

## **ELECTIONS:**

The first item of the afternoon session was election of posts.

- Chair: Nelly Pitteloud (Switzerland) proposed and unanimously approved
- Host Institution: University of Lausanne, Switzerland
- Vice Chair: Nelly Pitteloud proposed Pierre Bouloux (UK) whose nomination was unopposed and Prof. Bouloux was approved as Vice-Chair
- Finance Oversight: Gerry Sykiotis (Greece) & Beatriz Lecumberri Santamaría (Spain) volunteered and were approved
- Short Term Scientific Missions (STSM): Nelly Pitteloud nominated Andrew Dwyer (Switzerland) who was approved to oversee the STSM

The Chair presented slides giving an overview of the Cost Action, the structure of the network, and reviewed the aims and objectives of the Working Groups (WGs). This led to elections for the leaders of the WGs. The Chair nominated the following individuals which were unanimously approved:

- WG1 (Clinical Group) : Leo Dunkel (UK) - pediatric endocrinology, Jacques Young (France) - adult endocrinology, and JP Bourguignon (Belgium) - epidemiology and endocrine disruptors
- WG2 (Genetics Group): Catherine Dodé (France) and Nicolas de Roux (France) - genetics, and Ioannis Xenarios (Switzerland) - bioinformatics
- WG3 (Basic Science Group): Manuel Tena Sempere (Spain) and Ulrich Boehm (Germany)
- WG4 (Education & Training): Vincent Prevot (France) – basic scientist, and Mohamad Maghnie (Italy) – clinical investigator

This led to a robust discussion about the structure and function of the Scientific Steering Committee. It was decided that the Core Group will include the Chair, Vice-Chair, and WG leaders. The Scientific Steering Committee would be a larger group of 10 individuals who would provide perspective on developments in the field and would provide input on the direction of the Action. Ulrich Boehm (Germany) suggested that the composition of the Scientific Steering Committee could rotate based on the priorities to maximize the external input to the Action. This idea was met with agreement by the Management Committee.

The following 10 individuals were nominated and approved for the Scientific Steering Committee:

- Philippe Bouchard (France), William Colledge (UK), Paolo Giacobini (France), JP Hardelin (France), Alan Herbison (New Zealand), Ilpo Huhtaniemi (UK), Robert Millar (UK), Luca Persani (Italy), Taneli Raivio (Finland), and Gerasimos Sykiotis (Greece)

## **WEB-SITE & DATABASE:**

The Chair provided overview of the proposed web site which includes both public and private areas. This led to discussion regarding the key phenotypic features to be entered for patients into the database. The Chair stated that a draft “Minimal Data Set” had been prepared and that this would be distributed to the WG1 leaders for comment and editing prior to circulation to the broader community of clinicians and investigators. Also, a listing or “library” of investigative tools was discussed and that is will be an important element to assist investigators and foster collaboration.

The Chair introduced the database which is proposed for the COST Action (Slims) and Frederik Decouttere (Switzerland) presented a brief overview of the Slims system. Several points were raised:

- Beatriz Lecumberri Santamaría (Spain) inquired about the informed consent of samples. Andrew Dwyer (Switzerland) underscored that all samples entered into the database would be consented. This could be done by a local investigator or in collaboration with another investigator with an existing genetics protocol with approval by an ethics committee.
- Luca Persani inquired about the patient information (minimal data set). The Chair commented that a draft has been prepared and that this would be an important role of WG1 to finalize this as it is a major step towards harmonizing existing data sets.
- Nicolas de Roux inquired about the growing data on genotype and how it will be handled. The Chair commented that this will be a challenge and is of growing concern and that WG2 will need to make this a priority.
- Leo Dunkel (UK) inquired about data definition and data cleaning for the database. Andrew Dwyer (Switzerland) explained that defining ontologies in relation to the minimal data set will be a key task for WG1 and that Virginia Hughes (Switzerland) is the data manager working with Slims developers to ensure appropriate data cleaning checks/measures.
- Nicolas de Roux commented on the benefit of including mouse phenotypes and possibility to compare phenotypes across animal models. Frederik Decouttere (Switzerland) stated that this capability is within the functionality of Slims. Further, that is will be critical for WG3 to define the animal model “minimal data sets” enabling comparisons.

## **TIMTABLE & BUDGET:**

The Chair reviewed the timetable for the Action objectives and deliverables. The first year will include launching the Action web site (basic patient-based information, listing of referral centers and specialized providers, and investigator profiles). The WGs will need to focus on the initial decisions (i.e. minimal data sets) for constructing the database.

The Chair reviewed the budget for year 1. Several questions were posed to Dr. Magdalena Radwanska who provided input and suggested that perhaps the first year was operationally heavy and that 5 STSMs would be a success for the first year. She noted that one way to save on meetings was to utilize COST facilities which are available free of charge. Other comment:

- Jacques Young (France) requested a line item be added for publications.
- Ulrich Boehm (Germany) inquired about limitations (number and distance) to the STSNs. Dr. Radwanska said that generally there were not, but that the Vadecum part B (available on the COST web site) explains the process in detail.
- The budget for the Annual Meeting was changed to 48,000 €
- The Chair inquired about the budget for the customized database and Dr. Radwandksa noted that the COST financial controller may ask for a second opinion/offer

**NEXT MEETING:**

Discussion at the Kickoff Meeting indicated that it would not be worthwhile to hold a Action meeting at the ICE/ESE conference in Florence (May) or the Annual Meeting of the Endocrine Society in Houston (June) due to insufficient number so participants. The Chair is looking to plan a meeting in late August- Early September (location to be announced).