Symposium Sponsor

national down syndrome society
ndss

Science & Society Symposium

17:00	**Welcome and Introduction** *prof. Peter P. De Deyn (chairman Committee for Science & Society)* *Kandi Pickard (Chief of Staff, NDSS)*
	T21RS Committee for Science & Society: aims & achievements *Peter P. De Deyn*
17:15	**The pros and cons of having my relative with DS participate in clinical research** *Family debate moderated by Diana Bianchi*
17:45	**Medical policies for people with DS** *Four initiatives to integrate care and research + discussion* • *Sebastian Videla (FCSD)* • *Melissa Parisi (NIH/NICHD)* • *Michelle Whitten (Global)* • *Kandi Pickard (NDSS)*
18:40	**Break**
18:55	**Association Introduction Round (15x)** *DS associations as research partners*
20:05	**Summary** *Peter P. De Deyn*

t21 RESEARCH SOCIETY

T21RS Committee for Science & Society

Peter De Deyn (chairman)

T21RS Committees

Executive board

Roger Reeves(president), Marie-Claude Potier (secretary), Alain Dekker (treasurer) + chairmen of the committees

Advisory board

T21RS Office

Communication (Nicole Creau)

Registration/website

Treasury (*bank, chamber of commerce, Multisafepay, tax authority)*

Programme Committee

Mara Dierssen

Committee for Preclinical Research

Yann Herault

Committee for Clinical Research

André Strydom

Committee for Science & Society

Peter De Deyn

Committee for Education & Training

Renata Bartesaghi

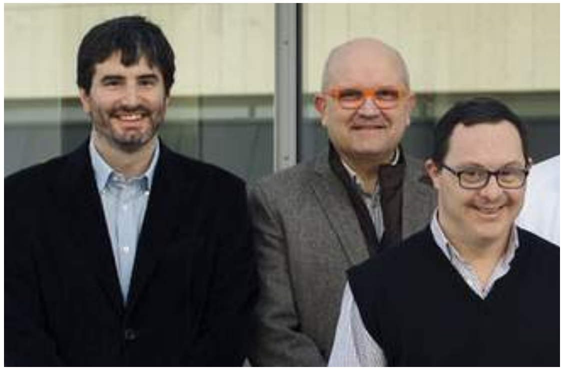
Committee for Sponsoring

Jean Delabar

Committee for Science & Society

Peter De Deyn (chair)
(BE) 2014 - today
University of Antwerp, UMCG

Alain Dekker
(NL) 2014 - today
University Medical Center Groningen



Juan Fortea, Sebastián Videla
(SP) 2014- today
Sant Pau Hospital Barcelona and Catalan Down Syndrome Foundation

Hannah Wishnek
(USA) 2014 – 2015
Univ. California San Diego Down Syndrome Center

Lotta Granholm
(USA/SW) 2016 - today
University of Denver

Cindy Lemere
(USA) 2016 - today
Brigham & Women's Hospital

Diana Bianchi
(USA) 2016 - today
NICHD

“Unpaid voluntary committee work in addition to their regular jobs in academia/clinic”

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**

Collaboration

Mutual publication of logo and website links

Committee for Science & Society

Question & Answer

T21RS Science & Society Bulletin

T21RS Science & Society Symposium *(bi-annual)*

DS associations

www.t21rs.org/societal-partners

T21RS invites all societies (most have done so already) to name a representative and sign up as T21RS Associated Member via www.t21rs.org/register

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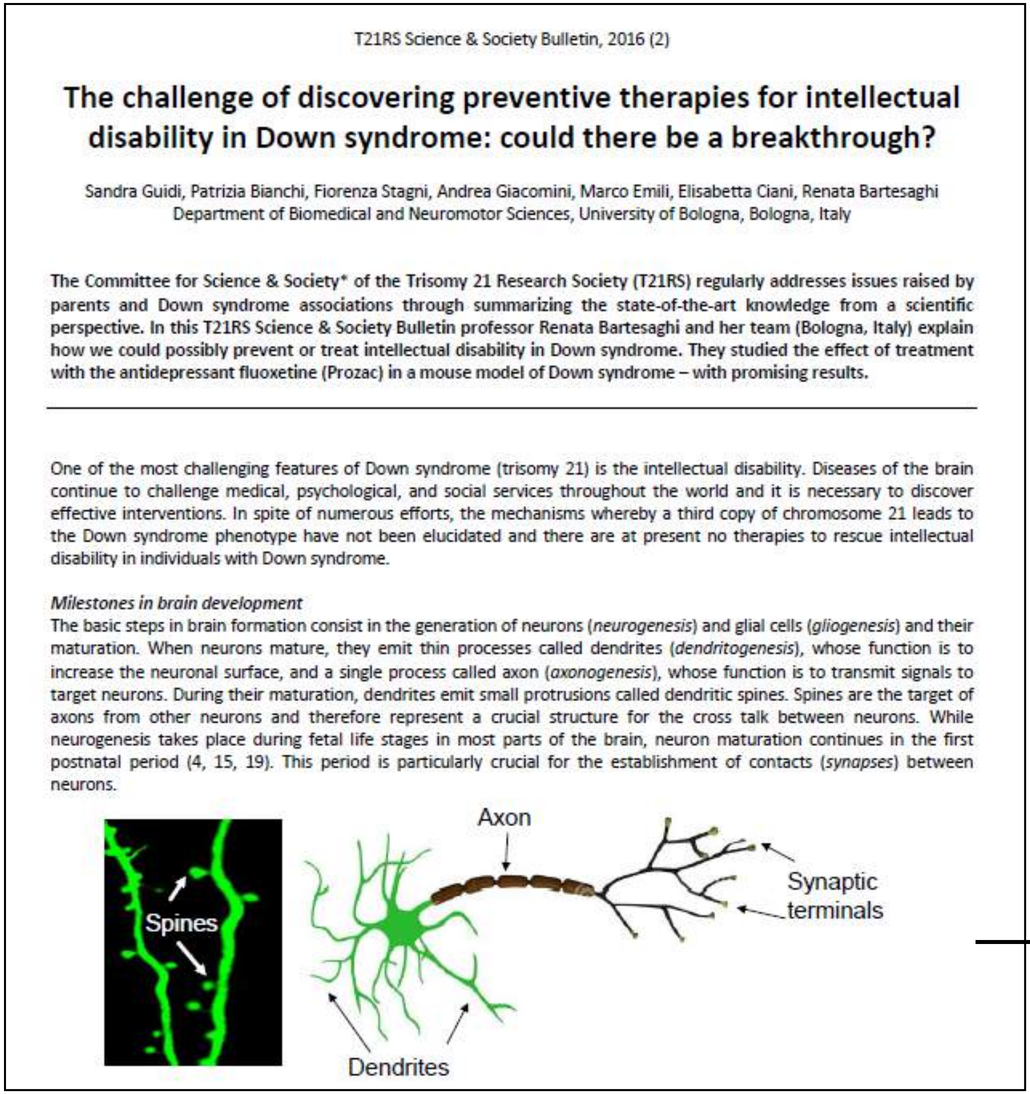
SOCIETY

Science & Society Bulletin



T21RS Science & Society Bulletin, 2016 (2)

The challenge of discovering preventive therapies for intellectual disability in Down syndrome: could there be a breakthrough?

Sandra Guidi, Patrizia Bianchi, Fiorenza Stagni, Andrea Giacomini, Marco Emili, Elisabetta Ciani, Renata Bartesaghi
Department of Biomedical and Neuromotor Sciences, University of Bologna, Bologna, Italy

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. In this T21RS Science & Society Bulletin professor Renata Bartesaghi and her team (Bologna, Italy) explain how we could possibly prevent or treat intellectual disability in Down syndrome. They studied the effect of treatment with the antidepressant fluoxetine (Prozac) in a mouse model of Down syndrome – with promising results.

One of the most challenging features of Down syndrome (trisomy 21) is the intellectual disability. Diseases of the brain continue to challenge medical, psychological, and social services throughout the world and it is necessary to discover effective interventions. In spite of numerous efforts, the mechanisms whereby a third copy of chromosome 21 leads to the Down syndrome phenotype have not been elucidated and there are at present no therapies to rescue intellectual disability in individuals with Down syndrome.

Milestones in brain development

The basic steps in brain formation consist in the generation of neurons (*neurogenesis*) and glial cells (*gliogenesis*) and their maturation. When neurons mature, they emit thin processes called dendrites (*dendritogenesis*), whose function is to increase the neuronal surface, and a single process called axon (*axonogenesis*), whose function is to transmit signals to target neurons. During their maturation, dendrites emit small protrusions called dendritic spines. Spines are the target of axons from other neurons and therefore represent a crucial structure for the cross talk between neurons. While neurogenesis takes place during fetal life stages in most parts of the brain, neuron maturation continues in the first postnatal period (4, 15, 19). This period is particularly crucial for the establishment of contacts (*synapses*) between neurons.

- Explains recent scientific findings or reviews current issues
- In understandable English
- Can be translated in the local language and published online or in magazines.

