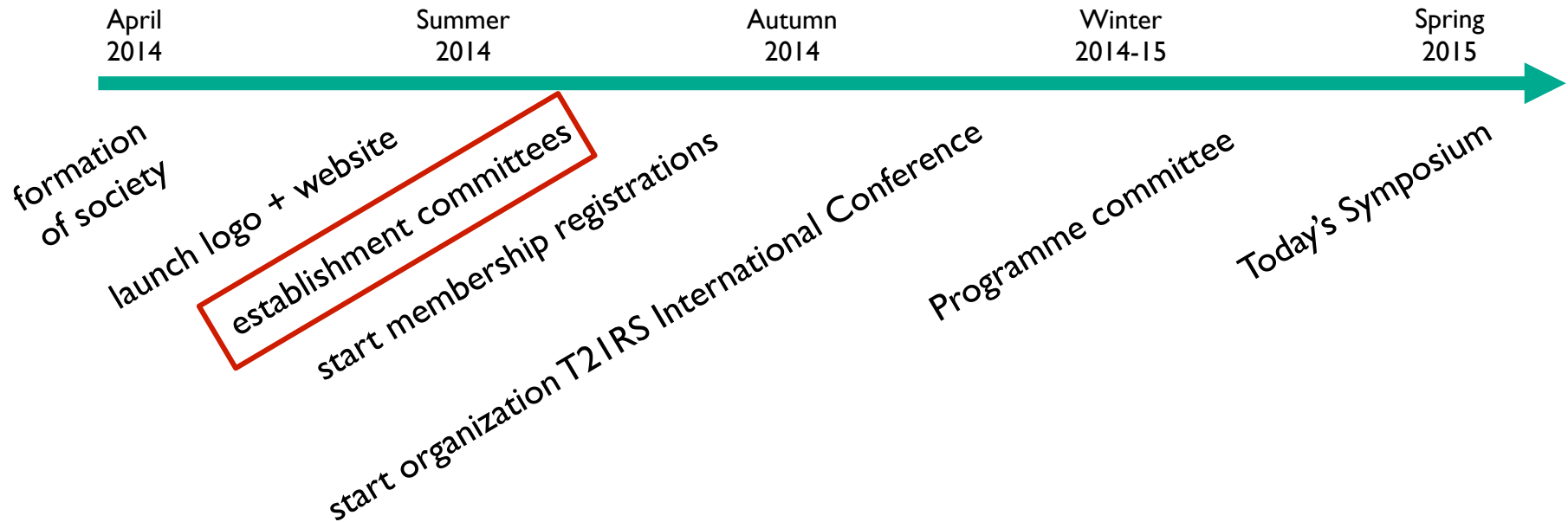
 [Click here to start the download](#)

Downloads per committee

Members
only



Timeline 2014-2015





Committee for Preclinical Research



Committee president: Yann Hérault (FR)

Members: Stylianos Antonarakis (CH), Lizzy Fisher (UK),
William Mobley (USA), Marie-Claude Potier (FR)

Aim: To establish **common protocols**, thereby harmonizing and
standardizing worldwide efforts that enable better
comparisons between studies across the globe.

Link: Committee reports and protocols will be available for all
T21RS members in the protected member environment
www.t21rs.org/research/preclinical-research



Committee for Clinical Research



Committee president: André Strydom (UK)

Members: Shahid Zaman (UK), Ira Lott (USA), Tonnie Coppus (NL), Juan Fortea (SP), Weihong Song (CA/CN)

Aim: Large scale cohort studies of health issues in DS, clinical trials of treatment options, creating a research registry, developing a data sharing platform, and agreeing a minimum dataset for future studies (standardisation).

