



# Prostate Digest

Information bulletin for Member Organisations of Europa Uomo

No. 1 September 2015

## Editor's Note:

*Prostate Digest* is a very basic document to keep member organisations of Europa Uomo informed of the activities of their Board members. Board members contribute items indicating events or activities they have in on behalf of Europa Uomo or their own national organisation. This edition will cover activities since the General Assembly in June up to the end of August. The Digest is designed to complement the Newsletter – “Do You Know” and will not contain articles. Items may contain references or links to articles of interest. Although August is normally a quiet month for meetings and activities due to the holidays it appears that a number of your Board members have been busy during this summer period.

The Secretariat send out circulars listed as Messages with a sequential number and year. The intention in listing them in the *Digest* is to provide a unified list to refer to if you have missed or misplaced the original notice. The publications and reports are to bring to the attention of member organisations any articles or reports on prostate diseases and Quality of Life issues that may be of interest to members. If members spot interesting journals, websites, reports and articles please send us the reference for inclusion in a future issue.

If you have future events you would like listed in a forthcoming *Prostate Digest* please send a brief note to Anja Vancauwenbergh in the Secretariat at [europauomo@skynet.be](mailto:europauomo@skynet.be) or to the Secretary, John Dowling, at [euomosecjd@gmail.com](mailto:euomosecjd@gmail.com). All notifications should be in English.

## Board Member & Secretariat Activities since June's General Assembly

Board Members 2015/16: Ken Mastris (2015) Chairman, Ekke BÜchler (2014) Vice-Chairman, André Deschamps (2015), Christian Arnold (2013) Treasurer, John Dowling (2015) Secretary, Malcolm Duncan (2013), Max Lippuner (2013), Günter Feick\*, Hein van Poppel\*, Alberto Costa\*

The year shown in brackets after each name indicates the year last elected to the Board for a 3 year term.  
\*Ex-officio Prof. van Poppel & Dr Costa are Scientific Committee members and Board meetings on request.

Also: Louis Denis (Strategic Consultant – until 16 Sept.), Anja Vancauwenbergh (Secretariat)

 Chairman Ken Mastris has been busy fund-raising for Europa Uomo as well as attending the AGM of TACKLE his own organisation, in July. Ken also confirmed his attendance at the Expert Group on Cancer Control in Luxembourg on 15-16 September. Toward the end July Ken did follow-up on grant applications for Patients and Professionals. In July he also had meetings in London on Every Moment Matters, Red Door and with Astellas Pharma. The Chairman received a proposal from Bayer on Partnership event in Vienna during ECCO-ESMO in September. To be considered by the Board. Ken was also involved in phone conferences with Bayer Germany and a meeting in London with Bayer UK.

 Secretary John Dowling has edited and launched a new internal Board Bulletin to keep members of the Board in touch with each other's activities. He also edits this *Prostate Digest* to inform Europa Uomo affiliates of some of the activities of Board members. Also active with his own organisation in writing material for MAC - Men Against Cancer. Attended as Prostate patient representative at the ceremony by the Irish Minister for Health adopting new Clinical Guidelines for Prostate Cancer Diagnosis and Treatment. Summary Report is 84 pages! Full report considerably more. Both available on: <http://health.gov.ie/patient-safety/ncec>.

Also, attended as patient representative, an information meeting for prostate patients who had undertaken radiotherapy treatment over the past 15 years. The presented by Prof. John Armstrong of St. Luke's Cancer Hospital and Prof. Steve Pennington of the Conway Institute, University College, Dublin. A full report will be submitted to the Newsletter for the December issue.