Online Bulletin Archive:
www.t21rs.org/science-society/t21rs-science-society-bulletin

→ 2016 bulletin on brain development and fluoxetine (Prozac) treatment
by prof. Renata Bartesaghi and her team

Science & Society Bulletin

- **T21RS S&S Bulletin, 2015 (1): Depression in Down syndrome: a big problem?**

- **T21RS S&S Bulletin, 2015 (2): Alzheimer's disease in adults with Down syndrome: a challenge**
  by Rafael Blesa, Katy Trias, Juan Fortea and Sebastián Videla, Barcelona, Spain

- **T21RS S&S Bulletin, 2016 (1): Pain experience in adults with Down syndrome**
  by Nanda de Knegt, VU University, Amsterdam, The Netherlands

- **T21RS S&S Bulletin, 2016 (2): The challenge of discovering preventive therapies for intellectual disability in Down syndrome: could there be a breakthrough?**
  by Sandra Guidi, Patrizia Bianchi, Fiorenza Stagni, Andrea Giacomini, Marco Emili, Elisabetta Ciani and Renata Bartesaghi, University of Bologna, Bologna, Italy

We welcome:

- Input for new ideas/themes
- Clinicians/scientists who would like to write a new bulletin

A few examples:

deutsches
down-syndrom
infocenter

STICHTING Down syndroom

Germany

Deutsches DS Infocenter
'Leben mit Down-Syndrome' magazine

The Netherlands

Stichting Downsyndroom
'Down Up' magazine

WISSENSCHAFT

t21 RESEARCH SOCIETY

T21RS – Mehr DS-Forschung

Trisomy 21 Research Society (T21RS) ist die erste gemeinnützige wissenschaftliche Organisation von Wissenschaftlern, die im Bereich Down-Syndrom forschen. T21RS ist eine internationale Gesellschaft, der über 100 führende Wissenschaftler und Mediziner aus der ganzen Welt angehören und die den Kontakt sucht zu Familienangehörigen von Menschen mit Down-Syndrom und DS-Organisationen.

Trisomy 21 Research Society (T21RS) steht nicht nur Wissenschaftlern offen. Über das Komitee für Wissenschaft und Gesellschaft und die brandneue Webseite T21RS.org wird der Kontakt gesucht zu Down-Syndrom-Organisationen, Familienangehörigen und Pflegekräften von Menschen mit Down-Syndrom sowie weiteren interessierten Personen. T21RS befindet sich im Zentrum der Wissenschaft und bildet als solches eine neue zentrale Quelle für wissenschaftlich fundierte Informationen über das Down-Syndrom.

Deshalb sind unsere wichtigsten Ziele die Förderung der Forschung im Bereich Down-Syndrom, die Unterstützung der Zusammenarbeit von Wissenschaftlern auf der ganzen Welt, zum Beispiel durch die Organisation einer alle zwei Jahre stattfindenden internationalen T21RS-Konferenz (2015 in Paris) und die Vereinheitlichung von Protokollen für präklinische und klinische Forschung. Zudem bieten wir Schulungen und Unterstützung für junge Studenten an, die sich für Forschung im Bereich Down-Syndrom begeistern.

Unsere Mitglieder erforschen das Down-Syndrom in all seinen Einzelheiten, das heißt verhaltenspsychologische, psychische und entwicklungsbezogene Aspekte sowie neurobiologische und genetische Eigenschaften vom allgemeinen klinischen Profil bis hin zu Forschungen auf zellulärer und molekularer Ebene. Von der Lebenssituation der Menschen bis hin zu den Mausmodellen mit Down-Syndrom, wie dem häufig eingesetzten Ts65Dn-Mausmodell und Zellstudien in Laboren. Gemeinsam wollen wir die Zusammenarbeit auf nationaler, europäischer und internationaler Ebene stärken und die Forschung im Bereich Down-Syndrom einen Schritt weiter bringen.

T21RS für Sie
Committee for Science & Society

Neben der wissenschaftlichen Vernetzung der Down-Syndrom-Gemeinschaft möchte T21RS eine Quelle für wissenschaftlich fundierte Informationen für die breite Öffentlichkeit darstellen. Wir sind uns bewusst, dass wissenschaftliche Ergebnisse häufig schwierig zu verstehen und dass wissenschaftliche Fachzeitschriften in englischer Sprache unnötig komplex sind.

Deshalb wurde das Komitee für Wissenschaft und Gesellschaft gegründet. Es wird von Professor Peter Paul De Deyn (University Medical Center Groningen, Niederlande; University of Antwerp, Belgien) geleitet. Dieses Komitee arbeitet mit lokalen Down-Syndrom-Organisationen zusammen, unter anderem der Stichting Downsyndroom Nederland, Downsyndroom Vlaanderen und dem Deutschen Down-Syndrom Info-Center.

Wir möchten u.a. aktuelle wissenschaftliche Erkenntnisse auf unserer Webseite erklären. Dazu wählt das Komitee für Wissenschaft und Gesellschaft Veröffentlichungen über das Down-Syndrom aus, beispielsweise einen Artikel über Depression oder neue Erkenntnisse bei der Suche nach geeigneten Markern für die Alzheimer-Krankheit. Die wichtigsten Erkenntnisse werden in verständlicher Sprache zusammengefasst und es wird erläutert, welche Auswirkungen sie auf das tägliche Leben haben können.

Unterstützung/Mitgliedschaft

Wenn Sie unsere Ziele unterstützen möchten, aber kein Wissenschaftler sind, möchten wir Sie trotzdem bei T21RS willkommen heißen. Privatpersonen oder Vereine können außerordentliches Mitglied von T21RS werden und so die Forschung im Bereich Down-Syndrom unterstützen. Sie erhalten regelmäßig Nachrichten von T21RS und können zu einem reduzierten Teilnehmerpreis an der internationalen T21RS-Konferenz in Paris teilnehmen. Natürlich können Sie auch einfach auf T21RS.org eine Spende tätigen. Jegliche Unterstützung ist willkommen.
Vielen herzlichen Dank.

Information: www.t21rs.org
Übersetzung: Patricia Gifford

T21RS: een ambitieus internationaal onderzoekscentrum voor Downsyndroom

De T21RS (Trisomy Research Society) is een internationale vereniging zonder winstoogmerk voor wetenschappers die onderzoek doen naar Downsyndroom. De SDS gaat met de vereniging samenwerken en we stellen hen graag aan u voor. • Redactie

Het genootschap bestaat uit meer dan honderd vooraanstaande wetenschappers en onderzoekers uit heel de wereld. Toch is T21RS er niet alleen voor wetenschappers. Ze hebben een Commissie Wetenschap & Samenleving en een gloednieuwe website: www.T21RS.org. Daarmee willen ze in contact komen met Downsyndroom-organisaties, familie en zorgverleners van mensen met Downsyndroom en andere geïnteresseerden. T21RS staat midden in de wetenschappelijke ontwikkelingen en wil het nieuwe centrale informatiepunt voor wetenschappelijke kennis over Downsyndroom gaan vormen.

In de afgelopen tien jaar is er meer vooruitgang geboekt in het wetenschappelijk onderzoek naar Downsyndroom dan in de 200 jaar daarvoor. Desondanks blijft het wetenschappelijke veld in hoge mate verdeeld. Om het onderzoek naar Downsyndroom verder te stimuleren en de wetenschappelijke samenwerking te verbeteren, is op 17 april 2014 in Nederland de T21RS opgericht. De dagelijkse Raad van Bestuur en de Raad van Advies zijn bemenst door internationaal toonaangevende wetenschappers die met heel hun hart onderzoek naar Downsyndroom doen. De lijst met hun namen is te vinden op www.T21RS.org/nl.

Gelukkig gaat deze groep net als de SDS ervan uit dat wetenschappelijk onderzoek bijdraagt aan het begrijpen van Downsyndroom. De leden werken dagelijks in universiteiten, academisch ziekenhuizen, onderzoeksinstituten en gezondheidscentra aan het dichterbij brengen van het uiteindelijke doel: Downsyndroom in al zijn details bloot te leggen, teneinde mensen met Downsyndroom, hun familie en hun verzorgers beter te kunnen helpen.

De belangrijkste doelstellingen van deze groep zijn: het stimuleren van onderzoek naar Downsyndroom, het bevorderen van internationale samenwerking tussen onderzoekers – bijvoorbeeld door het organiseren van de tweejaarlijkse T21RS International Conference (juni 2015: Parijs) – en het opstellen van gestandaardiseerde protocollen voor preklinisch en klinisch onderzoek. Daarnaast willen ze training en ondersteuning gaan bieden aan jonge onderzoekers die geïnteresseerd zijn in Downsyndroom, door middel van bijscholing en subsidies.

De leden van deze onderzoeksgroep doen in de breedste zin van het woord onderzoek naar Downsyndroom. Van gedragsmatige, psychologische en ontwikkelingsaspecten tot neurobiologie en genetica. Van het klinische totaalplaatje tot het niveau van cellen en moleculen. En van de menselijke praktijk tot modellen van Downsyndroom, zoals het veelgebruikte muismodel Ts65Dn of studies op celniveau.

Door de krachten te bundelen en de samenwerking op nationaal en internationaal niveau te versterken, willen ze het onderzoek naar Downsyndroom een stap vooruit brengen.

De SDS gaat met deze groep samenwerken. Een van de voornemens is dat T21RS zeer regelmatig artikelen zal aanleveren voor Down+Up. Dit past bij een van hun doelstellingen, namelijk wetenschappelijke kennis toegankelijk maken voor groot publiek. Speciaal hiervoor is de Commissie Wetenschap & Samenleving in het leven geroepen, onder leiding van professor Peter Paul De Deyn. Hij is verbonden aan de universiteiten Groningen en Antwerpen. Deze commissie zal speciaal zorgen voor de informatie richting de SDS, onze Vlaamse collega's Downsyndroom Vlaanderen en onze Duitse collega's van Down-Syndrom InfoCenter.

