

Board Meetings and Telephone Conferences

The Board of Europa Uomo met face to face on 16/17 September in Brussels on the occasion of the EPAD (European Prostate Awareness Day) and on 13/14 November at the EMUC (European Urological Multidisciplinary Congress) in Barcelona. In addition, the Board had sought to improve its own internal communications by holding telephone conferences in September and October.

EPAD

The big happening for Europa Uomo in the past quarter was the holding of an event in the European Parliament to mark European Prostate Awareness Day (EPAD). A fuller report was carried in the newsletter *Did You Know?* which is published in September.

Prof. Louis Denis

The tireless and indefatigable Louis Denis stepped down as Strategic Consultant to Europa Uomo in September after EPAD. Louis has been a major force in the development of Europa Uomo, he was a founder member back in 2003 and served for many years as Secretary to the organisation until 2012. He later came to the assistance of EUomo when he took up the role of Strategic Consultant in 2014. The Board will be arranging a dinner in 2016 to mark his service to the organisation.

Liaison Officers

After informal discussions with most of the Liaison Officers in Brussels in September, the role of the Liaison Officers Club has been enhanced with adoption at the November Board meeting of a memorandum on the functions, terms, appointment and reporting arrangements for Liaison Officers. The terms of the memorandum on Liaison Officers will be circulated to member organisations, at the next General Assembly, in the form of draft additional bye-laws for their consideration and approval.

Essentially Liaison Officers will act as Europa Uomo representatives at conferences and on external committees. The following are the initial group of Liaison Officers:

Board members: Ken Mastris, Ekke Büchler, André Deschamps, Christian Arnold, Malcolm Duncan, Max Lippuner, John Dowling and Günter Feick (*ex-officio*).

Other LOC members: Louis Denis, Brigitte Dourcy-Belle-Rose, Erik Briers, Paul Anders, Roger Wotton, Will Jansen, Joaquim Domingos and Maria Luisa Dinis Domingos.

Board Member Activities mid-September to mid-November

In the UK our Chairman, **Ken Mastris**, is kept busy as Secretary of TACKLE. He has also been representing Europa Uomo at the Cancer Control Conference in Luxembourg, and he was a speaker at the EPAD event and also at EMUC in Barcelona. Ken also had a round of meetings with pharma companies, including a meeting with Astellas Pharma on advanced prostate cancer. Ken also represented EUomo at the ESMO-ECCO conference in Vienna. Ken Mastris also presented at the ECCO patient advocacy committee on *Pain, Pride and Prejudice* and presented at the "Men who speak up" campaign supported by Bayer. Ken also attended the 3i Pathways 3rd Stand Alone meeting in Berlin in

late November. In early December he also met H. Larkin from AIPES (Association of Imaging Producers & Equipment Suppliers).

André Deschamps was busy dealing with reporters locally in Belgium at the time of the EPAD conference for an article on prostate cancer, he also attended a conference on behalf of EUomo dealing with an aspect of the fast developing field of genomics – EGAN and ROCHE had a conference in Basel on Gene Sequencing. He also drafted the Memorandum on Liaison Officers which was adopted at the Board meeting in November. André was also a member of the delegation (with **Prof. Louis Denis, Brigitte-Dourcy-Belle-Rose and Anja Vancauwenbergh**) which was invited by our Dutch member, PKS, to discuss arrangements for the General Assembly in the Netherlands in 2016. Since the meeting, a very ambitious programme for a GA in Rotterdam has been proposed by PKS and the Board meeting in November approved the plan in principle.

In Germany our member organisation BPS led by **Günter Feick** has published an updated prostate cancer patient guidelines online.¹ In addition, BPS and German Cancer Society (DKG) submitted expression of interest to MOVEMBER for participating with 25 certified Prostate Cancer Centres from Germany in the MOVEMBER worldwide research study on health outcomes measurement “COMPARE AND REDUCE VARIATION“. The BPS development association “Förderverein Hilfe bei Prostatakrebs” prepared and participated in the 2015 MOVEMBER campaign. BPS also joined the initiative “Transparent Civil Society“. BPS together with German Association for Urology issued press release on clinical trial “PREFERE”ⁱ. Günter Feick leads BPS celebration of its 15th anniversary. Günter Feick also led the BPS participation in annual congress of the German Association of Urology with over 6,000 physicians and scientists. BPS representatives served as chairs, and represented patients’ and BPS interests in congress work groups.

