



Scientific Advisory Board (SAB) – Monday June 3th, 2013

Minutes of Meeting

Attendees (in alphabetical order)

Dr Martine BORGHRAEF, KUL
Dr Nicolas DECONINCK, HUDERF
Dr Anne DE LEENER, ULB Erasme
Mrs Catherine de WOOT de TRIXHE
Pr Frank KOOY, U Antwerpen
Pr Steve MAJERUS, ULg
Dr Marlène MICHEL
Pr Marie-Cécile NASSOGNE, UCL St Luc
Dr Anke VAN DIJCK, U Antwerpen
Pr Hilde VAN ESCH, KUL
Pr Christine Verellen DUMOULIN, IPG

Attendees (for the Association X Fragile Belgique - XFB)

Mrs Isabelle CREVOULIN
Mr Olivier CREVOULIN
Mrs Dominique DAMAS
Mr Paul DAMAS
Mrs Françoise GOOSSENS
Mrs Béatrice MEURANT
Mr François RYCX

Excused

Dr Céline BAURAIN, UCL St Luc
Dr Philippe CUVELIER
Mrs Adélaïde DELHAYE
Dr Guy DEMBOUR, UCL St Luc
Pr Ghislain MAJEROTTE, UMons
Pr Bernard DAN, HUDERF
Mrs Caroline DEOM
Pr Gaétan GARRAUX, ULg
Dr Eric Willaye, SUSa, UMons
Mr Robert BOURMORCK, XFB

Introduction

How to read these minutes

SAB = Scientific Advisory Board of the Association X Fragile Belgique

XFB = Association X Fragile Belgique, section de l'AFrAHM

AFrAHM = Association Francophone d'Aide aux Handicapés Mentaux

EFXN = European Fragile X Network

FRAXA = US-based foundation promoting all research to find a cure for Fragile X

NFXF = National Fragile X Foundation (in the United States)

Points for action owners are **highlighted in red**

Governance

Mr François RYCX and Olivier Crevoulin, delegates for the Scientific Advisory Board, open the session and welcome the participants.

They present the associations, AFRaHM and X Fragile Belgium association (XFB), and his Scientific Advisory Board.

After discussion, it has been decided the SAB will meet twice a year. The next session is planned on Monday November 18th, in Brussels. **Action to all to let us know before Sept 18th if the date doesn't work for you** (info@x-fragile.be)

Action plan XFB.

Dominique Damas, chairman of the Association XFB, presents the action plan for 2013.

- Raise Fragile X awareness with all paediatricians and GP (généraliste/huisarts)
- Propose adapted educational projects
- Professional Press Book and re-energise our external visibility
- Organize information sessions on key themes for Fragile X families
- Provide a clear and practical information on pedagogy and school support
- Promote start of clinical trials in Belgium
- Social activities for families to bond together and with professionals
- Publish an informative quarterly newsletters for families and professionals

More info on www.x-fragile.be.

European Fragile X Network & other associations

Françoise Goossens presents the European Network, a community of all national fragile X associations - <http://www.fragilex.eu/>. The network leads on specific project or European scope and is also a knowledge sharing platform for all national associations. Face to face meeting are taking place at least once per year and follow ups are done via emails and telephone conferences.

SAB objective 1: promote research & clinical trials.

Latest results of the clinical trials

The SAB exchanges information about last evolution of the research.

- AFQ056 - Clinical trials will start in KUL and UCL St Luc for Novartis mGluR5 antagonist with adolescents (12-18y), starting this summer. Strict screening threshold. Requires full methylation of FMRP gene (typically ¼ of full mutation population excl. mosaic)
- STX209 - The recent announcement of Seaside Therapeutics to stop the delivery of Arbaclofen (Gaba-B) to patients who participated to the study was discussed and commented with regards to Seaside financials challenges, disappointing results with autism target groups and the added value vs. Baclofen already available as generic medicine
- Next to the very well documented mGluR5 and Gaba-B theories, we also browsed through the other researches:
 - Minocycline: supported by one medical group, this is an antibiotics, test done in KUL a few years ago with only 2 patients was of course not statistically representative but yielded no visible improvements.
 - Gaba-A: seems very promising, to watch
 - Ganaxolone: phase 2 clinical trial (epilepsy), looking to start trial also in Belgium. This will be decided in the second half of 2013, target group still undefined but likely to be adults and adolescents. **Action for Pr Frank Kooy / Dr Anke Van Dijck to keep us informed if more concrete information is available before next SAB**
 - Stem cells: Dr Claudia Bagni is also doing basic research on Stem Cells. **Action for Hilde Van Esch to share key progress when available**

Research on cognitive skills and behaviours improvement / orthopedagogy

Pr Steve Majerus propose not to limit the discussion to the clinical trials but to extend this to the research about cognitive knowledge and behavioural aspects of the X fragile symptom. **Action to Pr Steve Majerus & François Rycx to re-launch the recruitment of Fragile X persons for his study (started, info received 13/6 from Pr. Majerus).**

We agreed collectively we need to improve our guidance material towards schools and PMS. Using a professional in orthopedagogy will help, both for credibility with schools as well as for their professional approach. The *Service d'Aide Précoce* (SAP) can help but some are fully loaded and do not always have the specialist skills required.