Op dit moment ligt hun expertise vooral op het gebied van depressies en de ziekte van Alzheimer. Eerste publicaties over deze onderwerpen kunnen we in 2015 verwachten.

Ook niet wetenschappers kunnen een kijkje nemen op de website van T21RS. De Stichting Downsyndroom zal alle verrichtingen van deze groep volgen en iedereen op de hoogte houden van de voortgang en vooral van de beloofde nieuwe onderzoeksresultaten die ten gunste komen aan mensen met Downsyndroom.
Zie voor meer informatie www.T21RS.org.

38 • Down+Up 108

Future / initiatives

- Increase number of T21RS Science & Society Bulletins
  - Input for new ideas/themes
  - We welcome clinicians/scientists who would like to write a new bulletin in collaboration with the Committee
- Intensifying collaboration with currently associated societies
  - Based on joint discussions and input (also today!)
- Expanding our network of collaborations in Europe, USA, and the rest of the world
  - T21RS Associated Membership

Contact:
p.p.de.deyn@umcg.nl

T21RS

Association Introduction Round

Saturday 10th June 2017

Peter De Deyn (chairman)

t21rs.org/science-society/t21rs-science-society-symposium-2017

Association Introduction Round

t21
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SOCIETY

national down syndrome society
ndss

t21somie
FRANCE

GLOBAL
DOWN SYNDROME
FOUNDATION®

Down's Syndrome
Association
A Registered Charity No. 1061474

21
FUNDACIÓ CATALANA
SÍNDROME DE DOWN

FOUNDATION
Jérôme Lejeune
search, healing, defend

BAND OF ANGELS

DSi
Down
Syndrome
International

FONDATION AMIPI
Bernard Vendre

Research Down Syndrome
LuMind™
FOUNDATION

The
Matthew
Foundation

alana

A.F.R.T.

DOWN
ASSOCIATION

Down Syndrome
OPTIONs
Optimizing Potential Through Integrative Opportunities Now

T21RS Symposium Bulletin

2017

T21RS Science & Society Symposium

Bulletin

T21RS Science & Society Symposium – Saturday June 10th 2017

Sponsored by the National Down Syndrome Society (NDSS)

Location: Feinberg Conference Center, Feinberg Pavilion, Northwestern Memorial Hospital at 251 E. Huron Street, Chicago, Illinois 60611, USA

Session coordination: T21RS Committee for Science & Society
Session chair: Peter De Deyn

T21RS Committee for Science & Society
Peter Paul De Deyn (Belgium, chairman), Alain Dekker (NL),
Juan Fortea (SP), Sebastian Videla (SP), Lotta Granholm (US, SW),
Cindy Lemere (USA), Diana Bianchi (USA)

Overview of Down syndrome associations presenting at the T21RS Science & Society Symposium during the T21RS International Conference in Chicago

T21RS SCIENCE & SOCIETY | www.t21rs.org/science-society

- Background on all participating associations in the Association Introduction Round
  - General overview
  - Key research links
- Provided by the associations themselves
- Freely available: www.t21rs.org/science-society/t21rs-science-society-symposium-2017

t21 RESEARCH SOCIETY

1

Kandi Pickard
Chief of Staff

representing

National Down Syndrome Society (NDSS)
New York City, NY, USA

www.ndss.org

Symposium Sponsor

national down syndrome society
ndss

NDSS Mission & Vision

MISSION

- The mission of the National Down Syndrome Society is to be the leading human rights organization for all individuals with Down syndrome

VISION

- The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations and become valued members of welcoming communities

national down syndrome society
ndss®

NDSS Four Areas of Programming

- National Advocacy & Public Policy Center creates systemic change through legislative advocacy
- The National Buddy Walk® program honors and celebrates individuals in their communities
- Public Awareness initiatives bring new and positive presentations of Down syndrome to the public
- Community outreach programs provide comprehensive and accurate information and resources on Down syndrome

Advocacy & Public Policy

Community Outreach

Public Awareness

Buddy Walk®

What NDSS is Doing

HEALTH CARE & RESEARCH

EDUCATION

ECONOMIC SELF-SUFFICIENCY

COMMUNITY INTEGRATION

EMPLOYMENT

Aging and Caregiving Guide

NDSS' National Inclusive Education Task Force

ABLE Alliance for Financial Empowerment

85 – 49 – 21+ (Advocacy – Action – Implementation)

Inclusion in all areas

national down syndrome society ndss #DSWORKS

Ready, Willing & ABLE!

national down syndrome society ndss

t21 RESEARCH SOCIETY

2

Michelle Sie Whitten
President & Chief Executive Officer

representing

Global Down Syndrome Foundation

Denver, CO, USA

T21RS Founding Sponsor
Conference Sponsor

GLOBAL DOWN SYNDROME FOUNDATION®

www.globaldownsyndrome.org

Global Down Syndrome Foundation Affiliate Organizations

GLOBAL DOWN SYNDROME FOUNDATION
- Fundraising & Development
- Outreach, Advocacy & Education

CRNIC INSTITUTE FOR DOWN SYNDROME
- Basic Research
- Clinical Research

SIE CENTER FOR DOWN SYNDROME
- Pediatric Medical Care
- Clinical Research

ROCKY MOUNTAIN ALZHEIMER'S DISEASE CENTER
- Medical Care
- Basic & Clinical Research

Coming Soon:
ADULT CLINIC
- Adult Medical Care
- Clinical Research

Global & Affiliates

The Global Down Syndrome Foundation is part of a network of affiliate organizations that work closely together on a daily basis to deliver on our mission, vision, values, and goals:

Global was established as a 501(c)3 in 2009 and is "Dedicated to significantly improving the lives of people with Down syndrome through Research, Medical Care, Education, and Advocacy"

Affiliates

- Established with a lead gift from Anna & John J. Sie Foundation
- Must work closely together to benefit people with Down syndrome
- Must be self-sustaining financially

