

To the Presidents of the FEAM Academies To the FEAM National Delegates

Brussels, December 2012

Dear Professor Irinel Popescu, Dear Colleagues,

I write to inform you of recent activities and challenges at FEAM, first concerning its financial and internal situation and secondly concerning our science policy portfolio. This correspondence follows a recent FEAM Officers and strategy meeting, which confirmed the extremely positive work of our Federation during those last few years and the pressing need to invest further into it to firmly establish it on the European scene. In both cases, your urgent feedback and concrete support, especially where policy actions are required at the national level, are extremely important.

## I. Internal and financial situation:

Since I was elected President of FEAM during the Spring Conference of Madrid, in May this year, the most important task has been trying to solve a difficult short-term financial situation, which might force us to take pain inducing measures, and to envisage mid-term financial solutions to firmly establish the FEAM secretariat and develop the activities of our Federation. The actual budget of FEAM is made up of the early contributions of the 14 member academies, with a maximal contribution of 6000€ each. The total amount for 2012 is approximately 40,000€, which is below that of 2011 and of 2010. From this budget is paid the salary of our part-time executive director in Brussels, the travel costs of the Officers and the FEAM contribution to the yearly Spring Conference. However, due to the delays in the 2012 contribution of some countries and the increase in policy activities during those last years, the situation is now extremely critical. Presently, the salary of the executive director is paid thanks to the private contribution of one of the Officers, who made an extremely generous loan to FEAM. In addition, my expenses as FEAM President are covered by the Spanish Academy and those of the Italian and the British Officers by their respective academies. However, additional short-term solutions for 2013 are now needed.

Recently, I have been in contact with some member academies in order to find possible solutions and 3 of them (Austria, Germany and the UK) are committed to give additional contributions, direct and indirect, to support FEAM in 2013 (see below for details) on the following conditions : (1) modifying the statutes to give FEAM an up-to-date governance and, if needs be, to allow for a transfer of the FEAM secretariat to a host academy outside of Belgium, with dedicated resources including staff members, while maintaining and developing our office in Brussels, (2) the concrete support and commitment of other academies in developing FEAM, and (3) the preparation of a business plan for the next years. As a result, we are in the process

of developing a concrete business plan for the years ahead, which will be sent to you as soon as possible for comment and which will include (1) some proposals for future science policy activities with a high-fundraising potential and (2) the submission of an operating grant proposal to be submitted in the context of the EU health programme during the first quarter of 2013. Your feedback, preferably by 14 January 2013, on the propositions from our Austrian, German and UK academies is important.

At this stage, I would also like to invite you:

(1) **to confirm your exact financial support in 2013 (and 2014** as this will set the level of cofinancing to be demanded from the EC in the context of applying for an operating grant – 40% to be financed by FEAM and 60% by the EU) and whether this annual fee could be paid in January (the 2013 invoice is enclosed),

(2) to envisage an additional donation like the conditional offers made by Austria, Germany (10 000 euros each) and the UK (via the Wellcome Trust, which is prepared to co-finance a policy officer at FEAM),

(3) **to cover the expenses of one or more national delegates** to attend the next FEAM Spring Conference to be hosted by the Irish Academy of Medical Sciences in Dublin on 27 and 28 May 2013.

There is an urgent need to discuss modifications to the statutes and we aim to set up a small committee to this effect soon. Modifications recommended include the introduction of 3 or more Vice-Presidents (one for each important scientific and policy matter), combined with the possible disappearance of the General Secretary position as well as the introduction of a steering committee, to provide information for the items to be promoted and elaborated at FEAM. Of course, in this case, the nomination and election of the President should not be the actual near automatic promotion of the single Vice-President. Although a dedicated committee will be in charge of elaborating proposed modifications within the next 2 to 3 months, your early feedback in principle is important.

All these changes will need to be introduced formally after being discussed at the 2013 Dublin Spring Conference and, considering the difficult financial situation, we hope that your academy will ensure the presence of at least one of its national delegates.