Dr Martine Borghgraef shares her experience of building a Fragile X handbook with pilot schools in Flanders. Next to the resulting document, the process to build the handbook was very beneficial to participating schools and families. A key criteria for success is for the professional to spend time on the field, in schools. Beatrice Meurant has used this document in the past and found it very useful. **Action for Dr Martine Borghgraef to send a copy of the report to XFB (info@x-fragile.be)**

We also shared the experience of NFXF with a 200-page practical guide for teaching to Fragile X kids. It is included in the CD-ROM distributed to participants. File name is "*Lesson-Planning-Guide-for-Students-with-FXS.pdf*". Also attached below:



Lesson-Planning-Guide-for-Students-with-F

Contacts with US FRAXA – possibility for sponsorship

Dominique Damas relates the contact she had with the chairman of the Fragile X association of Quebec. FRAXA is the US-based foundation sponsoring research programmes to find a cure for Fragile X. They would like to get more international exposure and are prepared to fund more European research projects. We now have a strong relationship with the president (Katie Clapp) and medical director (Michael Tranfaglia). There are possibilities for sponsoring of research activities by FRAXA and XFB offered to support the application process through informal contacts.

Action to all to see if specific projects would fit the FRAXA conditions for funding.

XFB objective 2: Inform Belgian families

Conference 2013/2014

XFB is looking for proposals: what can be the main topic of a public conference.

- Targeted audience: families
- Topic: still open
- Language: organizing a national conference has many advantages but more expensive and more difficult to organize. Both options (local or regional conference) still open. XFB (Olivier Crevoulin) already contacted Werkgroep Fragiël (we contacted Mr. Victor De Nies to invite Fragiël to this SAB but they could not send anyone). Pr Hilde Van Esch recommended we also contact Mr. Peter Mulkens. **Action for XFB**

Action for XFB to come back to SAB with practical propositions.

Next NFXF international Conference conference

The next NFXF conference will be held on July 16-20 2014, in Anaheim, CA, USA. Dominique Damas & François Rycx (who attended the previous conference in 2012) encourage the members of the SAB to join them in 2014. 4 families already expressed a strong interest to participate to the conference. More information will be available soon - <http://www.fragilex.org/community/international-fragile-x-conference/>

XFB website

The website of the XFB association (<http://www.x-fragile.be>) has recently been fully refreshed. SAB members collectively agreed to review the website. **Action to all to feedback any website change request** via info@x-fragile.be.

All SAB members also agree to have their name and organization published on our website under the SAB section.

XFB objective 3: Increase Fragile X awareness with Belgian paediatricians.

Fragile X presentation to Belgian paediatricians

The « Groupement des pédiatres belges d'expression française » holds his next conference in October 2013. At this occasion, XFB is looking to present a stand and we are negotiating the opportunity to present Fragile X. **Pr. Nassogne & Dr De Leener** accepted (subject to agenda confirmation) to give the medical keynote on Fragile X. **Action for XFB to confirm dates and organization**

Fragile X screening questionnaire

In order to raise awareness of Fragile X and reduce age of first diagnostic, XFB is looking for a “checklist” to be made available to the professionals (school/doctors,...) and/or families (in this case in a simplified version). There is a questionnaire from Fryns & Borghgraef, dating from 2001. Dr Borghgraef authorizes the use of 2001 questionnaire on our website (with the usual references) and confirms that there is no updated version. She insists that this has to be done with caution and the necessary disclaimer.

Postcard to send to all Belgian pedestrians

Building on the NFXF success story, XFB will send a postcard to all French speaking Belgian paediatricians to raise Fragile X awareness within that community. A first review of the text is done during the SAB meeting (see attached document with the corrections/improvements already done on June 3rd). **Action to all to review this document once more and confirm their OK to XFB** via info@x-fragile.be.



Postcard X Fragile
v2.docx

Once the lay-out is final, the postcard draft will be sent to SAB for a last control/vetting. We will also share the final version with Fragiél for a potential campaign with Dutch speaking paediatricians.

XFB objective 4: Share a clear position on associated disorders.

Due to time limitations, this topic will be discussed during the next meeting.

Next meeting.

Proposed date: November 18, 2013. To be confirmed as soon as possible.