



**Annual Report
of the Board
for 2016/17**

1. Introduction by the Chairman

It gives me great pleasure to introduce the second Annual Report for Europa Uomo which sets out, for our members, supporters, interested parties and the health authorities, what we have done, what we have achieved over the past twelve months and to give some indication of our future plans, subject to the General Assembly's direction.

The year under review represented significant progress building on previous work and I thank all those who contributed. Europa Uomo continues to develop its role as the voice of prostate cancer patients at a European level.

During the year we developed our website with the assistance of our webmaster Nancy Verbrugghe who has also been instrumental in developing our Facebook page and in launching our Twitter account. During the past year the Board conducted a survey of member organisations about our communications. In line with the views expressed by members in the survey we have consolidated our messaging and newsletter functions into the weekly Update which commenced publication in February. We will monitor members in the coming year as to how effectively their needs are being met and what additional steps may be required.

Once again, my thanks go to all our sponsors for their contributions to our funds - details are including in the report and on our website.

Thanks go to Anja Vancauwenbergh and Brigitte Dourcy-Belle-Rose for their support to the board together with Louis Denis and Luc Dewilde of OCA.

Working in partnership with all stakeholders is the way forward for Europa Uomo and this in mind thanks go to the EAU and ESO represented by Hein Van Poppel and Alberto Costa.

There are challenges for us in the years ahead in the areas of funding and in dealing with the changing political relationships within our European family.

We have to tackle the inequality of access to treatment and drugs in Europe.

New treatments and drugs come at a cost to the health sectors and this will be an issue to future prostate cancer patients.

Finally, my thanks go to the officers, Board, Tackle UK, and our membership who do the work on a voluntary basis in fighting for men and families who are suffering from this silent disease.

Ken Mastris
Chairman

2. Executive Summary

- ❖ **Board Meetings:** Seven meetings – The Board now meets more frequently than in the past in order to better maintain a work momentum. The face to face meetings are augmented by telephone conferences when required. [Section 3]
- ❖ **Strategy:** Having spent a good deal of 2015/16 in developing a strategy document which was adopted by the GA in 2016 the Board prioritised its implementation. This is done by indicating the activities carried out under the Goals adopted in the Strategy. [Section 4]
- ❖ **Funding and Financial Report:** The presentation of the financial report is recast to emphasise the shift to a project based activity and to allow the Board to align expenditure accordingly. The report also includes the audited Balance Sheet for 2016 and the Actual Outcomes against Budget for 2016 as well as the projected Outturn 2017 and an Outline Budget for 2018. [Section 5]
- ❖ **Liaison Officers:** The role of Liaison Officers was co-ordinated by Ken Mastris. [Section 6]
- ❖ **EPAD:** The organisation has been seeking to develop the role of European Prostate Awareness Day in co-operation with other organisations. In 2016, in conjunction with the Polish Urology Association an EPAD event was mounted in Krakow at the time of the PUA congress. [Section 7]
- ❖ **Meeting Reports:** The Board attends a number of conferences annually and Section 8, 9, 10, 11 and 12 provide short reports of the principal events.
- ❖ **European Medicines Agency:** The EMA has been at the forefront of involving stakeholders, including patients in its regulatory work. Patient representatives are present on the scientific committees and in working parties. Patient representatives are also invited to attend other consultative meetings such as, marketing authorisation applications. [Section 13]
- ❖ **Membership:** The application of Estonia brought to 24 the number of countries who have enrolled in Europa Uomo. The Board has committed resources to advancing the number of members but also to helping national organisations to strengthen their functioning. [Section 14]
- ❖ **Communications:** Following a relaunch the website continues to be updated and the Facebook account has been active during the year. Following a Survey of member organisations the Board launched a weekly bulletin Update. The publication commenced on 8 February. [Section 13]
- ❖ **Appendices:** For the convenience of delegates this report contains the text of the Statutes and Bye-Laws.

3. Board Membership

The Board has seven elected members. Each member is elected by the General Assembly for a term of three years (renewable for a further term of three years). At the GA in 2016 there were three vacancies occurring on the Board. One of the outgoing Board members, Max Lippuner, did not stand for re-election. The other two outgoing members were Christian Arnold and Malcom Duncan each of whom was eligible for re-election. There were four candidates for three places and the successful candidates were Christian Arnold, Will Jansen, and Stig Lindahl.

The new Board met before the end of the General Assembly at which the officers were elected:

The full Board for 2016-17 was:

Chairman:	Ken Mastris (UK),
Vice-Chairmen:	Ekke Büchler (Austria) Will Jansen (The Netherlands),
Treasurer:	André Deschamps (Belgium),
Secretary:	John Dowling (Ireland),
Other members:	Christian Arnold (France), Stig Lindahl (Sweden).

Ex-officio members:

Board appointed: Günter Feick (Germany) continued as an *ex-officio* member.

Partner nominated: Prof. Hein Van Poppel (EAU),
Dr. Alberto Costa (ESO),
Prof. Louis Denis (OCA).

The current Board met in August (Brussels), September (Krakow), November (Milan), January (Brussels), March (London), April (Antwerp) and our final meeting is due in June (Vienna).

In addition to the responsibilities in the statutes for Chairman, Treasurer and Secretary, the other Board members took on particular portfolios. Ekke Büchler undertook to develop contacts with our eastern European members and to organise a patient seminar in conjunction with the General Assembly. André Deschamps agreed to focus on the implementation of the strategy adopted in Hoorn in June. John Dowling took on the task of developing communications with members, Ken Mastris worked with our webmaster Nancy Verbrugghe to develop our website and Facebook. Ken also took over co-ordination of LOCs from André Deschamps. Stig Lindahl undertook to develop relations with our new member in Estonia and to maintain contact with our member organisation in Lithuania.

The Board is very grateful to our *ex-officio* members for their assistance and advice during the year.

This year there is one board position where Ekke Büchler's term of office is due to expire at the GA in Vienna. Nominations were called for and at the closing date on 5 May 2017 two nominations had been received. Joaquim Domingos (Portugal) and Pentti Tuohimaa (Finland).

4. Europa Uomo Strategy

The Strategy was adopted by the General Assembly June 2016. This is the First Implementation Report.

Chapter 1: Vision and Mission

Vision

- A future where no man suffers or dies from prostate cancer

Mission

- Achieve better treatment, care and quality of life for all prostate cancer patients across Europe
- Provide an effective EU-wide voice representing the needs and priorities of National organisations

Chapter 2: Goals

Goal 1: Request early detection of prostate cancer

Current situation:

- ❖ Population-based screening for prostate cancer is still discouraged by physicians and researchers even though the ERSPC study and prostate cancer mortality statistics reflect reduction in mortality rates upon PSA utilisation for the early detection of prostate cancer.
- ❖ Access to PSA testing is discouraged in some EU countries and men are not informed about prostate cancer risks and treatment.

Goal 2: Help establish Prostate Cancer Centers and raise quality to top world level in all European States

Current situation:

- ❖ International Consortium of Health Outcome Measurement (ICHOM): Patient Related Outcomes (PROs) for localized low/medium risk prostate cancer consented and published.
- ❖ ICHOM PROs added to prostate cancer treatment guidelines and reports of certified prostate cancer centers, Germany.
- ❖ PROs for advanced prostate cancer consented and published; Prof. Denis is co-author of the ICHOM dataset for advanced prostate cancer.
- ❖ EAU will take the lead in establishing a limited amount of expert PCUs in different countries.
- ❖ In some EU states prostate cancer centers are already in existence.
- ❖ ESO will explore with Europa Uomo to audit PCUs. This is not an accreditation or certification process but simply a “recommendation” procedure from the patient viewpoint, a kind of Trip Advisor from the experience of the “clients” to signpost those centres which are more “patient friendly” than others.

