



Scientific Advisory Board (SAB) – Monday November 18th, 2013

Minutes of Meeting

Attendees (in alphabetical order)

Mme Djida AMRANE
Dr Nicolas DECONINCK, HUDERF
Mrs Caroline DEOM, ASELF
Pr Gaétan GARRAUX, ULg
Pr Frank KOOY, U Antwerpen
Pr Steve MAJERUS, ULg
Mme Françoise MOMBEEK, Plateforme Annonce Handicap
Pr Christine VERELLEN-DUMOULIN, IPG

Mrs Isabelle CREVOULIN
Mr Olivier CREVOULIN
Mrs Dominique DAMAS
Mr Paul DAMAS
Mrs Françoise GOOSSENS
Mr François RYCX
Mrs Nora VAN BEVEREN

Excused

Dr Martine BORGHRAEF, KUL
Dr Anne DE LEENER, ULB Erasme
Mrs Catherine de WOOT de TRIXHE
Dr Marlène MICHEL
Pr Marie-Cécile NASSOGNE, UCL St Luc
Dr Anke VAN DIJCK, U Antwerpen
Pr Hilde VAN ESCH, KUL
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
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

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

Governance

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

The next session is planned on Monday May 5th, in Brussels (Uccle/Ukkel with easy parking).

Awareness Campaign

Postcard for paediatricians & GP

The latest postcard is shared with the SAB and minor edits are agreed. Novartis has agreed to finance it in full (printing and sending costs)

It was also recommended to see how we can leverage the *ONE / Kind & Gezin*. **Action for XFB to make contact with ONE/K&G to assess how to best collaborate.**

Other awareness activities

We discussed the interest of doing a similar awareness postcard campaign for non-doctors, more focused on the right intervention strategies. **Action for XFB to propose a draft during next SAB.**

We also discussed how we can best encourage parents with a diagnostic for their child to inform their families as soon as possible, given the hereditary nature of Fragile X. The French legislation was recently changed to make it mandatory for the doctors to inform the wider family (subject to a protocol respecting the anonymity of the patient). **Action for Pr. Christine Verellen-Dumoulin to assess what can be done in Belgium**

Plateforme Annonce Handicap (PAH)

Mme Mombeek presented the PAH and distributed the key folders (for professionals, for parents). A folder targeted at brothers & sisters is in preparation. Most of the participating SAB members confirmed that they are working in close partnership with the PAH and actively using their folders.

All information can be found on: <http://plateformeannoncehandicap.be/>

Premutation – improving diagnostic and support in Belgium

Awareness in Belgium

FXTAS – still limited awareness in Belgium. Pr. Garraux presented the key features of FXTAS to his team in Liege. Ongoing research helps continuously refine the clinical spectrum of FXTAS.

FXPOI – professionals raised the idea of having a postcard targeting gynaecologists - **Action for XFB to propose a draft during next SAB.**

Child & Teenagers (<18 years old)

The SAB agreed that premutation is already having an impact on child and teenagers. It is not only about 50+. But the situation varies from person to person and a DNA test will only be done if there are visible symptoms, not systematically. If the DNA test is done, the SAB agreed that it is very important to communicate the full results to the relevant persons (impacted person and their parents if <18). The discussion stressed the importance to request genetic counselling early in the process.

Supporting schools & non-medical professionals

Speech therapy: good material already available from G. Bussy - **Action for Mme. Caroline Deom to share material from G. Bussy referenced during SAB (I could not find it online).**

Psychological support: we discussed the proposal to organize a “prémuation day” similar to what the French association did late 2013. We will try to integrate this into the planning for our 2014 conference. SAB validated that occupational therapy (psychomotricité relationnelle) is very important for Fragile X child, up to 12-14 years old. **Action for Mrs. Didja Amrane and Catherine de Woot to introduce the XFB team to the “Fédération belge des psychomotriciens”.**

Round table (various)

- Need for more information on pre-mutation for both families and professionals
- Get better diagnostic and forecast based on number of CGG repetition and medical imagery
- Ganaxolone clinical trial due to start soon in Belgium; targeting young teenagers – **Action for Pr Frank Kooy / Dr Anke Van Dijck to keep us informed if more concrete information is available before next SAB. XFB offered support with its address list**
- **Action for Pr. Frank Kooy to share list of existing medicines already on the market that could prove useful for Fragile X patients**
- New diagnostic techniques being developed for pre-birth diagnostic with a simply blood sample from the mother. **Action for Pr. Christine Verellen-Dumoulin to share more details at next SAB**

Next meeting.

Proposed date: Monday May 5th, in Brussels (Uccle/Ukkel with easy parking)