-  John has also commenced preliminary work with Günter Feick and they will be joined by Max Lippuner and André Deschamps on revision of Europa Uomo Statutes for the 2016 GA in Amsterdam.
-  Treasurer Christian Arnold offered Hugo Boliou the position of accountant to Europa Uomo for 2015/16 and was delighted that M. Boliou has accepted. Christian has also been overseeing the processing of many financial matters related to the General Assembly.
-  Vice-Chairman André Deschamps has researched Webinar options for improving communications between Board members between the relatively infrequent face-to-face Board meetings. André also testified as a prostate cancer survivor for a film which will be available for prostate cancer patients in hospitals in Belgium. He also attended a prostate cancer symposium in August, chaired by Prof Hein van Poppel. Andre also represented Europa Uomo at the forthcoming Egan-Roche Workshop on Gene Sequencing on 3/4 September in Switzerland.
-  Malcolm Duncan, Editor of the newsletter Did You Know?, went on his summer holidays shortly after the GA but was in virtual daily contact with the Secretariat and other members of the Board - it is as if he were still back in Milan. Malcolm has been working on the next issue of the newsletter which is due in late September as well as working on a special issue for EPAD.
-  Ex-officio Board member Günter Feick has been busy with preparations for the German Movember Campaign next November. Günter is also a member of the drafting team for the revision of the statutes for the GA 2016 in Amsterdam. Günter commenced in August a month-long project for the participation of 5 certified German prostate cancer centres in the global Movember project "Compare/Reduce Variation" – He is also playing his role in his organisation's support for US All Trials Registered & All Results Reported Campaign <http://www.alltrials.net>. Also working for the completion of Guidelines for Standardised Prostate Cancer Rehabilitation Care in Germany and as if that was not enough he has commenced preparation for the German Association of Urology Annual Congress 2015 in Hamburg and 2016 EAU Congress in Munich.
-  Strategic Consultant Prof. Louis Denis has been working extremely hard on the programme for 16 September to mark EPAD - European Prostate Awareness Day. Prof Denis had been due to step down from his role on 1 December, but due to his heavy personal and professional schedule over the coming months he has agreed with the Chairman that he will step down from his Strategic Consultant role at the conclusion of EPAD. Prof. Denis will remain active with Europa Uomo as a Liaison Officer and continue to contribute to the Newsletter and Website.
-  Secretariat: Final preparations for the European Prostate Awareness Day -EPAD- on 16 September in the European Parliament, Brussels. Anja Vancauwenbergh has been registering attendees and obtaining clearances with the Parliament for those attending and otherwise liaising with the Parliament authorities and with MEP De Backer who is acting as host in the parliament to Europa Uomo for the event and is co-Chairing one of the sessions.
-  Prof. Denis, Vice-Chairman Deschamps and Anja Vancauwenbergh have accepted the invitation of PKS (our Netherlands affiliate) to attend the "Donateurs Day" on 14 October and to commence preparations for the GA 2016 in Amsterdam.
-  Prof. Denis notified the details of the new Board elected at the General Assembly to the Belgian authorities. And formal notification of acceptance of the changes has been issued.
-  Board meetings to take place September, November & March with additional on-line meetings.
-  In July, the Chairman and Secretary visited the Secretariat in Antwerp and met with Anja Vancauwenbergh also in attendance Vice-Chairman, André Deschamps. The officers present were briefed by Strategic Consultant, Prof. Louis Denis. Draft Criteria were drawn up for the selection and appointment of Europa Uomo representatives to meetings, working groups and conferences

## In case you missed them: Messages from the Secretariat since the GA in June

- Messages 38 a-e/2015: are available to download from the Website ([www.europa-uomo.org](http://www.europa-uomo.org)) or see Secretariat Warsaw General Assembly Presentations.
- Message 39/2015: Radionuclide-based therapy in mCRPC.
- Message 40/2015 Annual Report of EMA on interactions with patients, consumers and healthcare professional and their organisations. See the EMA website: [www.ema.europa.eu](http://www.ema.europa.eu).
- Message 41/2015 Bayer invitation for virtual events in September.
- Message 42/2015 Active Citizenship Network (ACN) Newsletter.
- Message 43/2015: ESMO Clinical Practice Guidelines re diagnosis, treatment & follow-up of Prostate Cancer.
- Message 44a/2015: 27 July - Minutes of Europa Uomo Meetings issued to member organisations.
- Message 44b/2015: 27 July – Minutes part II.
- Message 45/2015: High PSA Anxiety & low health literacy skills: Annals of Oncology 24/04/2015.
- Message 46/2015: ECCO members' Newsletter July Issue.
- Message 48/2015: Five genetically-different types of prostate cancer identified. <http://www.dailymail.co.uk/wires/pa/article-3179604/Five-genetically-different-types-prostate-cancer-identified.html>.
- Message 49/2015: Press Release by Astellas Pharma on Scottish Medicines Consortium decision not to recommend early use of Enzalutamide (XTANDI).
- Message 50/2015: EMA documents on PCWP/HCPWP meeting of 4 June. See: [http://www.ema.europa.eu/ema/index.jsp?curl=pages/news\\_and\\_events/events/2015/05/event\\_detail\\_001158.jsp&mid=WC0b01ac058004d5c3](http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/events/2015/05/event_detail_001158.jsp&mid=WC0b01ac058004d5c3).
- Message 51/2015: The new, revamped website is now live. See: <http://www.europa-uomo.org>.
- Message 52/2015: Reminder of EAU Patient Information Guidelines on Prostate Cancer. See <http://patients.uroweb.org/prostate-cancer/what-is-prostate-cancer/>.
- Message 53/2015: Patient Information from Prostate Cancer UK. English versions can be found at <http://prostatecanceruk.org/prostate-information/other-languages#english-versions>.

## Journals and Reports which may be of interest

Executive Summary of Bayer Patient Advocacy Summit 2015 received – “Partners in Cancer Care: The Patient voice in Clinical Development”.

Two reports on European Medicines Agency meetings in June involving the Patients' and Consumers' Working Party available from the Secretariat. Also official EMA report of 4 June PCWP/HCPWP joint meeting with EMA representatives. See link at Message 50/2015 above.

CancerConnect – Prostate Cancer Newsletter – A US Website. See: <http://cancerconnect.com> and click on the link for prostate cancer newsletter.

The next Prostate Digest will issue in late October. Feedback please to the Editor at [euomosecjd@gmail.com](mailto:euomosecjd@gmail.com). Your suggestions also as to what you want to see in the [Digest](#).