Link: Committee reports and protocols will be available for all T2IRS members in the protected member environment www.t2irs.org/research/clinical-research



Committee for Education & Training



Committee president: Renata Bartesaghi (IT)

Members: Annette Karmiloff-Smith (UK)
Carmen Martinez-Cué (Spain)

Aim: To organize schools for young scientists interested in Down syndrome, establish a **network of DS host laboratories**, provide **conference grants** to students, issue thesis **prizes** in order to stimulate research on Down syndrome

Link: www.t21rs.org/education



Committee for Sponsoring



Committee president: Marie-Claude Potier (FR)

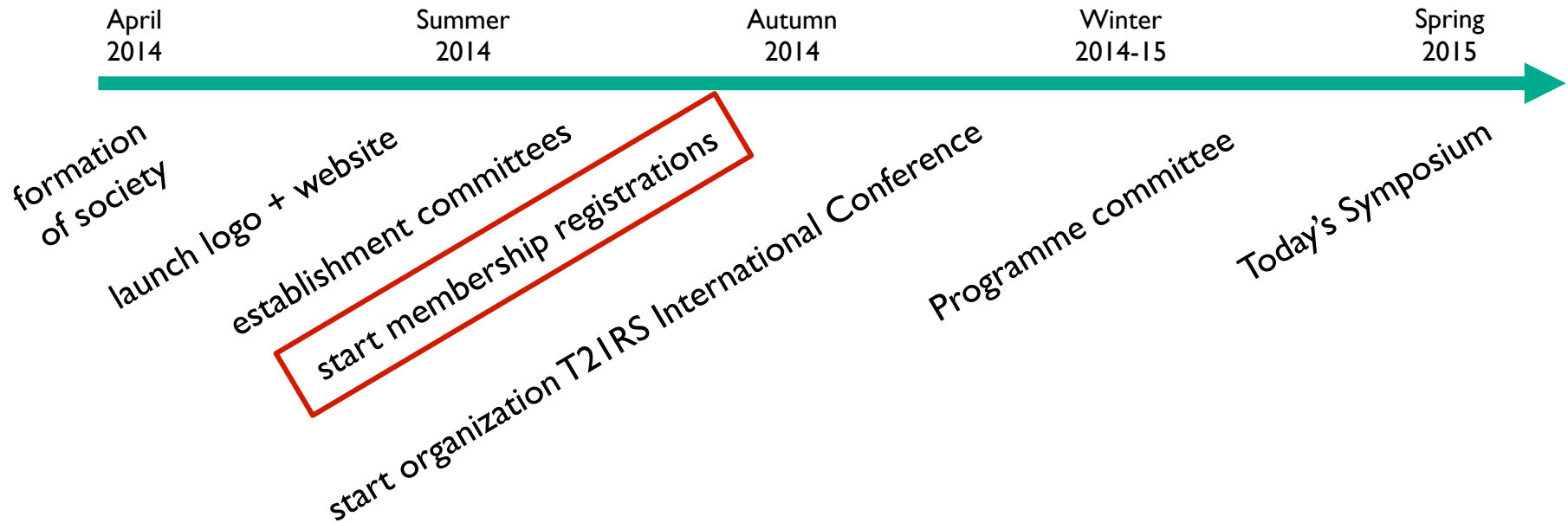
Aim: Funding, sponsoring & partnerships
Contact with founding supporters

Link: www.t21rs.org/sponsoring-and-partnership

E-mail: sponsoring@T21RS.org



Timeline 2014-2015





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Membership

1. Full membership for researchers, clinicians, health care professionals

- Master/PhD students
- Postdoctoral fellows
- Academic staff members/ clinicians

2. Associate member

Named by an Association or Foundation with an interest in research and/or health care related to Down syndrome, and with which the society wishes to enter into a relation that will benefit the aims of the society.