Goal 3: Have in place and review therapy guidelines and patient information in all European States based upon best evidence

This goal is subdivided into three elements:

- I. EUomo representation in the EAU guidelines working group
- II. To have in place current medical, scientific guidelines and patient guidelines in all European states
- III. Proof of guidelines application

Current situation:

- ❖ EAU guidelines and patient information sheets are developed and available in 14 languages.
- ❖ EUomo representatives are members of the working group.
- ❖ Those guidelines are used as an input for guidelines in the country-specific guidelines. For different reasons country-specific guidelines are not always identical to the EAU guidelines.

Goal 4: Encourage new support groups in new European States

Current situation:

- ❖ There is a gap between the economically advantaged states and other disadvantaged states.
- ❖ EUomo encourages and support patient groups in the new member States.
- ❖ Estonia formed a patient group with Europa Uomo assistance and the GA in 2016 accepted them as a member of EUomo.

Goal 5: Develop EUomo organizations, staff and funding

Current situation:

- ❖ LOC strategy developed.
- ❖ Statutes and bye laws restructured.
- ❖ EPAD events were organized and will be repeated when appropriate.
- ❖ New website launched.
- ❖ Newsletter published.

Goal 6: Support a coordinated European research program with patient advocate representation

This goal is divided into 4 component parts in order to ease the description of a concept that addresses the sequence of the necessary work steps:

- Obtain the support of EU Parliament and EU Commission for coordinated research in Europe.
- Obtain the support of EU Parliament and EU Commission for the registration and reporting of all trials in Europe
- Representation of EUomo in EMA work groups/commissions such as the Committee for Medicinal Products for Human Use (CHMP), the Committee for Advanced Therapies (CAT), the Clinical Trial Facilitation Group, etc.
- The organisation of coordinated prostate cancer research for faster and better results with patient representation.

Current situation:

- ❖ Parliamentary support has been achieved with the research funding program Horizon 2020, however this is but the first modest step towards the coordination of research (at least 3 independent organisations are required from different EU countries).
- ❖ This has been achieved, but the EUdRACT register of clinical trials is only available in English. <http://www.eudrapharm.eu/eudrapharm/clinicaltrials.do>
- ❖ EUomo has representatives in EMA in different committees and working groups. The reports of those work groups are available on the EMA website.

Chapter 3: Projects

In order to achieve our goals, we have developed several projects. Each project has its own timing and assigned budget. Some projects are linked to one specific goal. Others are linked to more goals.

The scheme underneath shows the link between goals and projects.

Project	Goal 1 Awareness	Goal 2 PCUs	Goal 3 Guidelines	Goal 4 New groups	Goal 5 Organisation	Goal 6 Research
Awareness campaign: a tough nut to crack						
Representation at EU-level to meetings						
New member states/ Polish hub						
Website and new media, communications						
Training patient advocates						
Audits in PCU						
Early diagnosis in states with less developed healthcare						

Project 1: Awareness campaign: a tough nut to crack

Project Description		Publish adverts in different media
Project timing	Start date	11/2016
	Finish	12/2018
Project financing	Total amount	15 000 €
Project deliverables		Measure response to site pages related to campaign

Achieved so far:

- ❖ Publication in December 2016 in Brussels Airlines magazine
- ❖ Publication in *Cancerworld* in March 2017

Project 2: Representation at EU-level meetings in order to spread goals and influence results

Project Description		We send representatives to EMA, ESO, steering committees, EU task force, ECPC, CANCON and others
Project timing	Start date	1/2017
	Finish	12/2017
Project financing	Total amount	20 000 € a year
Project deliverables		List and reports of meetings where we were represented. Reports to board

Achieved so far:

See list of attended meetings attached to the report at appendix 1.

Project 3: Initiatives in new member states / Polish hub

Project Description		Develop activities specific for New member states training, awareness, new patient groups
Project timing	Start date	10/2016
	Finish	12/2018
Project financing	Total amount	30 000 €
Project deliverables		Training sessions Dedicated personnel Patient sessions

Achieved so far:

- ❖ Information session for 70 Polish PC patients during EPAD in Krakow
- ❖ Discussions with Gladiators in order to establish Polish Hub
- ❖ Training session in Vienna, June 2017 for 40 PC patients from Slovakia and Poland

Project 4: Maintain and design new pages and content for website and use of new media

Project Name		Project 4: Maintain and design new pages and content for website or new media
Project Description		In order to inform all stakeholders make sure that content of website and social media is up-to-date and easy to access
Project timing	Start date	5/2017
	Finish	12/2018
Project financing	Total amount	25 000 €
Project deliverables		Content of site and social media

Achieved so far:

- ❖ New website launched
- ❖ Survey amongst members on needs for communication
- ❖ New weekly newsletter (Update) launched in February 2017
- ❖ Page on website added in order to support awareness campaign
- ❖ Twitter account and Facebook account established

Project 5: Training patient advocates

Project Description		Organise a two-day training session for patient advocates Organisational and travel costs will be involved.
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		Day 1: Training on PCa. Day 2: Patient advocate skills.
Project timing	Start date	3/2018
	Finish	4/2018
Project financing	Total amount	60 000 €
Project deliverables		Training session. Programme To Be Arranged

NB: This project will be subject to GA approval and support from sponsors.

Project 6: Auditing PCUs

Project Description		ESO has asked us to be involved in PCU audits. These audits will lead to an “approval” of the unit and a recommendation for patients.
Project timing	Start date	2018
	Finish	2019
Project financing	Total amount	30 000 €
Project deliverables		Patient recommendation for PCU

This project is supported and sponsored by ESO.

Project 7: Early diagnosis in newer states

Project Description		Promotion of initiatives which will result in earlier diagnosis of PCa
Project timing	Start date	2017
	Finish	12/2018
Project financing	Total amount	10 000 €
Project deliverables		Documentation in local language and increasing early diagnosis in developing countries

5. Funding of Europa Uomo and Financial Report

Summary:

- Income and sponsorship from pharma has changed
- Sponsorship will be project-based with approx. 50% of sponsors
- Timing issue between income and expenditure
- Planning over more years needed

The funding of Europa Uomo comes from small contributions from member organizations through their annual dues, contributions from partner organisations, especially the European Association of Urologists (EAU) and the European School of Oncology (ESO) , and a number of pharmaceutical companies.

The policy of the Board has been to raise sufficient funds to carry out its tasks.

Patient groups are living in a changing world. Due diligence, avoidance of conflict of interest and EMA guidelines are imposing stricter rules on those receiving funds and similarly our sponsors.

Open bookkeeping will be key to our further success. We like to be ahead of the game. That is why we distinguish in our 2017/2018 budgets for the first time the sponsorship given for our core activities and those for projects.

We have defined 7 projects to work on for the next two years. Some of these projects have been there already in one shape or form, and some are new. Especially the project number 5 which will be subject to GA approval and extra sponsorship. The budget assumes that we will go forward with it and can find the necessary sponsors.

This way of working will induce a time gap between income and spending. Sometimes the income will be first, sometimes the expenditure.

That is why a sound financial follow up of the projects has been set up. We will report on the first year in our next annual report.