Linda Crnic Institute for Down Syndrome
100 Scientists with 38 Labs

Alzheimer's Disease


Bettcher


Dell'Acqua


Hoeffer


Kennedy


Potter


Xue

Cognition, Autism and Brain Function

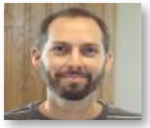

Chen


Maclean


Jones


Maier


Mueller


Santos


Shaikh


Stitzel

Immunology


Lenz


Hsieh


Shen


Spritz


Sullivan

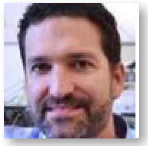

Yeager

Stem Cells and Development

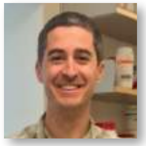

Bilousova


Klymkowsky


Link


Old


Olwin


Pearson

Advanced Genetics and Genomics


Blumenthal


D'Alessandro


Dowell

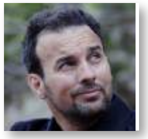

Johnson

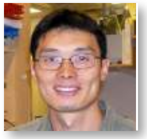

Liu


O'Connor

Leukemia

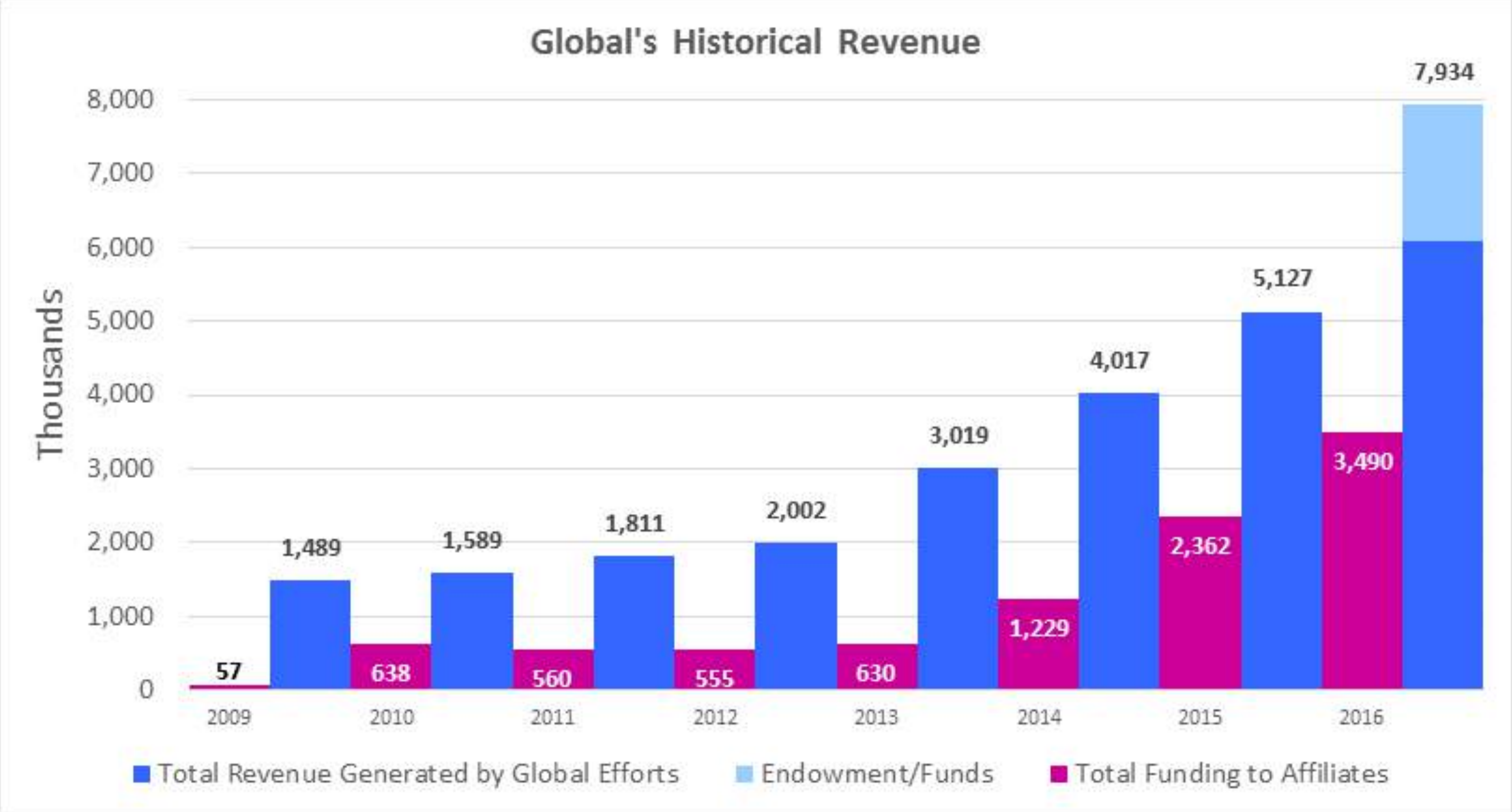

DeGregori


Espinosa


Yi

Global Down Syndrome Foundation
How Far We've Come!

Our total funding/grants to Affiliates (including direct to Affiliate donations organized by Global) has grown from $57K in 2009 to $3.49 million in 2016



New Global Headquarters Debuting June 2018

GLOBAL DOWN SYNDROME FOUNDATION™

THANK YOU to T21 Research Society and all the scientists and families!

How You Can Get Involved

- Become a Member for only $20 per year
- Donate online at www.globaldownsyndrome.org
- Sponsor a Global Event or Health & Wellness Program
- Volunteer at an event or program

GLOBAL DOWN SYNDROME FOUNDATION™

t21
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3

Catherine Lemonnier
MD & Research Director (Direction Recherche)

representing

Fondation Jérôme Lejeune

Paris, France

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search, healing, defend

www.fondationlejeune.org

Research Care Advocate

Life protection

Bioethics

Understand Down syndrome

Find treatment

INSTITUT
Jérôme Lejeune
soigner, chercher, former

Outpatient clinic
« Baby to Senior »
8400 patients

FONDATION
Jérôme Lejeune
chercher, soigner, défendre

THE RESEARCH at Jerome Lejeune Foundation:

Understand the diseases (DS and rare diseases)

- **Protein: protein Ch21 interaction**
- **Cells roles** and synapse, and Genes (Dyrk1a and CBS)

To therapeutics

- **Models:** animal (*Rat T21), yeast IPSc*
- **Focus on Cross pathologies** Autism and ALZ, Oncology (*Oncodefi)*
- **DYRK1a inhibitors** (Collaboration with Manros®, and Barcelona/ICM team on EGCG -TESDAD/ Perseus-)
- **CBS inhibitors:** CiBles21
- **Support to IJL and Clinical Research**

MEANS

- ***Private donations***
- **Scientific Board**
  25 scientists
- **Collaboration with other Foundations** (*Sisley d'Ornano* and Bettencourt Schueller*[#]*…*)

KEY NUMBERS

- **4 M€ per year Research** funds allocation
- **Call for grants projects: 19 M€** allocated for the last 20y on **630 different – 18 countries-**
- **One Post-doctoral** per year* (Portugal) 65k€/y
- 2 young Searchers Prices/y
- **Meeting support** (T21RS, DyrK1a…)

FONDATION
Jérôme Lejeune
chercher, soigner, défendre

INSTITUT
Jérôme Lejeune
soigner, chercher, former

Outpatient Clinic:

Intellectual deficiencies from genetic origin

Patients:
From Birth to Senior
Down Sd to Rare diseases

Multidisciplinary
and long visits

Clinical Research Unit

- **Clinical trial,**
ACTHYF,
PERSEUS,
RESPIRE21…

- Epidemiologic analysis

Free Bio Bank
BIOJEL

KEY NUMBERS

- **3.9 M€ Budget** (80% FJL and 20% public)
- **34 Health Care professionals**
- **8400 patients in the cohort; 3800 patients (2016); 40 new patients per month**
- **800 attendees to training (care workers, families)**
- **10 Research programs**
- **BioJeL**

5500 Resources
24% Plasma
31 % ADN
19 % LC lines
26 % PBMC

FONDATION
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chercher, soigner, défendre

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SOCIETY

4

Hampus Hillerstrom
Vice Chair

representing

LuMind RDS Foundation
Marlborough, MA, USA

T21RS Founding Sponsor
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Research Down Syndrome
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www.lumindfoundation.org

Research Down Syndrome
LuMind
FOUNDATION

Our Mission

We stimulate biomedical research that will accelerate the development of treatments to significantly improve cognition, including memory, learning and speech, for individuals with Down syndrome

www.lumindrds.org

#lumindrdsCARES

$15M in Grants to Date has led to Important Advances in Down Syndrome Research

2004

- Funded research at top institutions including Stanford, John Hopkins, UCSD, University of Arizona and Emory University.
- Identified 10 new potential therapeutic drug targets relevant for Down syndrome (including sonic hedgehog, USP16, APP)
- Developed several Down syndrome-specific cognitive test batteries for use in clinical trials (ACTB, A-MAP)
- Supported 4 major clinical trials (Roche, AC Immune, Balance Therapeutics, Transition Therapeutics)
- Stimulated several NIH initiatives (incl. registry, biomarkers, AC Immune, A-MAP)

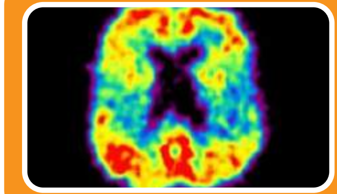
2017

- Established clinical testing network and strong scientific advisory board

LuMind RDS supports researchers who can advance our targeted research goals and collaborates whenever possible

Research Down Syndrome
LuMind
FOUNDATION

LuMind RDS is Focused on Four Scientific Research Categories



Prevent Alzheimer onset

- Encourage industry-led clinical trials of therapeutic approaches
- Develop necessary resources: assessment scales, registry, other

Improve cognition

- Translate Down syndrome-specific approaches to clinical trials
- Validate Down syndrome-specific cognition targets

Develop gene therapies

- Silence extra chromosome
- Restore the right level of specific gene(s)

Advance understanding

- Discover novel targets (stem cells, sequencing/phenotyping)
- Improve mouse models to better test novel targets

LuMind's sole focus is to discover and develop groundbreaking Down syndrome research

t21 RESEARCH SOCIETY

5

John Blascovich
President & Chair

representing

The Matthew Foundation
Manhasset, NY, USA

T21RS Founding Sponsor

The Matthew Foundation

www.thematthewfoundation.org

The Matthew Foundation

The Matthew Foundation's mission is to improve the quality of life for people with Down syndrome throughout their lifetime. The areas of focus are:

- supporting research and care
- promoting inclusive practices
- developing employment programs

because the foundation appreciates that different needs are present during different periods in a person's life.

The Matthew Foundation makes deep impact through specific programs. These programs are carefully selected to ensure that they can either provide very meaningful impact across a broad population base or the impact is multi-layered. And the foundation only takes on programs where the team has unique expertise and can further the program given its relationships and capabilities.

Commitment to Research

The Matthew Foundation believes strongly in the importance and potential of research improving the quality of life for people with Down syndrome.

- Trisomy 21 Research Society -The Matthew Foundation is a Founding Sponsor.
- Endowed Fund for Down Syndrome Research at Stanford University - The Matthew Foundation established the first and currently only endowed fund for Down syndrome research at Stanford. This endowed fund along with the longstanding reputation for research excellence attracts new talent to the field. Through our relationship with the alumni base, we are are working to channel additional support to DS research.
- Research information sessions – for the past several years, The Matthew Foundation has organized well attended information meetings to inform local communities about the potential and importance of research. We find these events have improved the understanding of current research, and help broaden support for future efforts.

The
Matthew
Foundation

Other areas of interest

In addition to research, The Matthew Foundation is committed to ensuring people with Down syndrome are afforded opportunities and included in society.

