



## Scientific Advisory Board (SAB) – Monday November 24<sup>th</sup>, 2014

### Minutes of Meeting

<b>Attendees (in alphabetical order)</b>	<b>Excused</b>
Dr Guy DEMBOUR, UCL St Luc	Mme Djida AMRANE
Pr Frank KOOY, U Antwerpen	Dr Céline BAURAIN, UCL St Luc
Pr Steve MAJERUS, ULg	Dr Martine BORGHRAEF, KUL
Pr Marie-Cécile NASSOGNE, UCL St Luc	Dr Philippe CUVELIER
Dr Anke VAN DIJCK, U Antwerpen	Pr Bernard DAN, HUDERF
Pr Christine VERELLEN-DUMOULIN, IPG	Dr Nicolas DECONINCK, HUDERF
	Dr Anne DE LEENER, ULB Erasme
Mr Peter MULKENS, Werkgroep Fragiel X	Mrs Adélaïde DELHAYE
	Mrs Caroline DEOM, ASELF
Mr Olivier CREVOULIN	Mrs Catherine de WOOT de TRIXHE
Mrs Dominique DAMAS	Pr Gaétan GARRAUX, ULg
Mr Paul DAMAS	Pr Ghislain MAJEROTTE, UMons
Mrs Françoise GOOSSENS	Dr Marlène MICHEL
Mr François RYCX	Pr Raphaël OLSZEWSKI, ULg
	Pr Hilde VAN ESCH, KUL
	Dr Eric WILLAYE, SUSa, UMons
	Mrs Béatrice MEURANT, XFB
	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

### *Governance*

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

After a round of table, they pass to the agenda.

## Debriefing of the Fragile X conference (Brussels, X-X-2014)

Key messages from the professionals:

- Good balance between detail and ease to understand for all audiences.
- Exhaustive- many topics covered, multidisciplinary and quality speakers
- It is still preferable to have one main target audience: families OR professionals. Conference on Saturdays is usually more convenient to attract more doctors. An alternative is to have a speaking slot on Fragile X at an existing medical conference such as the GBPF or BKPN.
- For next conference, suggestion to submit an application for ethics accreditation

## Feedback on 18 000 postcards sent to all doctors & paediatricians

- Postcards in Dutch & French have been distributed to SAB participants to share with their colleagues and patients.
- Special target for young graduates from medical schools
- Recommendation to prepare posters to show
  - Hospital waiting rooms
  - Kind & Gezin
  - Consultations ONE

## Takeaways from 14<sup>th</sup> International Fragile X conference (Anaheim, July 2014)

Discussions on latest clinical trials and sharing the presentation "Medical Problems in Fragile X Syndrome. The presentation is available on our website, for SAB members only (need to login first):

<http://www.x-fragile.be/wp-content/uploads/Medical-problems-in-Fragile-X.pdf>

## Consensus documents of the Fragile X Clinical & Research Consortium (FXCRC)

Detailed review of the consensus documents. They represent the consensus obtained by the Fragile X clinics member of the FXCRC on 17 different topics.

See: <http://www.x-fragile.be/consensus-documents-from-the-us-fragile-x-clinical-research-consortium/>

## **Clinical Trials update**

Pr. Frank Kooy and Dr. Anke Van Dijk share the latest details on Ganaxolone trial starting in U Antwerpen. They are recruiting 10 participants (6-17 years old) till end February. Both Werkgrop Fragiel X and XFB will relay this proposition to their members and contacts.

## **Other**

Pr. Majerus shares that the results of his study on Fragile X show more encouraging results than anticipated and is proceeding to a second wave of recruitment. This will also be relayed by our associations to our members and contacts.

The XFB quarterly paper "L'X presse" will also be send per mail to the member of the SAB.

## **Next meetings – save the dates!**

Proposed dates are:

- Monday May 4, 2015
- Monday November 30, 2015

François RYCX