Our accounts have been audited and no problems were found. So the statements underneath are a true and honest.

In accordance with Belgian law for not-for-profit organisations it is necessary that these financial reports be considered and approved by the General Assembly so that the Board may be discharged.

Europa Uomo is compliant with the EMA guidelines on the funding of recognised patient organisations in terms of the number of pharma companies from whom it draws financial support and the requirement that it is not more than 35% dependent on any one source.

Balance at December 31, 2016 (in euro)

ASSETS

Bank accounts

Business Compact account	141.762,34	
Savings account	50.279,14	
		192.041,48

Amounts receivable

Grant Pharma	25.000,00	
		25.000,00

Deferred expenses

Registration K Mastris PCa Europa 2017	150,00	
Board meeting Brussels 25/01/2017	1.794,00	
EAU annual meeting London	4.113,49	
		6.057,49

Total assets

223.098,97

LIABILITIES

Deferred income and accrued expenses

Memberships paid in 2016 for 2017	100,00	
Maintenance website December 2016 paid in 2017	405,00	
Refund travelling expenses ESTRO 2016 paid in 2017	1.002,42	
		1.507,42

Capital of the association

Balance at 31/12/2015	228.176,31	
Balance 2016	-6.584,16	
Capital at 31/12/2016		221.591,55

Total liabilities

223.098,97

Income 2016 - Budget vs. Actual

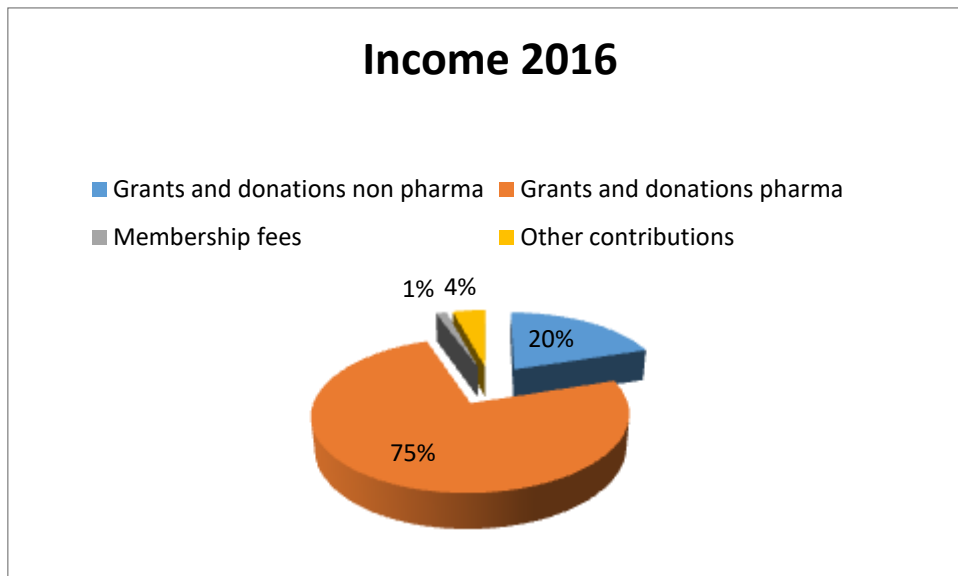
Income 2016	Budget €	Actual €	Delta €
Total grants & donations non-pharma	€ 30.000	€ 30.800	€ 800
Total grants and donations pharma	€ 165.000	€ 115.000	€ -50.000
Annual membership fees 2015	€ 2.100	€ 2.100	€ -
Income other	€ 3.000	€ 6.332	€ 3.332
Bank interest	€ -	€ 50	€ 50
Total income	€ 200.100	€ 154.282	€ -45.818

Expenditure 2016 - Budget vs. Actual

Expenditure 2016	Budget €	Actual €	Delta €
Secretariat	€ 50.000	€ 50.000	€ -
Other secretariat costs	€ 1.000	€ 880	€ -120
Project awareness	€ -	€ 1.100	€ 1.100
Design & Creation new website	€ 2.000	€ -	€ -2.000
Monthly maintenance website	€ 1.620	€ 5.000	€ 3.380
Internet	€ 180	€ 133	€ -47
Audit fee + fee tax return	€ 2.500	€ 2.305	€ -195
Legal publications	€ 150	€ 125	€ -25
Contingency	€ 5.000	€ -	€ -5.000
Insurances	€ 600	€ 524	€ -76
Membership ESMO	€ 175	€ -	€ -175
Membership FAIB	€ 190	€ -	€ -190
Refund travelling costs meetings	€ 50.000	€ 37.982	€ -12.018
Other meeting costs	€ 70.000	€ 62.220	€ -7.780
Bank charges	€ 250	€ 211	€ -39
Withholding tax on bank interest	€ 50		€ -50
Tax on assets non-profit organisations	€ 400	€ 387	€ -13
Total expenditure	€ 184.115	€ 160.867	€ -23.248

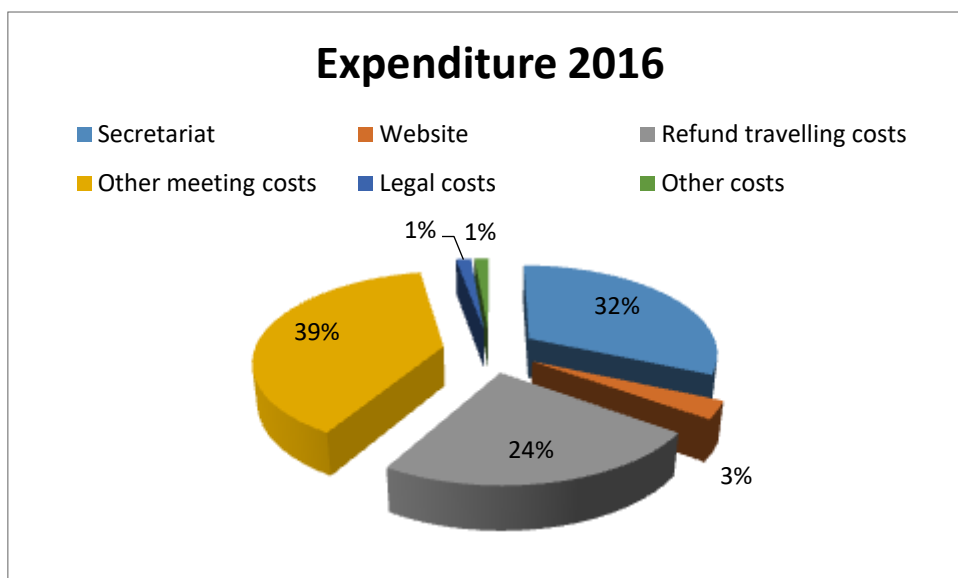
Difference income-expenditure	€ 15.985	€ -6.585
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Income distribution