Super Fest is an example of working on multiple levels to advocate for inclusion. Super Fest is disability inclusive football and cheerleading clinic the day before the Super Bowl where people with and without disabilities can participate together. Multifaceted support:

- Political - President George. H. W. Bush, who signed American Disabilities Act into law, Honorary Chairperson
- Media - ESPN, ESPN Radio, TuneIn (NFL App), Compass Media
- NFL team executives - Head Coach, General Manager, Team President - and NFL Cheerleaders
- Private/individual support from CEO/Pres/EVPs of major corporations
- Extensive local media coverage

The
Matthew
Foundation

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6

Renaud Touraine
Vice President

representing

Trisomie 21 France
Saint-Étienne, France

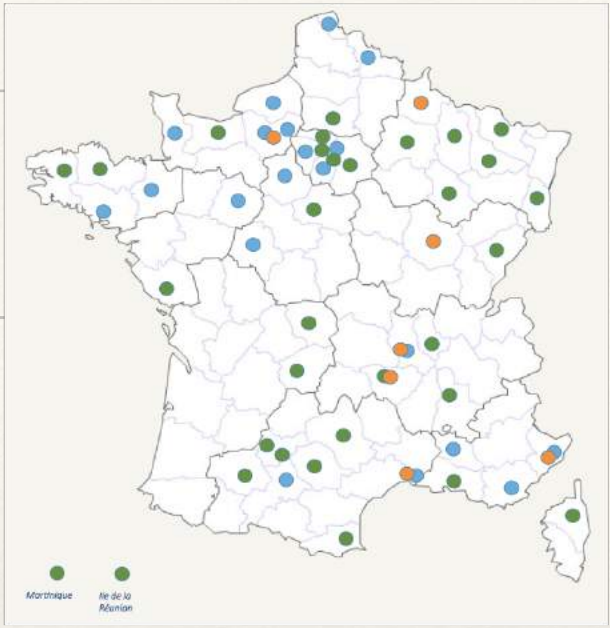
T21RS Founding Sponsor

t21somie
FRANCE

www.trisomie21-france.org

Trisomie 21 France

http://www.trisomie21-france.org



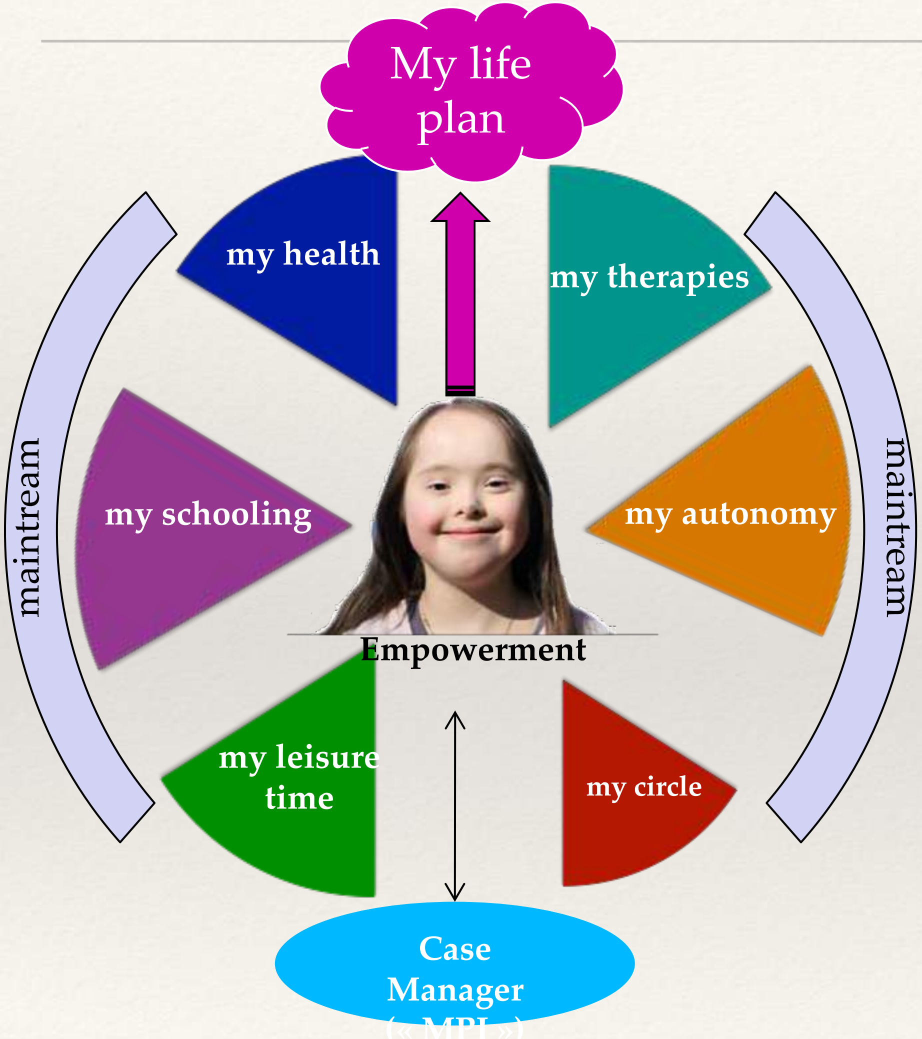
- Long-standing non-confessional association since 1973
- Oldest and largest french Down Syndrome (DS) association
- 52 local associations, > 3000 members
- Including 20 with support services (public funding)
  - > 1000 persons with DS supported
  - MD, Physiotherapists, Speech Therapists, Physical/occupational Therapists, Psychologists, Educators, social workers
- **Confidence in the abilities of people with DS** and partnership : persons / families / professionals
- **Self-determination**
- Advocacy for school, social and professional integration. Self advocacy and peer advocacy
- In **mainstream settings**
- Novel and innovative programs, i.e
  - Support for employment (S.A.T. Hors les murs, emploi accompagné)
  - Personalized support in mainstream environments (P.R.I.S.M.E.)

Focus on Saint Etienne

- Oldest T21France Association
- Close relationship with the Genetic Department at the University Hospital of St Etienne (MD, PhD, Neuropsychologists) →
- 3 support services
  - « SESSAD »: For children (early intervention, support for rehabilitation, education and school in regular primary and secondary schools)
  - « SAVS »: For teenagers and adults (support for social inclusion, independent living)
  - « SAT Hors les murs »: Support for employment in mainstream companies or public services

An innovative kind of support : « PRISME » : to help find rehabilitation ressources within the community, coordinate them with the family/person and provide the teachers at school or manager / mentor at work with additional links

PRISME / SAT Hors les murs



Broker / Gatekeeper / Advocacy

- Purpose: access to a stable job in mainstream settings
- Persons are employed by the « SAT » and seconded to the firm where they have their job trainings
- Means: a team (educators, psychologist, occupational therapist, secretary and director)
  - Help before, during and after job trainings: regular assessments, finding a job training position, …
  - Close support at work when needed and link with the company : confidence for the manager and the mentor.
- A partnership program : if the company and the supported person are both satisfied, the job training is extended, … up to a permanent employment. The person is no longer employed by the SAT, but a support is kept for some time after then.
- Since 2008 : 63 persons (1/3 DS, 2/3 other ID)
- **19 got a permanent job** (for 15 there is still somme kind of « relaxed » support)
- 30 persons actively supported this year

t21 RESEARCH SOCIETY

Gillian Bird
Information & Training Services Manager

representing

Down's Syndrome Association (DSA)
London, UK

Conference Sponsor

Down's Syndrome Association
A Registered Charity No. 1061474

www.downs-syndrome.org.uk

DSA mission

To create the conditions that all people with Down's syndrome need to live full and rewarding lives.

- We fight for the rights of people with Down's syndrome
- We provide information on all aspects of Down's syndrome
- We encourage and monitor research into health and education
- We involve adults with Down's syndrome in our work

How we help research

- We highlight areas of need
- Advise on projects and support research proposals
- Advise on accessibility of materials
- Support recruitment
- Raise awareness of research
- Disseminate research findings
- Help put research into practice through policy work and campaigns
- Facilitate research through DSA contacts.

Example

'Defeating Dementia', University of Cambridge UK

- We advised on the proposal
- Supported recruitment through membership and connections
- Facilitated workshops
- Produced resources (e.g. factsheets)
- Disseminated progress
- Provided some funding

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8

Band of Angels

Rochester Hills, MI, USA

www.bandofangels.com

BAND OF ANGELS

t21 RESEARCH SOCIETY

Claudia Moreira
Scientific Advisor

representing

Alana
São Paulo, Brazil

www.alana.org.br

alana

Alana

- Claudia Moreira, PhD. Scientific Advisor.
- Alana Foundation is the American branch from Alana, a Brazilian NGO.
- Alana is a nonprofit civil society organization that brings together programs that pursue conditions for children to fully experience their childhoods. Founded in 1994, Alana has been maintained by an endowment fund since 2013. Its mission is to “honor the children”.
  - Main location: São Paulo, Brazil

Alana Foundation

- In US, Alana Foundation is a 501(c)(3) not for profit, scientific and educational organization dedicated to promote research and enhance the community's knowledge of child development, in general, and Down syndrome, in particular.
  - Main location: Miami, USA

How can we contribute to research

- To accomplish our mission, we provide grants to non-profit organizations in order to facilitate research in child development, in general, and **Down syndrome**, in particular.
- We believe that being part of a **network** is the key to improve research, science and education. In this **network** it is pivotal to have partners from academic, business and social fields. It is essential to have a hands-on perspective in order to achieve our goals.

Research Projects in Progress

Dr Alberto Costa, CWRU and Dr Ana C. Brandão, HIAE/BR

- The Use of Memantine to Improve the Cognitive Abilities of Adolescents and Young Adults with Down Syndrome.

