

Scientific Advisory Board Fragile X

Monday May 5th, 2014



Introduction

- Round table - intro
- Simply using your native language
- Feel free to intervene at all time – this is your meeting

Agenda

- ◆ Conferences for professionals & families in Brussels X-X-2014
- ◆ Awareness campaign for doctors – re-enforcing postcard campaign
- ◆ Clinical Trials
 - ◆ Novartis stopping AFQ056 – UCL/KUL
 - ◆ Ganaxolone – Antwerpen
 - ◆ Roche,...
- ◆ Update from *Association X Fragile Belgique, Werkgroep Fragiel X & European Fragile X Network (EFXN)*
- ◆ Latest news - Medical & non-medical research

Friday X-X-2014 Conference for professionals & families

Fragile X :

- Premutation & associated disorders
- Multidisciplinary intervention strategies

Place to be : Brussels, UCL Woluwe



Draft agenda

- ◆ Morning - scientific update focused on Fragile X premutation & associated disorders
 - ◆ 0830-0900 : Welcome - coffee
 - ◆ 0900-0915 : Introduction – Dominique Damas, Belgian Fragile X Association + Scientific lead
 - ◆ 0915-1000 : Genetic overview, Fragile X premutation and full mutation – Pr. Nicole Philip ? (France - Marseille) - TBC
 - ◆ 1000-1045 : FXTAS – Pr. Jacquemont (Canada/Switzerland)
 - ◆ 1045-1100 : Break
 - ◆ 1100-1145 : FXPOI – Dr. Anne Bachelot ? (France – Paris) - TBC
 - ◆ 1145-1230 : Round Table with Pr. Jacquemont, Pr. Nassogne, ... - some topics prepared in advance and interactivity with attendees
- ◆ Networking Lunch
- ◆ Afternoon focused on multidisciplinary intervention strategies

Note : some of the slots below may be duplicated to ensure learning is done in small groups (i.e. we need more speakers)

 - ◆ 1330-1430 : EIS tool supporting schools and professionals alike – Dr. Nathalie Nader ?, Psychology , UCL
 - ◆ 1430-1515 : Improving behaviors with kids, teenagers and adults with Fragile X – Dr. Isabelle Roscamp? Laurence Roussel ?
 - ◆ 1515-1530 : Break
 - ◆ 1530-1615 : iPad & Fragile X – Mrs Caroline Deom, speech therapy, co-president ASELF
 - ◆ 1615-1645 : Round table with Dr. Nader, Roscamp, Mrs Deom,... - some topics prepared in advance and interactivity with attendees
 - ◆ 1645-1700 : Conclusion & closing – Dominique Damas, Belgian Fragile X Association

Awareness Campaign

early detection & right intervention

Postcard for pediatricians & GP sent this month

How to maximize impact?

(Contacts with SSMG, GBPF and ... ?)

Debrief Groupement des Pédiatres



Clinical Trials

AFQ056 (Novartis) – UCL/KUL – Pr. M.-C. Nassogne

Ganaxolone - Antwerpen – Dr. Anke Van Dijck

Other global clinical trials - how to extend to Belgium



Parent support group update

Association X Fragile Belgique

Werkgroep Fragiel X

European Fragile X Network (EFXN)



Our associations

Belgium :



France, Nederland, Nordics,
Germany, Spain, Italy, UK,
Portugal, Switzerland, ...



EUROPEAN
FRAGILE X
NETWORK



14TH INTERNATIONAL FRAGILE X CONFERENCE

Orange County, CA · July 16–20, 2014

<http://www.fragilex.org/community/international-fragile-x-conference/>

◆ BASIC SCIENCE

- ◆ BS-1. FMRP & Molecular/Cellular Studies/Animal Models
- ◆ BS-2. FXTAS/FXPOI Research/Animal Models

◆ CLINICAL SCIENCE

- ◆ CS-1. The Continuum of Cognitive and Behavioural Involvement in Women with the Fragile X Premutation
- ◆ CS-2. Adulthood in FXS: Understanding Daily Life, Self-Determination, Guardianship Decisions
- ◆ CS-3. Arousal, Anxiety and Attention in Fragile X across the Lifespan
- ◆ CS-4. Behavior and FXS
- ◆ CS-5. Narrative Language
- ◆ CS-6. Autism and FX Studies
- ◆ CS-7. Fragile X Syndrome
- ◆ CS-8. Mavoglurant
- ◆ CS-9. FXTAS
- ◆ CS-10. Speech & Language
- ◆ CS-11. Premutation Issues #1
- ◆ CS-12. Premutation Issues #2
- ◆ CS-13. Neuroimaging Studies
- ◆ CS-14. Molecular Studies and Screening
- ◆ CS-15. Outcome Measures in FXS
- ◆ CS-16. Neurological and Medical Issues – Premutation
- ◆ CS-17. Service Delivery to Underserved Populations

- 70+ conference slots
- 1000+ attending of which 200+ professionals

Latest News to share?

Round table

Next meetings

Proposed dates :

Monday November 17, 2014

Monday May 4, 2015



Thank you!

Your personal commitment makes the difference and gives hope to families



Association X fragile Belgique

💧 Website:

www.x-fragile.be

💧 Facebook:

<https://www.facebook.com/AssociationXFragileBelgique>

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Werkgroep Fragiël X

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