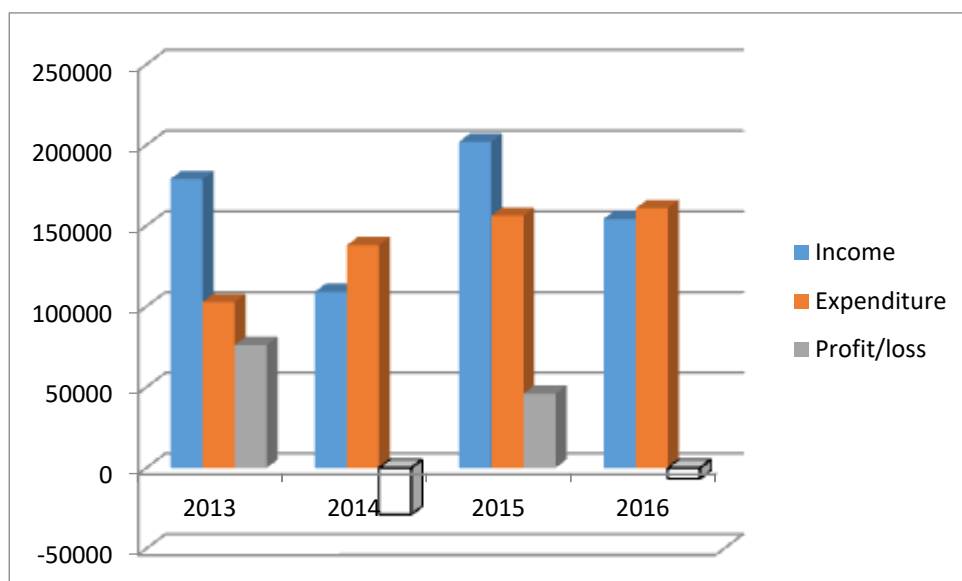
Grants and donations non pharma	€ 30.800	19,96%
Grants and donations pharma	€ 115.000	74,54%
Membership fees	€ 2.100	1,36%
Other contributions	€ 6.382	4,14%
Total income	€ 154.282	100,00%

Expenditure distribution



Secretariat	€ 50.880	32%
Website	€ 5.133	3%
Refund travelling costs	€ 37.981	24%
Other meeting costs	€ 62.220	39%
Legal costs	€ 2.430	2%
Other costs	€ 2.223	1%
Total	€ 160.867	100%

Difference income- expenditure over the last 4 years



Income 2017 and 2018 budget

	Budget € 2017	Budget € 2018
Total grants and donations non-pharma	30.000	50.000
Total grants and donations pharma non-project based	90.000	90.000
Total grants and donations pharma project based	100.000	145.000
Annual membership fees 2015	2.100	2.100
Income other	3.000	3.000
Total income	225.100	290.100

Expenditure 2017 and 2018 budget

	Budget € 2017	Budget € 2018
Secretariat	50.000	50.000
Other secretariat costs	1.000	1.000
Project 1: Awareness	7.000	7.000
Project 2: Attendance to meetings	30.000	30.000
Project 3: New members states	10.000	10.000
Project 4: Website and communication	10.000	15.000
Project 5: Training session advocates	7.000	53.000
Project 6: Audit PCU units	5.000	25.000
Project 7: Early diagnosis in countries with developing healthcare systems	10.000	
Internet	200	200
Audit fee + fee tax return	2.500	2.500
Legal publications	150	150
Insurances	600	600
Memberships	300	300

Refund travelling costs meetings	30.000	30.000
Other meeting costs	55.000	55.000
Bank charges	250	250
Tax on assets non-profit organisations	500	500
Contingency	5.000	8.000
Total expenditure	224.500	288.500

Forecast difference income expenditure	600	1.600
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6. Liaison Officers

The concept of the Liaison Officers Club – otherwise known as LOCs - was developed in the year prior to the Warsaw General Assembly in 2015. The enabling provisions were set out in the Bye-Laws adopted at that GA. Since then the initial group of LOCs has been expanded and a procedure has been developed governing how the LOCs will be deployed on behalf of Europa Uomo and the reporting arrangements when they represent the organisation at meetings and conferences. Ken Mastris took over responsibility for co-ordination of LOCs from André Deschamps.

The cohort of Liaison Officers in 2016-17 comprises; Paul Enders, Erik Briers, Roger Wotton, Maria Louisa Domingos, Brigitte Dourcy-Belle-Rose, Joaquim Domingos.

7. European Prostate Awareness Day (EPAD) – Krakow, September 2016

One of the public projects undertaken by the Board in conjunction with the EAU in 2016 was the EPAD function held in September in Krakow, Poland.

The EPAD was held in conjunction with a urology conference organised by the Polish Urological Association (PUA). Following the conference a patient seminar was undertaken and several Polish and other European speakers made presentations on prostate cancer. Discussions were held with the PUA and our Polish affiliate – Gladiator on the way a virtual office in conjunction with Gladiator – known as the Polish Hub – might be organised. These matters remain under consideration.

8. Conferences & Meetings Attended

Members of the Board and Liaison Officers attend a wide range of meetings on behalf of Europa Uomo. Usually it is thought sufficient to send one or two representatives but on occasions, because of the nature of the conference, additional representatives attend. It is hoped that the new reporting procedures for Board representatives and LOCs will enable the Board to review where best to deploy its limited resources. In order to maximise the value to be gained, a small number of conferences attended are also used to arrange meetings of the Board. This also provides the Board with the opportunity to obtain the most up to date information from the Conference sessions.

A listing of meetings and conferences attended by Europa Uomo representatives is set out in Appendix 1 to this report. In addition, short accounts on two of the meetings attended by the Board as set out below.

9. European Multidisciplinary Meeting on Urological Cancers (EMUC)

The EMUC meeting was held in November 2016 in Milan and was attended by the Board. EMUC brings together a range of specialists from urology, radiation oncology, medical oncology, pathology and epidemiology. Prostate cancer is one of the main areas of interest at the meeting so it provides an excellent learning opportunity for Board members to hear leading clinicians and researchers present on the latest developments in prostate cancer diagnosis and treatments.

A meeting of the Board was held during EMUC.

10. European Association of Urologists Congress – London, March 2017

The EAU is biggest congress of its type in Europe with some 14,000 attendees – not only urologists but many scientists and clinicians in various fields of endeavour associated with a range of urological diseases – prostate disease being prominent among them. The Board of Europa Uomo traditionally attends the Congress in conjunction with the holding of a Board meeting. Liaison Officers were also invited and they attended part of the Board meeting. Our partner *ex-officio* Board members also attended.

The occasion of the EAU Congress not only provides an opportunity for the Board to meet about its own business, but Board members, together with LOCs, have the valuable opportunity to take part in special presentations by leaders in the field of prostate cancer diagnosis and treatment on various aspects of prostate cancer.

11. The Tackle Patient Symposium at the EUA17

The Annual Congress of the EAU is a great opportunity to learn of the latest developments in field of prostate cancer and this year's gathering in London proved no exception. In addition to attending sessions from the world's leading urological and oncological experts, the Congress also affords the Europa Uomo Board members present to do some organisational business. It was also an occasion where the EAU generously provided our UK member, **Tackle**, with the opportunity to hold a seminar for members.

At the Congress Board members and LOCs were given the up-to-date information on dealing with prostate patients. While the benefit was greatly appreciated, these presentations underlined the extent of the inequality in Europe and parts of the UK where not all will have access to the best treatment and the available drugs.

At the Patients' Symposium, chaired by Professor Frank Chinegwundoh, Trustee of Tackle, we were delighted to have great speakers deliver on a cross-section of topics: *Lina Carmona Echeverria* on developments in Prostate Cancer; *Lawrence Drudge-Coates* on Bone Health; *Rebecca Porta* on the role of Orchid Male Cancer; and *Chris Booth* on the PCa testing debate. More than 65 people attended the seminar of whom the majority were Tackle members. To facilitate those who could not attend, **Tackle** was able, with the financial support of Europa Uomo, to video all the presentations which are now available on our YouTube site: <https://www.youtube.com/channel/UC1rmACnr0pc5Z6gV-QW4NBQ>
And also on <http://www.tackleprostate.org> and <http://www.europa-uomo.org>.