Dr Alberto Costa, CWRU and Dr Li-Huei Tsai, MIT

- **Project 1:** To create and study a series of human-induced pluripotent stem cell (iPSCs) models of Down syndrome.
- **Project 2:** Breeding of the Ts65Dn mice with the Δp35KI mouse model of p25 inhibition.
- **Project 3:** HDAC inhibitor treatment in Ts65Dn mice.
- **Project 4:** Deep imaging in the intact DS mouse model brain

alana

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10

Bessy Benejam
Neuropsychologist

representing

Catalan Down Syndrome Foundation
Barcelona, Spain

www.fcsd.org

21
FUNDACIÓ CATALANA
SÍNDROME DE DOWN

THE FUNDACIÓ CATALANA SÍNDROME DE DOWN

About us	Fundació Catalana Síndrome de Down (FCSD) is a non-profit private organization founded on March 30, 1984 and declared to be of public utility on October 24 of that year.
Our mission	To improve quality of life for people with Down syndrome or other intellectual disabilities, enabling their full inclusion in society as well as their attainment of well-being, self-determination, personal development, respect, and dignity at the highest levels.
Our vision	A world in which people with disabilities participate fully in society on equal terms with everyone else.
Objectives	To set up, expand and improve any services deemed necessary in order to address known and emerging needs. | To serve as a standing body for biomedical, psychological, educational and social research, study and training. | To implement other activities related to the two above objectives in order to meet the social, personal and family needs of people with disabilities.
SERVICES AND PROGRAMS	Since 1984 the Fundació Catalana Síndrome de Down has been providing support from pre-natal diagnosis and birth until adult age. Its services and programs are directed towards persona with DS or other intellectual disabilities.

CHILD DEVELOPMENT AND EARLY INTERVENTION
Consultation, diagnosis and treatment of infants from birth to age 6 whose development is delayed or at risk.

ADULT EDUCATION
Courses and workshops offered to adults to give them continuity in training.

JOB INTEGRATION SERVICE
Integration into the normal labour market through guidance, training, searching for companies and the following.

THERAPEUTIC ATTENTION SERVICE
Diagnosis, treatment and advice in mental health problems, speech therapy and physiotherapy. Psychological support and treatment for families.

MAINSTREAM SCHOOL SUPPORT SERVICE
Intervention in groups of school-age children with Down syndrome to assist learning, communication, relationships and identity in order to facilitate inclusion.

CONNECT - LEISURE AND PARTICIPATION
Developing skills to organize and enjoy free time by planning and developing leisure and holiday activities.

INDEPENDENT LIVING SUPPORT SERVICE "I'M GOING HOME"
Personal support to allow each individual to decide where and with whom they want to live.

ATTENTION TO FAMILIES
Aimed as families to promote welfare and quality of life through guidance and information about our own resources or external ones, and encourage other activites and support programmes.

DOWN MEDICAL CENTER

Preventive medicine based on the **FCSD Preventive Medicine Checklist** under constant revision since **1987**, covering **19 specialties.** Includes a **Preventive Health Programme** (since 1987), a **Therapeutic Attention Service**, and a **Down Syndrome and Alzheimer Disease Unit**.

TRAINING AND RESEARCH UNIT

Biannual International Conferences | Seminars, courses and lectures for parents, professionals and people with intellectual disabilities | Awards for students and professionals.

Some of our research in progress: *Study on Autism Spectrum Disorder in people with Down Syndrome. / Incidence of Alzheimer's disease in people with Down syndrome. Down Alzheimer Barcelona Neuroimaging Initiative.*

2016

1.898 Persons and their Families

2.415 Medical visits

2.759 Clinical history

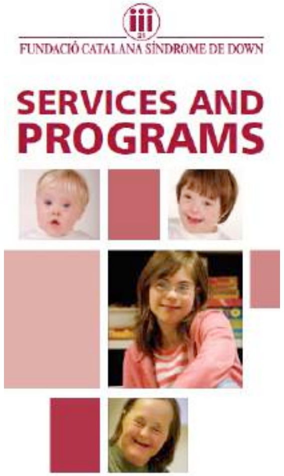
We conducted

7 investigations in

Neuropsychology
Child Neurology
Neurology
Clinical child psychology

In collaboration with

Hospital Sant Joan de Déu
Hospital de la Santa Creu i Sant Pau
Hospital del Mar



HUMAN RIGHTS ASSEMBLY

Improving the skills of empowerment of people with intellectual disabilities to **defend their rights**, represent the groups and make their voice heard in the media in society.

ÈXIT21

A communication project which aims to help people with intellectual disabilities break into the world of media, making use of new technologies to make their voices heard. ÈXIT21 aims to be the benchmark of communication for the FCSD.

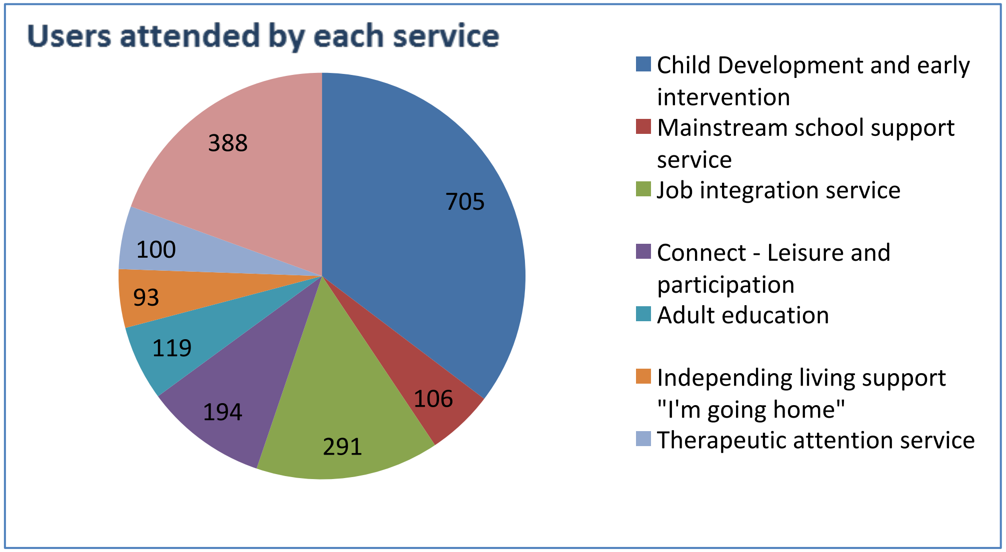
PUBLICATIONS

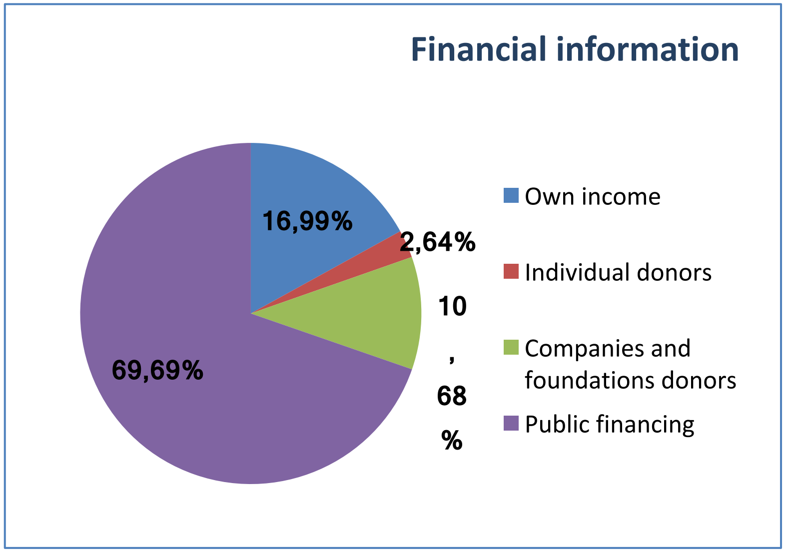
Quarterly review *SD-DS. International Medical Review on Down Syndrome.*

Publications of both original books and translations.

Production of audiovisual material.

The Fundació Catalana Síndrome de Down has devoted major efforts from its inception to raising awareness through a **combination of direct care**, **training** (for families, professionals and students) **research** and **publications**.





Our philosophy is based on **accompanying parents**, building up a future project for their children and **people with Down syndrome**, helping them to **build their identity**, key factors for a **better quality of life.**

Our **support** is based on a methodology which aims to reinforce the personal bonds through **respect**, **natural support**, while **avoiding invasiveness**.

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11

Helen Powell
Policy Development Manager

representing

Down Syndrome International
London, UK

www.ds-int.org

Conference Sponsor

DSi
Down
Syndrome
International

Down Syndrome International
Improving Life for People with Down Syndrome

Connecting the global Down syndrome community

- DSi is a GLOBAL NETWORK of member organisations and individuals from 136 countries across the world.

- We are committed to IMPROVING QUALITY OF LIFE for people with Down syndrome and promoting their right to be accepted and included as valued and equal members of their communities, wherever they are.

- We work with the international community, with specific focus on developing countries:

✓ to provide support and accurate, up-to-date INFORMATION;
✓ to REPRESENT people with Down syndrome and encourage communication and cooperation;
✓ to raise AWARENESS about Down syndrome.

How we do it

- Through our outreach training programmes ‘REACH OUT’ in developing countries;
- Via our MEMBERSHIP NETWORK: sharing information and representing people with Down syndrome worldwide;
- By organising the WORLD DOWN SYNDROME CONGRESS (WDSC), a biennial meeting place for the global Down syndrome community;
- By promoting WORLD DOWN SYNDROME DAY (WDSD) on 21 March, a day recognised by the United Nations, dedicated to people with Down syndrome.

21 World Down Syndrome Day
www.worlddownsyndromeday.org

Research interests

- DISSEMINATION OF HIGH QUALITY RESEARCH to the international community in a clear, factual, understandable, sensitive and unbiased way.
- PUBLICATION of selected research abstracts on our website quarterly.
- Development of INTERNATIONAL CONSENSUS GUIDELINES in healthcare and in other areas that affect the lives of people with Down syndrome, with input from expert advisors and stakeholders.
- PROMOTION OF T21RS by having a permanent link on the homepage of our website and featuring their bulletins in our newsletter.

t21 RESEARCH SOCIETY

12

Jean-Marc Richard

Vice President

representing

Association Française pour la recherche sur la Trisomie 21

Paris, France

A.F.R.T.

www.afrt.fr

AFRT – What is it?