3. Free donations

Status payed memberships

June 2nd 2015

1. Full membership

- | | |
|--------------------------------------|-----|
| • Master/PhD students | 40 |
| • Postdoctoral fellows | 14 |
| • Academic staff members/ clinicians | 112 |

2. Associate member	12
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TOTAL:	178
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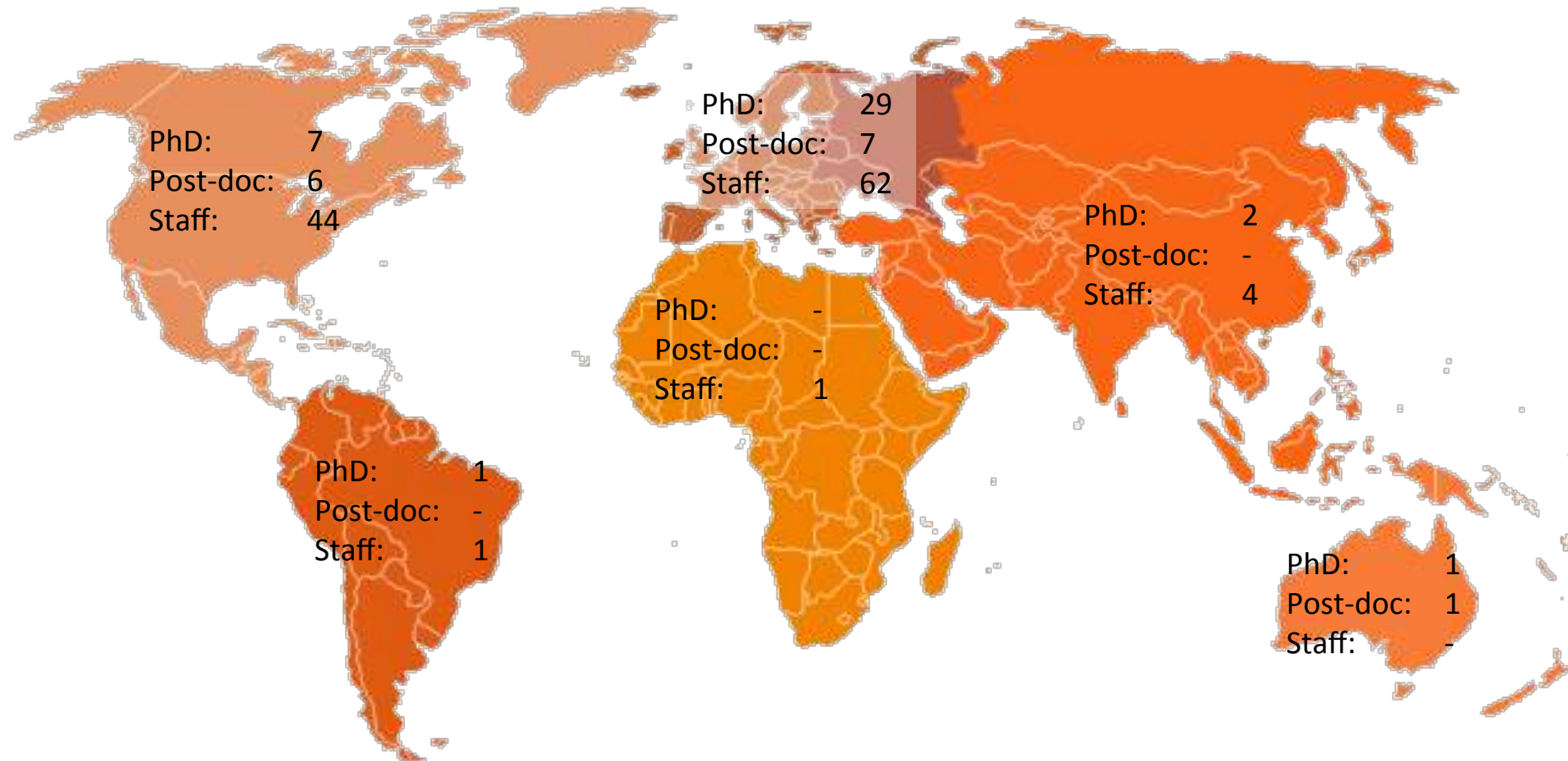




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Status payed memberships

June 2nd 2015





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Contact details presidency:
Contact details committees:
General information T21RS:

www.t21rs.org/about-us/executive-board
www.t21rs.org/about-us/committees
info@T21RS.org