12. Conference Presence

At many of these conferences, Europa Uomo is often provided with a stand or booth where information about Europa Uomo can be provided to conference delegates. At many of these meetings in recent years the organisation's conference stand has been manned by Joaquim Domingos and Maria Louisa Domingos sometimes assisted by local representatives. Joaquim and Maria Louisa have recently indicated that the wish to stand down from that role. The Board greatly appreciates the dedication of both to the role and

wishes them well. The Board proposes to consult with Maria Louisa and Joaquim how best the organisation might utilise the booth in the future.

13. European Medicines Agency (EMA)

The Agency, currently based in London, is a function of the European Commission and is the body which regulates medicines for use within the EU, Norway and Liechtenstein (European Economic Area – EEA), which are submitted by sponsors for use across the EEA. At the present time the Agency provides for patient representation on a number of its committees. The Pharmacovigilance Committee and the Committee for Advanced Therapies (CAT) are the two principal scientific committees. A Liaison Officer of Europa Uomo, Erik Briers, was successful in his application to the CAT where he is now an alternate member. The EMA also provides a forum - on the Patients' and Consumers' Working Party (PCWP) which meets with the representatives of the EMA on a quarterly basis. Europa Uomo is represented on this Working Party by Ken Mastris. During the past year André Deschamps has acted as an alternate for the Chairman when he was unable to attend. Will Jansen also attended a training seminar for patient and consumer organisation representatives in the use of social media.

The EMA terms for the reporting of all trials of medicinal and device products is proceeding to a long-awaited conclusion, but the fact that there will be no obligation on the sponsoring company to publish the reports in multi-language formats will limit the value of this otherwise welcome move. The EMA appears to accept industry's contention that such a requirement will impose an undue burden on the sponsoring companies.

We report last year that the EMA had asked the British Health Research Agency (HRA) to develop guidelines for the forthcoming inclusion of a layman's summary explanation of the trial in all trial reports. The HRA's recommendations last year were referred back for further consideration in late 2016 and the necessary steps are approaching final stage with the EMA and Commission and will be published as soon as the process is complete. Our Secretary, John Dowling was one of the patient representatives on the HRA Taskforce.

In 2016 the EMA invited patient organisations who are interested in renewing their membership of the EMA's Patients' and Consumers' Working Party to apply for a further term of membership of the Working Party. This application was successful. Our Chairman, Ken Mastris, is our representative.

At the time of writing, the question of the future location of the EMA after the UK leaves the EU has been receiving a good deal of media attention. Europa Uomo joined with other organisations in calling on the Council of Ministers not to delay the decision on the new location for the Agency. The EMA employs about 900 people many of whom are UK citizens. The potential loss of corporate memory and possible weakening of the regulatory system itself will not be assisted by any undue delay in nominating a new location for the Agency. At the very least, an early decision will allow the EMA to plan and make what will be undoubtedly a disruptive move in as efficient a manner as possible.

This EMA Code of Conduct to which Europa Uomo has subscribed is available on our website: <http://www.europa-uomo.org/about/code-of-conduct/>.

14. Membership of Europa Uomo

Membership is open to prostate cancer patient organisations in Europe. Twenty-four countries are currently represented by Europa Uomo. Work continues to develop and strengthen our membership in eastern Europe. Stig Lindahl has a programme of visits to prostate cancer organisation and, hopefully, when the Polish Hub is established, these efforts will bear some fruit. Ekke Büchler has organised a patient seminar in conjunction with the General Assembly in Vienna in June 2017 which will have patient

representative from a number of countries. The presentations will be in English and there will be simultaneous translations to German and Slovak.

We have been notified of the untimely death of two of last year's delegates; Kalev Lehtla (Estonia) and Thorkild Rydahl (Denmark) who died earlier this year. May they rest in peace.

15. Communications

There are inherent issues to be addressed in an international organisation where the language of business is not the mother-tongue of the majority of member organisations and their representatives. There are also difficulties for such an organisation which is dependent on the voluntary effort of a relatively small number of people. Former Board member Malcolm Duncan spoke at several GAs about the need to improve communications and when he was on the Board he made an invaluable contribution with the quarterly "*Did You Know*". The Board was also informed that a very significant proportion of its emails to members were not even opened by the recipients.

Duncan's resignation as editor brought the matter to a head. It was decided to canvass the member organisations to ask them what they wanted. In November a survey was conducted and based on the responses received it was decided to attempt to consolidate the messages from the Board and Secretariat, including information material and to issue a regular communication which is entitled *Update*. Since 8 February the *Update* has been issued weekly and appears to have been well received by those who open their emails from Europa Uomo.

The Board is anxious to obtain feedback from members on the *Update* but also on further ways in which communications can be improved. It intends to conduct a further survey towards the end of the year.

The Board has sought to develop other means of communication and in particular the website. It very much appreciates the work of our webmaster, Nancy Verbrugghe, for her efforts to keep the site up to date. Nancy has also developed our Facebook and Twitter accounts.

All *Update* issues are available at our website: <http://www.europa-uomo.org/newsletters/>.

Subscription to the *Europa Uomo Update* is free and can be done on: <http://www.europa-uomo.org/newsletters/subscribe-update-mailing/>.

16. Conclusion

The development of a patient organisation is only possible by the focussed efforts of its membership. It is not enough that the aims of our organisation are worthwhile and that there is a real need to be met on behalf of prostate cancer patients all across Europe. To be effective and to develop requires the correct strategy and the effort to realise it. This means being ready to change to meet the changing circumstances and needs of the organisation. The Board wishes to thank all those who have made their effort to develop and further the organisation.

Approved by the Board May 2017

Appendices

Appendix 1: Activities Europa Uomo (June 2016 – May 2017)

A. Deschamps, K. Mastris

Patient Advisory Board meeting Bayer

Chicago, USA

02-03.06.16

K. Mastris, L. Denis

General Assembly European Cancer Patient Coalition (ECPC)

Brussels, Belgium

03-05.06.16

K. Mastris

Plenary meeting Patient and Consumers' organisation Working Party (PCWP) - WCPWP + workshop on framework of collaboration with Academia (European Medicines Agency)

London, UK

14-15.06.2016

C. Arnold, E. Büchler, L. Denis, A. Deschamps, B. Dourcy-Belle-Rose, J. Dowling, M. Duncan, G. Feick, W. Jansen, S. Lindahl, M. Lippuner, K. Mastris, A. Vancauwenbergh

Board meeting Europa Uomo (Board 17.06.2016))

General Assembly Europa Uomo (Board + membership)

Board meeting Europa Uomo (new Board 18.06.2016)

Hoorn, the Netherlands

16-19.06.16

A. Deschamps, W. Jansen, K. Mastris

2nd European School of Oncology (ESO) Masterclass in Cancer Patient Advocacy: 'Working towards stronger and more effective advocacy in Europe 'We Can' meeting (KM, 24.06.2016)

Milan, Italy

24-26.06.16

K. Mastris

Strengthening interaction with academia (European Medicines Agency)

London, UK

30.06.16

K. Mastris, L. Denis, B. Dourcy-Belle-Rose

TEACH (Training and Education for Advanced Clinicians and HCPs) Summer School

LD: Co-chair Summer School

Presentation: Personalised Medicine: The Importance of Communicating to Patients (04.07.16)