- A **national association** of **parents**, **families** and **professionals** created in 1990 by scientists at Necker hospital in Paris.
- Some local associations, such as AFRT 78 started in 2015

- It aims at **promoting basic, clinical and epidemiological research**
- As well as **giving regular updates** about progresses in medical care and perspectives of research, with the newsletter 'News from Chromosome 21'

Address: Université Paris-Diderot, Paris
President : **Jacques Costils**
Board: 3 Vice-Presidents and 1 treasurer
Scientific panel: A scientific and medical committee composed of 12 members

Down syndrome Day

World
Down
Syndrome
Day

- In 2005, AFRT initiated the first **Down syndrome day** with a meeting in Paris. The topic was *‘From patients to research: understand to better help’*
- Since then, AFRT has organized **events** and **conferences** on **March 21** (03/21) **every year,** aiming at fruitful exchanges between professionals and families
- Recent events :
  - 2014 (Lyon): “Health and well being”.
  - 2015 (Paris): “Trisomy 21: New horizons”.
  - 2016 (Marseilles): “Becoming adult in an inclusive society”
  - 2017 (Grenoble): “Change the course of action”

9e
Journée Mondiale
de la Trisomie 21
World Down Syndrome Day
Lyon, 21 & 22 mars 2014
[illegible]

Grenoble
JOURNEE
MONDIALE
DE LA
TRISOMIE 21
12ème édition
16 - 17 - 18 mars 2017

More information on: www.afrt.fr

Initiatives and Perspectives

- For several years, AFRT has taken part in the National Festival of Science with posters and explanations for middle school and high school students and also for the general population
- AFRT co-organizes meetings such as the coming one in Toulouse in September 2017: *’Research on T21: a benefit for the general population’*

Initiatives and Perspectives

Past financial supports

- Since 1998, AFRT has given :
  - 15 fellowships for master degrees, e.g., B. Souchet who obtained striking results on DYRK1A and EGCG
  - 4 fellowships for one or two years of PhD
  - 10 grants for research
- Ongoing supported programs:
  - A new apparatus for easy apnea detection
  - An epidemiological survey of some ophthalmologic problems related to aging
  - A MD-thesis (pharmacy) on depression

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13

Agnes Toth
Medical Advisor

representing

Down Syndrome Hungary
Nyíregyháza, Hungary

www.downegyesulet.hu

DOWN
ASSOCIATION

DOWN
ASSOCIATION

www.downegyesulet.hu

Our Projects and Main Objectives

03 21
DOWN VILÁGNAP

Down-
háló

DOWN BABA
DOWN BABA

CS
CSODAVÁR

MINDENKINEK
BECSENGETTEK
MINDENKINEK
BECSENGETTEK

03 21
0321
KIHÍVÁS
Játék előítéletek nélkül

- Awareness
- Acceptance
- Collaboration
- Reverse integration
- Inclusive education
- Social Integration

Our contribution to research

a Down-szindrómások
értelmi képességeit támogató
táplálékkiegészítő

healthyDS

- Promotion
- Public Education
- Professional Education
- Networking

Share her health
information–
help others.

Join DS-Connect™: The Down Syndrome Registry today.
Get DS-Connected: **DSconnect.nih.gov**

NIH Eunice Kennedy Shriver National Institute
of Child Health and Human Development

14

Marie-Laure Blandin
Deputy Director
(Directrice en charge des apprentissages)

representing

Fondation AMIPI-
Bernard Vendre
Cholet, France

www.fondation-amipi-bernard-vendre.org

FONDATION AMIPI
Bernard Vendre

AMIPI-Bernard Vendre Foundation

<u>The rationale of our research & experimentation</u>

In 1965 Maurice Vendre suggested, with the backing of Professeur Robert DEBRE, the possibility that for people with learning difficulties may experience changes in their neural systems through specific learning activities

Researches have confirmed that

Learning via the repetition of cognitive demands,
promotes the development of neural networks
by strengthening or by creating, new synapses

Automotive Cable Harness Assembly : a way to learn and develop one's cognitive skills and a professional behavior

The choice of an industrial sector
to support learning of professional attitudes
and social independence
consistently with the various theories on brain plasticity

Amipi Foundation demonstrates the absolute needs of behavior therapy through

- 1/ usual traditional manual job
- 2/ factory with learning methodology
- 3/ objectives of new job out of the Foundation

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15

Alexandria Durkin
President & Executive Director

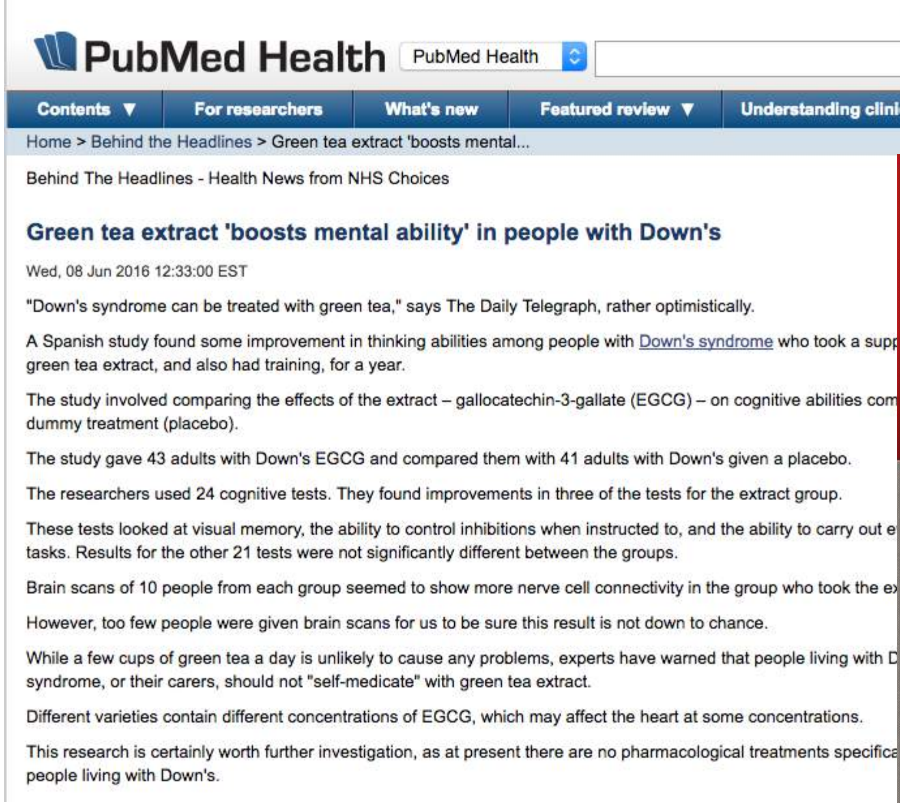
representing

Down Syndrome OPTIONs
Little Rock, AR, USA

www.downsyndromeoptions.org

Down Syndrome
OPTIONs
Optimizing Potential Through Integrative Opportunities Now

Prenatal Outreach



Behind The Headlines - Health News from NHS Choices

Green tea extract 'boosts mental ability' in people with Down's

Wed, 08 Jun 2016 12:33:00 EST

"Down's syndrome can be treated with green tea," says The Daily Telegraph, rather optimistically.

A Spanish study found some improvement in thinking abilities among people with Down's syndrome who took a supp green tea extract, and also had training, for a year.

The study involved comparing the effects of the extract – gallocatechin-3-gallate (EGCG) – on cognitive abilities com dummy treatment (placebo).

The study gave 43 adults with Down's EGCG and compared them with 41 adults with Down's given a placebo.

The researchers used 24 cognitive tests. They found improvements in three of the tests for the extract group.

These tests looked at visual memory, the ability to control inhibitions when instructed to, and the ability to carry out e tasks. Results for the other 21 tests were not significantly different between the groups.

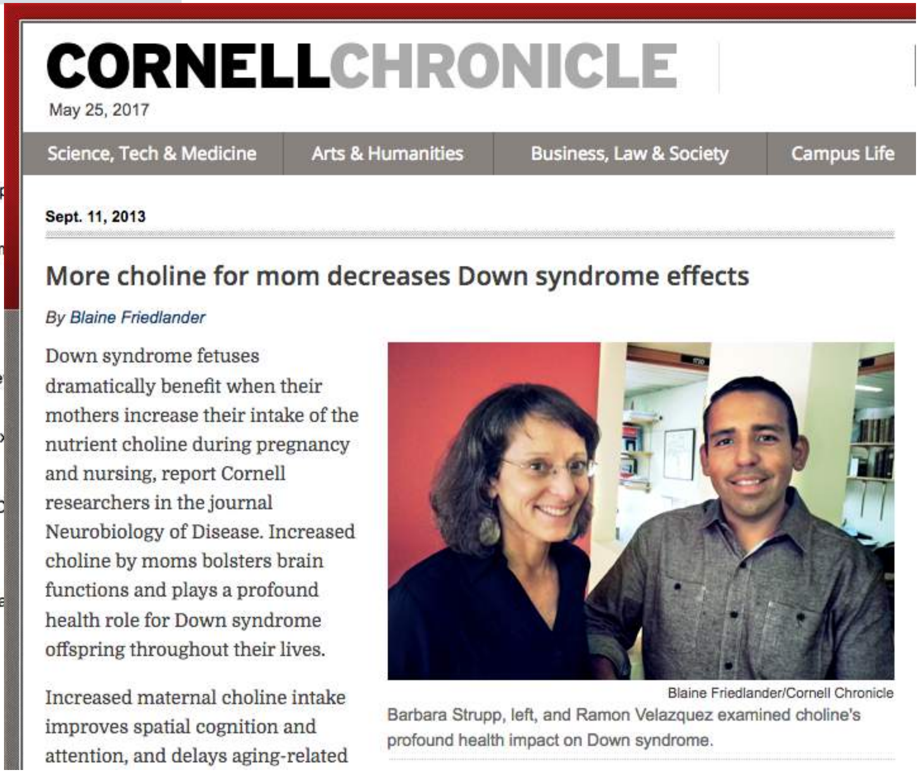
Brain scans of 10 people from each group seemed to show more nerve cell connectivity in the group who took the e

However, too few people were given brain scans for us to be sure this result is not down to chance.

