ISSUE 1 JANUARY 2021

FA Europe

The latest news, views and announcements

In This Issue

Progress in setting up the FA Europe organisation

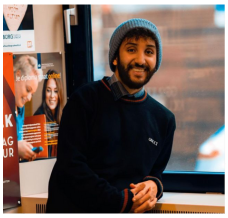
News about: Funding and Patient Support Group Development

European News

And more...

FA Europe Newsletter # 1 January 2021

Welcome to a New Year and to the new organisation, FA Europe! Firstly we are pleased to announce that we have two new helpers to assist with the setting up and running of FA Europe. Samir Aiddouch and Greta Bertolucci. Samir is now working as a part-time project manager, and Greta has joined us as a volunteer. You can expect to hear from both of them in future!



Samir

"It is my great privilege to be a part of this organisation! I have a bachelor's in Communication and Multimedia Design and a master's Crossover Creativity. Lily, my partner's sister, was diagnosed with FA before I met her. Ever since then I've been more aware of the disease. I edited the video for the kickoff meeting and now I'm ready to help the organisation. "

Greta

"Greta Bertolucci is 25 years old, she is Italian and a FA patient sibling. Her sister Virginia was diagnosed with FA when she was 8 y.o. and received the bone marrow transplant from Greta in 2008.
Graduated in International relations and European Studies, Greta also speaks English, Spanish and French and is very committed to having a positive impact within the European FA Community."

FA Europe

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Progress in setting up the FA Europe organisation

Although FA Europe may have appeared to have had a low profile since the Start up meeting in September, work has been going on in the background to prepare for the formal setting up of the organisation in the Netherlands as a Foundation.

The first draft of the Deed of Incorporation for the organisation has been produced by Mark de Groot, with legal support and is now being finalised. The Deed of Incorporation details the 'Articles of Association' which describe the basic structure of the organisation and defines the existence of an Executive Committee, and Advisory Board and a Scientific Board. Separately, and in consultation with current European Patient Support Group (PSG) representatives we will develop the bye-laws for the organisation, which will describe more fully the ways of working that we can all agree to. We have been working hard to set up the organisation in such a way that everyone has a say in decision making, and that membership is flexible, avoiding the need to amend and resubmit the Deed of Incorporation every time someone joins or leaves the Board. A separate email on this topic will be sent out to all PSG representatives in the week commencing 11th Jan, describing the proposals in more detail.

Several other actions arising from the Start-up Meeting are also being followed up. A letter is in preparation for medical specialists about the importance of the HPV vaccination for FA patients and ways to reduce the risks of getting cancer. In addition, a planning session for the proposed meeting of ENT specialists (funded through an additional grant) has recently been held.

Funding news

The Dutch Fanconi Anemia working group. (the Dutch Association Parents, Children and Cancer) has kindly provided a grant.

A donation of £2,500 from a company called GTEC has just been received by Fanconi Hope in the UK specifically to help them further the aims of FA Europe.

We are grateful to ZonMW, the Dutch National Health Care Institute, for providing a grant to cover the costs of a meeting of ENT specialists to be held in the Spring of 2021.

FA Europe Social Media

Samir will be increasing the visibility of FA Europe on social media through the use of the website, LinkedIn, Twitter and Instagram sites that have been set up in readiness.
You can now subscribe to newsletters such as this on our website www.faeurope.org.

Patient Support Group Development News

We have the good news from Erik Kjos-Hansen in Norway that they have now established a Norwegian FA support group on Facebook (Fanconi Anemia Norge). Currently they have 8 members representing 5 people with FA. They have agreed with the Rikshospital in Oslo that they will inform new/existing FA patients of the existence of the FA support group.

European News

EURORDIS Recommendations to achieve a mature ERN system in 2030
This paper, and the accompanying Policy Brief, reviews progress achieved so far and presents EURORDIS vision of a mature European Reference Network system that leaves no person living with a rare disease in uncertainty regarding their diagnosis, care and treatment. Read more

Rare 2030 Final Policy Conference and the EURORDIS Black Pearl Awards 2021: 23 February 2021 (13:30 – 18:30 CET).

The event marks the occasion to present the Rare 2030 policy recommendations for a new policy framework. Register for free here

Eurobloodnet European Reference Network.
Subscribe to the Eurobloodnet ERN Newsletter here

The European Joint Programme on Rare Diseases (EJP RD)

The EJP RD has launched an Internal Call for Innovation Project in Clinical Trials Methodology in Limited Populations. Read more

Within the Joint Translational Calls (JTC) of the European Joint Programme on Rare Diseases (EJPRD, patient organisations are eligible and indeed strongly encouraged, to apply as fundable partners of a consortium submitting a research proposal.

A Short Guide on Patient Partnerships in Rare Disease Research Projects, published last Autumn, is of potential interest to both patient advocates and researchers.
Read the Guide.

The EJP RD Short guide on patient partnerships in rare diseases research projects aims to encourage fruitful, sustainable and enduring partnerships between scientists and patient organisations, co-leading the way for systematic patient-centered research.

And finally....

Given the current COVID-19 situation it seems likely that all FA Europe meetings will need to be held online at least until the Autumn. However, one day we look forwards to getting together in person as a group to make new friendships and to have the face-to-face discussions that will spark ideas to further the aims and ambitions of FA Europe.

With best wishes for 2021, from the FA Europe Team.