Chair Plenary session 6 'Inhibitors Part II (05.07.16)

Chair Plenary session 9 'Report from the groups' (07.07.16)

Ken Mastris :Keynote speech (07.07.16)

Presentation: **Communication in Personalised Medicine**

Cascais, Portugal

05-07.07.2016

E. Büchler, L. Denis, A. Deschamps, J. Dowling, W. Jansen, S. Lindahl, K. Mastris, A. Vancauwenbergh, N. Verbrugghe

Board meeting Europa Uomo

Brussels, Belgium

09.08.16

W. Jansen

Milestone meeting on 'Prevention of Cancer'

Amsterdam, the Netherlands

15.09.16

W. Jansen

PCWP/HCPWP Workshop on Social Media (European Medicines Agency)

London, UK

19.09.16

K. Mastris

Patients and Consumers' organisation Working Party (PCWP) / Human Scientific Committee's Working Party with Healthcare Professionals' Organisations (HCPWP) joint meeting (European Medicines Agency)

London, UK

20.09.16

A. Deschamps

Association of Imaging Producers & Equipment Suppliers (AIPEs) symposium

Interview

<https://www.youtube.com/watch?v=eJEOG3jExI4>

Brussels, Belgium

28.09.2016

C. Arnold, E. Büchler, L. Denis, A. Deschamps, J. Dowling, W. Jansen, S. Lindahl, K. Mastris, A. Vancauwenbergh

Board meeting Europa Uomo (30.09.16)

Festival kultURO (Polish Urological Association) (30.09.16)

Opening Academic Year 2016/2017 Jagiellonian University (01.10.16)

Concert Endopower (01.10.2016)

European Prostate Awareness Day (EPAD) 2016

Krakow, Poland

30.09-01.10.16

A. Hansson, H. Tavo

European Society for Medical Oncology (ESMO) annual congress

Merck Patient Advocate Event (08.10.16)

Copenhagen, Denmark

07-11.10.16

K. Mastris

Teleconference PCWP (Patient and Consumers' organisation Working Party) topic group (European

Medicines Agency) on acknowledging and promoting visibility of patients' input in the Agency's activities
 London, UK
 13.10.16

K. Mastris
European CanCER Organisation (ECCO) Patient Advisory Committee meeting
 Brussels; Belgium
 19-20.10.16

C. Arnold, E. Büchler, A. Deschamps, J. Dowling, W. Jansen, S. Lindahl, K. Mastris, A. Vancauwenbergh
Conference Call Board Europa Uomo
 24.10.16

A. Deschamps, J. Dowling, S. Lindahl, K. Mastris, A. Vancauwenbergh
8th European Multidisciplinary meeting on Urological Cancers (EMUC) meeting
Europa Uomo Board meeting
 Milan, Italy
 24-27.11.16

K. Mastris
European Medicines Agency (EMA) Human Scientific Committees' Working Party with Patients' and Consumers' Organisations (PCWP) meeting with all eligible organisations
 London, UK
 30.11.16

K. Mastris
12th EGAN-Roche Workshop 'New trends in Medicines Development and Innovative Models for Patient Access'
 Basel, Switzerland
 10-11.01.17

E. Briers
European Medicines Agency (EMA) Committee for Advanced Therapies (CAT) meeting
 London, UK
 18-20.01.17

K. Mastris
PCa Round table International Centre for Parliamentary Studies (ICPS) 2017
 Brussels, Belgium
 24.01.17

C. Arnold, E. Büchler, L. Denis, A. Deschamps, J. Dowling, W. Jansen, S. Lindahl, K. Mastris, A. Vancauwenbergh,
Europa Uomo Board meeting
 Brussels, Belgium
 25.01.17

E. Briers, W. Janssen, K. Mastris
European CanCER Organisation (ECCO) annual meeting 2017 + EUomo booth
 Amsterdam, The Netherlands

27-30.01.17
 K. Mastris
Final CANCON conference
 St. Julians, Malta
 14-15.02.17

K. Mastris
European CanCER Organisation (ECCO) Patient Advisory Committee meeting
 Brussels, Belgium
 08.03.17

K. Mastris
Join Patients and Consumers' organisation Working Party (PCWP) / Human Scientific Committee's Working Party with Healthcare Professionals' Organisations (HCPWP) workshop on personalised medicine (European Medicines Agency)
Joint plenary meeting with Human Scientific Committee's Working Party with Healthcare Professionals' Organisations (HCPWP)
 London, UK
 14-15.03.17

C. Arnold, E. Briers, E. Büchler, R. Cuypers, L. Denis, A. Deschamps, J. Domingos, B. Dourcy-Belle-Rose, J. Dowling, P. Enders; K. Mastris, S. Lindahl, A. Vancauwenbergh
Europea Association of Urology (EAU) annual congress EAU Patient Group meeting (24.03.17)
European School of Oncology (ESO) 4th Observatory on Prostate Cancer (24.03.17)
Presentation L. Denis: 'The patient's perspective'
Board meeting Europa Uomo (25.03.17)
Patient Symposium Tackle (28.03.17)
 London, UK
 23-28.03.17

J. Dowling, K. Mastris
Scientific Advisory Group meeting at the European Medicines Agency (EMA)
 London, UK
 04.04.17

E. Briers
European Medicines Agency (EMA) Committee for Advanced Therapies (CAT) meeting
 London, UK
 10-12.04.17

C. Arnold, L. Denis, A. Deschamps, J. Dowling, W. Jansen, S. Lindahl, K. Mastris, A. Vancauwenbergh
Board meeting Europa Uomo
 Antwerp, Belgium
 26.04.17

C. Arnold, K. Mastris
36th European SocieTy for Radiotherapy & Oncology (ESTRO) annual meeting
 Vienna, Austria
 05-09.05.17

Appendix 2: Bye-Laws Europa Uomo



Bye-Laws (House Rules) to the Statutes of Europa Uomo as a registered Not For Profit organisation under Belgian Law

Note this English text is for the convenience of member organisations. The legal text is in Dutch and in cases of conflict the Dutch version takes precedence over the English text.

Bye-Laws (House Rules) adopted by the General Assembly of Europa Uomo, Warsaw, 2015 in accordance with Article 8.1(h) of the Statutes of Europa Uomo

These Bye-Laws are house rules to enable the Board and the General Assembly to properly give effect to the Statutes adopted in London 2014 and later registered under the laws of Belgium.

Wherever the wording of the Statutes is clear in terms of implementation no Bye-Laws are required. Whenever the Statutes are silent, or give insufficient guidance on implementation, Bye-Laws have been adopted.

These Bye-Laws cannot alter the Statutes and it was not open to the Board or General Assembly to make any proposals in the form of a Bye-Law which would, in effect, alter the meaning of a Statute.

Note: These Bye-Laws are based on the Statutes adopted at the General Assembly in London 2014. The use of the male pronoun "he" shall be taken to also comprehend the female pronoun "she".