John Dowling represented his organisation (Men Against Cancer) at a patient seminar re 15 year biomarker study on radiotherapy treated prostate cancer patients . A few days later he delivered a short paper to Biomedical Scientists at the ROCHE Diagnostics Ireland area meeting. In mid-September John attended EPAD in Brussels and then his first Board meeting as Secretary. In October he worked with colleagues on finalising papers for the Board on possible changes to the Statutes in 2016; also on a strategy discussion paper for 2016-18 and a business plan for 2016. He also prepared the second issue of the Board’s internal document *Board Bulletin*. John also attended the second Health Research Authority Taskforce meeting on draft guidelines for the Layperson’s summary for all medical trial reports at the end of September and at the end of November he attended the EMA’s PCWP meeting in London.

Ekke Büchler was involved in September in the first lecture of his organisation’s autumn/winter lecture series and in ordering a new Home page for his organisation’s website as well as launching a survey of 1000 men – half were asked about their car and the other 500 were asked about their prostates. The results were recently presented at a press conference on awareness of prostate cancer. Ekke had also proposed to the Europa Uomo Board that his home organisation would host a seminar for Austria, Slovakia, Czech Republic and Hungary – possibly in 2017 and he has been working with Max Lippuner, on scoping out the organisation of the event. Ekke, together with Ken Mastris and Christian Arnold represented EUomo at the Bayer Press Conference in Vienna. Ekke also supported the information point at the ECCO/ESMO Congress in Vienna with Esther Kumhofer.

¹ BPS Patient Guidelines <http://www.prostatakrebs-bps.de/medizinisches/grundlegende-informationen/596-patientenleitlinien-2015-stehen-nun-als-broschuere-und-zum-download-kostenfrei-bereit>

Christian Arnold and **Louis Denis** finalised a Sanofi grant of €15K and the contract for this was signed in November as also the contract with Astellas. This concluded a very successful round of fund-raising. A reassuring feature of the arrangements is that most of the funding is over a three-year period which gives Europa Uomo secure finances into 2018. Christian Arnold also attended the Prostate Cancer Research Institute Conference in Los Angeles on behalf of French prostate patient organisation Anamacap and the ECCO/ESMO Congress in Vienna in September. Christian has also written to all partners/sponsors letters to all our partners/contributors with a list of Europa Uomo main actions in 2015 and preparing these partners for renewed contribution in 2016 in conformity with multi-annual agreements. As a result of this he had to deal with a number of requests for further information.

Max Lippuner prepared an introductory letter and explanatory material for new groups to be formed or brought into membership of Europa Uomo. Material is being prepared with Ekke Buechler for the Czech Republic, Slovakia and Hungary in a preparation for the proposed EUomo MasterClass in 2017. Proofing work on draft changes to statutes and on liaison officers memorandum.

Malcolm Duncan works tirelessly on the newsletter and has produced a special edition of the newsletter *Did You Know?* for EPAD as well as the usual quarterly issues in September and December.

Secretariat: The Secretariat in the person of Anja Vancauwenbergh deals with many issues and much correspondence. It also does all the arrangements and preparations for meetings, including minutes, agendas, Board papers and the question of hotel reservations and conference registrations. Many of the important documents are circularised to member organisations in the Message series. For the convenience of those who may not have received the individual messages we provide a listing below:

Message 57/2015: CancerWorld – offer of free copy of CancerWorld in hard copy.

Message 58/2015: September issue of the Europa Uomo Newsletter 'Did You Know'.

Message 59/2015: HAI paper 'Direct Patient Reporting in the EU – A snapshot of Reporting Systems in 7 member states'.

Message 60/2015: 'ADVANCE' consultation on Code of Conduct (EMA).

Message 61/2015: European Commission calls for expression of interest to represent civil society in two scientific committees (PRAC & CAT) of the European Medicines Agency.

Message 62/2015: Written Declaration ECPC: 'Raising cancer Patients' Voice'.

Message 63/2015: 'EMA Consultation: Draft scientific guidance on post-authorisation efficacy studies'.

Message 64/2015: 'EMA Newsletter Human Medicines Highlights'.

Message 65/2015: 'EMA Communication: Safer use of medicines by preventing medication errors'.

Message 66/2015: 'General Assembly 2016' Preliminary notice.

Message 67/2015: 'December issue of the EUomo Did You Know? Newsletter issued.

Message 68/2015: Xmas wishes

Message 69/2015: EGAN-Roche Recommendation 2015

Message 70/2015: ECPC Newsletter 07/2015 November – December
