



Scientific Advisory Board (SAB) – Monday May 5th, 2014

Minutes of Meeting

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

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

Conference for professionals and families in Brussels X-X-2014

This date has been chosen because X-X is the European Day of Fragile X.

François RYCX presents the draft agenda. The conference will address two topics:

- in the morning: the fragile X premutation and the associated disorders (FXPOI, FXTAS);
- in the afternoon: the multidisciplinary intervention strategies towards fragile X people.

He asked if there are suggestions or remarks from the SAB.

So there are some suggestions:

- Pr GARAUX can be a backup for presentation of FXTAS if Mr JACQUEMONT cannot be available.
- Pr Steve MAJERUS could present the results of the studies on the cognitive impact of premutation.
- Pr VAN ESCH could present the result of studies of premutation with adults in Belgium.
- Pr MAJERUS suggests also the presentation of the results of the currently running research

The question is: do we want to have a simultaneous translation French-Dutch of the presentations, to extend the conference to Dutch speaking people? Peter Mulkens will investigate this question and will give feedback.

Françoise GOOSSENS suggests also the usage of posters to display the summary of some researchs.

XFB committee will work all these suggestions and come back with a definitive program.

Awareness Campaign

Postcard for paediatricians & GP

The postcard has been sent to the printer and will be soon distributed.

How to make some more publicity about this initiative?

Suggestions made are:

- To contact some paper for professionals : Journal des Médecins, La Lucarne, Domus Medica, Neurone, Percentile, Journal Belge des Pédiatres, ...
- Pr NASSOGNE propose to receive the list of the doctors without known address to check this last one.
- Dr Anke VAN DIJCK asks if the psychiatrists also have been addressed. The answer is negative.

Other awareness activities

Isabelle Crevoulin gives report of the presence of XFB at the conference of the Belgian French speaking paedestrians (GBPF):

- there was a lot of interest from the participants;
- contact has been taken with Dr. A. Mascart;
- there is now a possibility for a presentation of fragile X during the next conference;
- contact has been taken with company La Roche Posay about the problem of the skin fragility.

State of the clinical trials

- The clinical trials of AFQ056 molecule by Novartis have been recently stopped. They were limited to full methylated people. The trials had few results with adult people, so Novartis decided to stop the trials. In Belgium, there were two kids involved (1 at UCL, 1 at KUL).
- Dr Anke VAN DIJCK says UZA will soon start trials in full cooperation with USA. May be these trials can be extended to Wallonia. She will come back with a proposal.
- There are no news from ROCHE.
- Dr Anke Van DIJCK summarizes a lot of other currently running trials including Ganaxolone

Update about the state of relations between XF associations

Dominique DAMAS underlines the presence of Peter MULKENS. This is the start of more cooperation between both Belgian associations. She also presents a scheme of the relationship between European associations. To be highlighted: association X fragile Europe has no relationship with other European associations...

Peter MULKENS shortly presents the Belgian Dutch-speaking fragile X association : the “Werkgroep Fragiel X”.

14th International Fragile X Conference – July 16-20, 2014

This conference organised by the US NFXF association will be held in Orange County, California. The occasion to meet 250 professionals from all the world and more than 1000 participants!

XFB will be present and will give a feedback in the last months of this year.

Other

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 November 24, 2014
- Monday May 4, 2015

Don't forget our X-X conference!

Olivier CREVOULIN

François RYCX