Europa Uomo Bye-Laws

Article 1 Legal Form -name	No Bye-Laws Required
Article 2 Registered offices	No Bye-Laws Required
Article 3 Objectives and goals	No Bye-Laws Required
Article 4 Duration	No Bye-Laws Required
Article 5	
Introductory Paragraph	No Bye-Laws Required
Categories of Membership:	No Bye-Laws Required
Voting rights for Other Members:	No Bye-Laws Required
Use of Europa Uomo Name by national bodies	No Bye-Laws Required
Responsibilities of Europa Uomo Members	

The main responsibilities of Europa Uomo members are:

- 5.1.1** to actively support men with prostate cancer and prostate-related conditions in their own jurisdiction;
- 5.1.2** to actively promote prostate cancer awareness in their own jurisdiction and to participate in EPAD (European Prostate Awareness Day);
- 5.1.3** to ensure that they send at least one delegate (with English-speaking fluency) to the Annual and Special General Assemblies of Europa Uomo;
- 5.1.4** to participate in Europa Uomo sub-boards/committees and assignments (with English speaking fluency), and Master Classes, insofar as its resources allow;
- 5.1.5** to provide, where its resources allow, mentors for appointment to current and prospective Europa Uomo members who request such assistance;
- 5.1.6** to contribute, whenever possible, to the Europa Uomo Newsletter;
- 5.1.7** to contribute, whenever possible, to the Europa Uomo Website;
- 5.1.8** to furnish an Annual Report, including a financial report, of its activities for the year prior to the General Assembly;

5.1.9 to carry the vision and mission of Europa Uomo and all relevant information to its members, if possible, and insofar as resources may allow, adapted to the national languages, cultural and economic conditions leading eventually to equity in medical care for all European citizens.

5a Full Members

No Bye-Laws Required

5b Associate Members

No Bye-Laws Required

5c Supporting Members

No Bye-Laws Required

5d Honorary members

No Bye-Laws Required

Article 6 Termination of Membership by decision of the General Assembly

6.1 A motion to terminate the membership of an organisation may be proposed to a General Assembly where the organisation is considered to no longer fulfil the criteria for membership viz.,

- (i) its governing board no longer has a majority of prostate cancer patients;
- (ii) it no longer enjoys full administrative and organisational liberty and autonomy;
- (iii) it is no longer functioning in any meaningful way as a prostate patient support organisation;
- (iv) failure to pay membership dues for two consecutive years;
- (v) is found to have misled the General Assembly in a material fashion at the time of its application for membership.

6.2.1 A termination motion may be tabled by any three Europa Uomo members or by the Board

6.2.2 Such a motion to terminate membership shall be placed on the agenda for the next General Assembly;

6.2.3 The motion to terminate shall state which membership criteria have been breached;

6.2.4 All motions and accompanying documentation shall be in English.

6.3.1 Any motion(s) which fails to meet all the requirements of these bye-laws shall be deemed invalid.

6.3.2 Where a termination motion is considered by the General Assembly, fair procedures shall apply and these are set out in Appendix A to these bye-laws.

6.3.3 An organisation whose membership is terminated may nonetheless apply for re- admission to the Coalition as a Full Member or Other Member in accordance with the statutes of the Coalition – see Art. 5 and Art. 6.

6.4 On each third anniversary year of a member joining Europa Uomo the member organisation shall submit to the Board its current annual business reports. A short summary in English shall also be provided.

Article 7 Annual dues

No Bye-Laws Required

Article 8 Powers of the General Assembly

8.1(a) Changing the Statutes - See Article 9

No Bye-Laws Required

8.1(b) Appointing the Board

(i) Europa Uomo members can nominate any person from a member organisation for membership of the Board.

(ii) Nominations can be made during a General Assembly or before.

(iii) Nominations should include written information, CV or résumé, and a statement about the background and goals of nominee.

8.1(c) Nomination of Auditor

The nominee for auditor shall be approved by a majority vote.

8.1(d) Approving the Budget

(i) Budgets shall be proposed to the members for their approval not later than three months prior to the commencement of the budget year.

(ii) A statement of annual accounts shall include all assets and liabilities and the reports of the internal review and the independent auditor.

8.1(e) Discharge to the Board

The Board may be discharged by majority vote of members;

8.1(f) Dissolution

No Bye-Laws Required

8.1(g) Acceptance or exclusion of members

Members are accepted or excluded by majority vote of those voting delegates present or represented at the General Assembly;

8.1(h) Acceptance of Bye-Laws

Bye-laws may be approved by majority vote of voting delegates present or represented at the General Assembly.

8.2 Composition of General Assembly & Conflict of Interest

Where a Conflict of Interest may arise for a delegate the provisions of this Bye-Law 8.2 Appendix 2 shall apply

8.3 Assembly and Notice of meetings

No Bye-Laws Required

8.4 Quorum and Voting

No Bye-Laws Required

Article 9 Change of Statutes

No Bye-Laws Required

Article 10 Powers of the Board

10.1 Establishment of subordinate boards and committees Pursuant to the responsibilities of the Board to realise the goals and objectives of Europa Uomo the Board shall establish such sub-boards or committees as it deems necessary, including the following:

10.1.1 The Board shall establish a Scientific Advisory Group (SAG) and shall appoint its chairman and appoint to it specialists in prostatic diseases, scientific/medical research and such members of patient organisations, including those from Europa Uomo members, as the Board deems fit. The functions of the SAG shall be determined by the Board.

10.1.2 The Board shall establish a Finance Board under the chairmanship of the Treasurer and shall appoint, wherever possible, a person(s) expert in fund-raising for voluntary and/or patient bodies and such other persons as may assist Europa Uomo in the gathering of funds to finance its activities. The terms of reference shall be determined by the Board.

10.1.3 The Board shall establish a College of Liaison Officers (LOC) for Europa Uomo drawn from the nominations of member organisations. These Liaison Officers (LOC) shall be available to existing member organisations and prospective member organisations that seek and/or require assistance.

10.1.4 In all cases these Sub-boards and Special Working Groups/Committees shall report, through the main Board, to the General Assembly.

10.1.5 Subject to ratification by the General Assembly, the Board may enter into bilateral agreements with external organisations such as the Board consider may further the aims and objectives of Europa Uomo. Educational grants shall be exempted from the need for GA ratification

10.1.6 The Board may establish a Project Commission, with at least three members but not more than five members, to undertake special projects on behalf on the Board or as a result of a General Assembly decision. Where the Board appoints less than five members the Commission may co-opt additional members provided that the number of members does not exceed five members. The Board shall determine the Committee's terms of reference.

Appointment of consultants to the Board

10.1.7 To better realise the aims and objectives of Europa Uomo the Board may appoint suitable persons to a consultancy role. The nature of consultants' responsibilities and authorities may vary in accordance with the contents and assignments. A consultant to the Board shall be advisory or as the Board may determine. In general terms, however, a Board consultant should act on the instructions of the Chairman of the Board and report to the Board through the Chair and, as required, at Board meetings.

Ex-officio Appointments

10.1.8 Where the Board is of the view that the administration and management necessary to realise the goals and objectives of Europa Uomo would be enhanced it may also appoint suitable persons to the Board as *ex-officio* members on the basis that an ex-officio member shall have all privileges of a Board member, and shall receive all the information afforded to elected members of the Board and can appear at Board meetings but shall have no voting rights. The term of office of such ex-officio members shall be set down by the Board at the time of appointment. The Board may, with the approval of the General Assembly, renew such terms of office. These provisions do not apply to any ex-officio appointments made in accordance with Bye-Law 10.01.10.

Patrons

10.1.9 Where the Board is of the view that the realisation of the goals and objectives of Europa Uomo may be enhanced it may appoint suitable persons as Patrons of Europa Uomo. Such appointment(s) shall be subject to the approval of the next General Assembly, at which the Board shall outline its reasons for the proposed appointment(s).