## II. Scientific and science policy activities:

In spite of those challenges, FEAM has remained active in several dossiers (all information at <u>www.feam.eu.com</u>, all discussed at our bi-annual meetings with the DG Sanco) and some now require the important assistance of national Academies to ensure the adequate dissemination at the national level. They include:

- 1. Data Protection Regulation:
  - Under the leadership of Prof. Robert Souhami and with the support of his Academy and of Dr. Beth Thompson (Science Policy Adviser at the Wellcome Trust), in collaboration with colleagues and lawyers at the Trust, FEAM has prepared proposed amendments and a summary of its statement, now endorsed by several other European stakeholders. We are still seeking the endorsement of additional networks.

<u>http://www.feam-</u> <u>site.eu/cms/docs/publications/DPR/FEAMSummaryDPR\_ProposedAmendments</u> <u>November2012.pdf</u>

• Following a technical meeting with DG Sanco and DG Justice on 6 September 2012, the summary and the proposed amendments are now in the process of being sent to key MEPs and European Parliamentary Committees involved in this dossier according to the EP timetable.

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- We would be very grateful if you could bring these documents to the attention of your members and of your national decision makers, including your Ministry of Justice and your national representatives in Brussels. You will find enclosed a template cover letter, the statement and the summary together with the proposed amendments to this effect.
- FEAM has also joined the Healthcare Coalition on Data Protection, which brings together key stakeholders in Europe, in order to strengthen its action. Further information on a possible workshop in the European Parliament in January 2013 will follow in due course.
- 2. <u>Clinical Trials Regulation</u>
  - In early September 2012, Prof. Hubert E. Blum, Chair of the FEAM CTD working group, and Dr. Beth Thompson represented our Federation at a technical meeting organised on 5 September 2012 by the DG Sanco to discuss their proposed regulation proposal.
  - Today, we would like to invite our Academies to endorse the enclosed statement *Proposal for a Regulation on Clinical Trials, a joint statement from non-commercial and commercial organisations* as an important next step in pursuing our effort and we look forward to hearing from you at your earliest possible convenience but not later than 14 January 2013 if possible. Your support again is important. If FEAM endorses this statement, we will be in touch later to seek your help in ensuring the best possible dissemination at the national level.
- 3. Direct-to-Consumer Genetic Testing

Under the leadership of Prof. Volker ter Meulen, in collaboration with Dr. Robin Fears, the EASAC/FEAM project has continued its work by:

 preparing a summary of its report, which now needs to be circulated among Academy members and disseminated as widely as possible at the national level:

http://www.feam-

site.eu/cms/docs/publications/DPR/FEAMSummaryDPR\_ProposedAmendments November2012.pdf

- publishing a related article in the European Journal of Human Genetics: <u>http://www.nature.com/ejhg/journal/vaop/ncurrent/full/ejhg2012238a.html</u>,
- organising a successful launch of its report, in collaboration with STOA, on 3 December 2012 in the European Parliament. A summary of this meeting will follow.
- 4. One Health
  - FEAM contributed to a Special Issue on One Health in the Italian Journal of Public Health (Volume 9, Number 2, June 2012), following a session at the 2011 FEAM Rome Spring Conference: <u>http://ijphjournal.it/issue/view/407</u>. I would kindly ask you to inform your membership and colleagues.
  - An IAMP/FEAM workshop on *Integrated education in One Health (public health, animal health and environmental health)* with key stakeholders in the field will be hosted by the Hungarian Academy of Sciences on 5 June 2013. You will find further information in the enclosed draft proposal.
- <u>Conference on ageing (2012 Madrid FEAM Spring Conference)</u> A summary was prepared, with the support of Dr. Robin Fears and speakers: <u>http://www.feam-site.eu/cms/docs/publications/HealthyAgeingSessionMadrid2012.pdf</u>.
  would kindly ask to inform your membership and colleagues.

In addition, I would welcome your suggestions for possible speakers at the Dublin Spring conference on 27 and 28 May 2013, which will focus on *personalised medicine* and *the future* 

*of clinical research.* I will discuss those suggestions with the FEAM Office and Professor Noel G. McElvaney, Honorary President of the Irish Academy of Medical Sciences.

I thank you very much in advance for your ongoing support and I look forward to receiving your feedback at your earliest possible convenience.

With kind regards, Professor Jesus A. F. Tresguerres FEAM President