While a few cups of green tea a day is unlikely to cause any problems, experts have warned that people living with D syndrome, or their carers, should not "self-medicate" with green tea extract.

Different varieties contain different concentrations of EGCG, which may affect the heart at some concentrations.

This research is certainly worth further investigation, as at present there are no pharmacological treatments specifica people living with Down's.



Sept. 11, 2013

More choline for mom decreases Down syndrome effects

By Blaine Friedlander

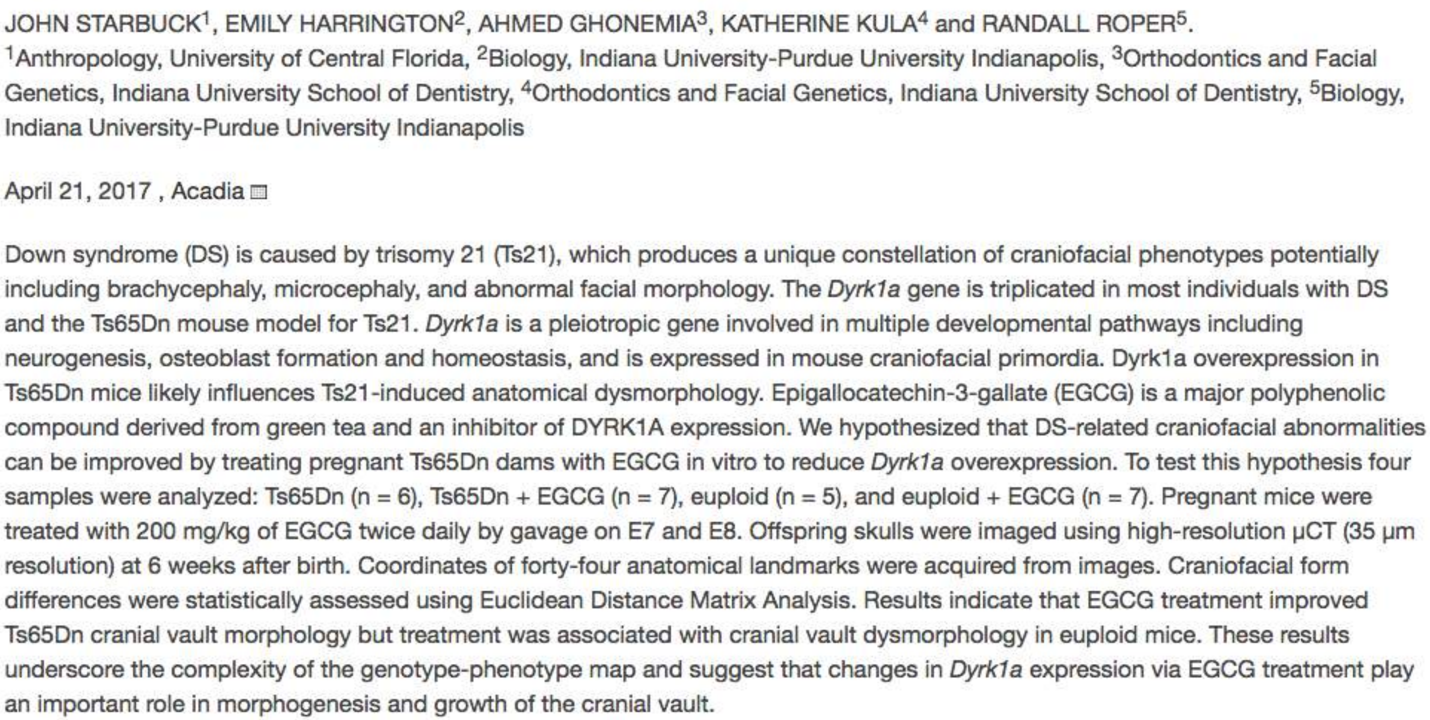
Down syndrome fetuses dramatically benefit when their mothers increase their intake of the nutrient choline during pregnancy and nursing, report Cornell researchers in the journal Neurobiology of Disease. Increased choline by moms bolsters brain functions and plays a profound health role for Down syndrome offspring throughout their lives.

Increased maternal choline intake improves spatial cognition and attention, and delays aging-related

Blaine Friedlander/Cornell Chronicle

Barbara Strupp, left, and Ramon Velazquez examined choline's profound health impact on Down syndrome.

Research Partners



The 86th Annual Meeting of the American Association of Physical Anthropologists (2017)

Programs > 2017 > Poster Session > Poster Abstract

The Influence of EGCG on Cranial Vault Morphology

JOHN STARBUCK[1], EMILY HARRINGTON[2], AHMED GHONEMIA[3], KATHERINE KULA[4] and RANDALL ROPER[5].
[1]Anthropology, University of Central Florida, [2]Biology, Indiana University-Purdue University Indianapolis, [3]Orthodontics and Facial Genetics, Indiana University School of Dentistry, [4]Orthodontics and Facial Genetics, Indiana University School of Dentistry, [5]Biology, Indiana University-Purdue University Indianapolis

April 21, 2017 , Acadia ▤

Down syndrome (DS) is caused by trisomy 21 (Ts21), which produces a unique constellation of craniofacial phenotypes potentially including brachycephaly, microcephaly, and abnormal facial morphology. The *Dyrk1a* gene is triplicated in most individuals with DS and the Ts65Dn mouse model for Ts21. *Dyrk1a* is a pleiotropic gene involved in multiple developmental pathways including neurogenesis, osteoblast formation and homeostasis, and is expressed in mouse craniofacial primordia. Dyrk1a overexpression in Ts65Dn mice likely influences Ts21-induced anatomical dysmorphology. Epigallocatechin-3-gallate (EGCG) is a major polyphenolic compound derived from green tea and an inhibitor of DYRK1A expression. We hypothesized that DS-related craniofacial abnormalities can be improved by treating pregnant Ts65Dn dams with EGCG in vitro to reduce *Dyrk1a* overexpression. To test this hypothesis four samples were analyzed: Ts65Dn ($n = 6$), Ts65Dn + EGCG ($n = 7$), euploid ($n = 5$), and euploid + EGCG ($n = 7$). Pregnant mice were treated with 200 mg/kg of EGCG twice daily by gavage on E7 and E8. Offspring skulls were imaged using high-resolution μCT (35 μm resolution) at 6 weeks after birth. Coordinates of forty-four anatomical landmarks were acquired from images. Craniofacial form differences were statistically assessed using Euclidean Distance Matrix Analysis. Results indicate that EGCG treatment improved Ts65Dn cranial vault morphology but treatment was associated with cranial vault dysmorphology in euploid mice. These results underscore the complexity of the genotype-phenotype map and suggest that changes in *Dyrk1a* expression via EGCG treatment play an important role in morphogenesis and growth of the cranial vault.

Connecting Research to Parent to Practitioner


JDSM
Journal of Dental Sleep Medicine
OFFICIAL PUBLICATION OF THE AMERICAN ACADEMY OF DENTAL SLEEP MEDICINE

Journal of Dental Sleep Medicine

Volume: 04 **Number:** 02 4/10/2017

CASE REPORTS

Oral Appliance Treatment in a Patient with Down Syndrome

http://dx.doi.org/10.15331/jdsm.3734

B. Gail Demko, DMD, D. ABDSM

Sleep Apnea Dentists of New England, Weston, M
Medicine

Treatment of patients with physical and
difficult undertakings in dental sleep me
physical difficulty placing, removing, an
They understand the instructions that are given and comprehend the possibilities of side effects. Patients with Down syndrome, mild dementia, and those with physical limitations such as cerebral palsy and status post cerebral-vascular accident may find OA therapy extremely challenging. Many of these

T21RS thanks all associations

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national down syndrome society
ndss

t21somie
FRANCE

NIH
NICHD

GLOBAL
DOWN SYNDROME
FOUNDATION®

Down's Syndrome
Association
A Registered Charity No. 1061474

21
FUNDACIÓ CATALANA
SÍNDROME DE DOWN

FOUNDATION
Jérôme Lejeune
search, healing, defend

Research Down Syndrome
Lumind™
FOUNDATION

DSi
Down
Syndrome
International

BAND OF ANGELS

The
Matthew
Foundation

alana

A.F.R.T.

DOWN
ASSOCIATION

FONDATION AMIPI
Bernard Vendre

Down Syndrome
OPTIONs
Optimizing Potential Through Integrative Opportunities Now