Partner Organisations

10.1.10 Where the Board is of the view that the realisation of the goals and objectives of Europa Uomo would be enhanced by agreements with partner organisations, it may invite the partner organisation to nominate an *ex-officio* member to the Board, recognising that the partner organisation shall determine the possible replacement and term of office of such appointee. Such member shall have all the privileges of a Board member, and shall receive all the information afforded to elected members of the Board and can appear at Board meetings, but have no voting rights.

Insofar as is feasible, the Board and the Partner Organisation shall set a term for the appointment for such *ex-officio* Board member which is compatible with the terms of office of full Board members.

10.1.11 All members of sub-boards/committees shall have equal privileges and voting rights.

Responsibilities of Board Members

10.2.1 The Chairman shall assign at least one area of responsibility to each Board Member other than the Treasurer and the Secretary.

10.2.2 The Board Member shall report on his area of responsibility at each Board meeting.

10.2.3 The Board Member shall submit a report in writing on his activities to the General Assembly one month prior to the General Assembly.

Conflicts of Interest for Board Members

10.2.4 Where a Conflict of Interest arises in connection with a member or prospective member of the Board, the Bye-Laws as set out in Appendix B shall apply.

Board Meetings, Time Limits, Non-Attendance of Board Members

10.3.1 The Board, at the conclusion of the General Assembly, shall meet to agree the dates of Board meetings.

10.3.2 The Board shall review and appoint/reappoint the members of permanent sub-boards/Committees established under Art. 10.1 not later than three months following the General Assembly.

10.3.3 Not later than four months following the General Assembly the Board shall agree and issue to all member organisations its work programme for the following three years, to be adapted each year.

10.3.4 Any member of the Board who fails to attend two successive meetings between the end of an Annual General Assembly and the commencement of the following Annual General Assembly shall offer their resignation from the Board unless a reason for their absence acceptable to the Board is proffered to the Secretary in writing by the said Board member within 10 working days of the second missed Board meeting. Such a Board member who fails to furnish an explanation acceptable to the Board within the stipulated time shall not take any further part in the functioning of the Board or any sub-board on which he served. At the next Board meeting the former Board member shall be the subject of a formal motion that the former Board member shall be deemed to have resigned. The member may appeal the Board's action to the next General Assembly.

10.3.5 English is the working language of the Board and the organisation generally. Candidates for the Board shall make a declaration that they can speak and read English with sufficient fluency as will permit them to properly fulfil the role of a Board member.

10.4 Decisions of the Board

No Bye-Laws Required

10.5 Register of Resolutions & Employee Provision

No Bye-Laws Required

Article 11 Legal representation and third parties

No Bye-Laws Required

Article 12 Annual Report, Budget and Accounts (See also Bye-Laws re 8.1(d) re: budget and statement of accounts)

12.1 The Secretary's Annual Report shall be presented to the Board not later than one month before the date on which formal notification to members is issued for the General Assembly and the report shall be distributed for approval to member organisations with the notification of the General Assembly.

12.2 The Treasurer's Report shall be presented to the Board not later than one month before the date on which formal notification to members is issued for the General Assembly and the report shall be distributed for the approval to member organisations with the notification for the General Assembly.

Finance and Budget

12.3 A Finance Board established under Bye-Law 10.1.2 shall prepare the budget.

12.4 It is not necessary that all members of the Finance Board/Committee should be Board members. If a member organisation has a qualified accountant (possibly retired or semi-retired) it may be asked to provide the services of that person to act on the Finance Board as either an elected or appointed member. The Treasurer shall be the reporting link to the main Board.

12.5 Detailed budget rules and rules for travelling costs shall be drafted by the Finance Board and, when adopted by the main Board, considered and approved by the General Assembly.

12.6 The general functions of the Finance Board should be set out in Bye-Laws as follows:

- (i) to have prepared three-monthly reports of income and expenditure to issue to the Board quarterly;
- (ii) to monitor expenditure and income against budget and report to the Board;
- (iii) to determine and agree on the likely sources of revenue and agree a fund-raising Plan of Action;

- (iv) in conjunction with the Chairman to meet with likely donors;
- (v) to furnish a quarterly financial statement to the Board and member organisations;
- (vi) to prepare provisional accounts for inspection and/or audit as required by Belgian law;
- (vii) to prepare a provisional budget for the year ahead for circulation to the member organisations no later than January of the year in which it applies;

12.7 Other members of the Board shall report on their assigned portfolios in writing to the members of the General Assembly and their reports shall be issued with the notice of the convening of the General Assembly.

Article 13 Dissolution of Europa Uomo

No Bye Laws Required

Article 14 Liquidation, assets

No Bye-Laws Required

**Article 15 General: Other Provisions where Bye-Laws are Appropriate
Newsletter and Website**

15.1 The organisation's publications like the newsletter and website represent the organisation and as such should not be the prerogative of any one person or one member organisation. The Newsletter and Website are provided for in Bye-Laws along the following lines:

- (i) An Editorial Board, appointed by the main Board, shall have operational responsibility for the Newsletter and Website.
- (ii) The main Board of Europa Uomo shall appoint three persons to the editorial board. At least one of these appointees shall be a member of the Main Board. The Editorial Board shall have the power to co-opt in turn a further two members provided its membership does not exceed five and no one member country shall have a multiple membership on the Editorial Board. At least one of the persons appointed by the main Board or co-opted shall be, whenever possible, a person with some experience of on-line journalism or public affairs.
- (iii) The Editorial Board shall elect its own Chairman, and shall appoint the Newsletter Editor and the Europa Uomo Webmaster, subject to the approval of the main Board.
- (iv) No article or contributions should appear in the Newsletter or be put up on the website without having been read and agreed by at least two members of the Editorial Board in advance of publication or posting.
- (v) The Editorial Board shall present a proposed budget for the following year to the Finance Board before the end of December each year.
- (vi) The Editorial Board shall report to the General Assembly each year.

Participation of guests in Board meetings and General Assemblies

- 15.2**
- (i) The Board may invite such guests as it may deem beneficial to attend Board meetings and General Assemblies.
 - (ii) Guests in attendance at Board meetings or General Assemblies may speak as requested by the Chair or by permission of the Chair.

Europa Uomo communication rules and systems

- 15.3**
- (i) Europa Uomo outgoing correspondence shall be approved by the Chairman and Secretary and in the event that one or other of these officers being unavailable, one of the Vice-Chairmen may temporarily substitute for the Chairman, and the other Vice Chairman may temporarily substitute for the Secretary.
 - (ii) The Secretary of Europa Uomo is responsible for implementing and maintaining appropriate forms of communications management for both electronic, paper and telephone communications, including an accessible registry of incoming and outgoing correspondence and documents and a system of bringing forward correspondence and other documentation for action by pre-set dates so that no correspondence is left unattended or unanswered.
 - (iii) The Secretary shall obtain reports of the various sub-boards/committees at least two weeks before each ordinary Board meeting.

Bye-Laws Appendix A

Fair Procedures for the Termination of Membership of Europa Uomo

- A1 A motion to terminate the membership of an organisation may be tabled by: (a) the Board of Europa Uomo; (b) by a motion signed by the governing bodies of at least three full member organisations of the Coalition.

A2 Such motion(s) to terminate membership shall be furnished to the Secretary of the Board not less than 30 days in advance of the date of any forthcoming General Assembly or be accompanied by a request for a Special General Assembly called to deal with such a motion.

A3 The motion to terminate membership shall indicate the reasons why the proposers believe the member is in breach of the criteria for membership as set out in Article 5 and Bye-Law 5. Any supporting documentation for the motion must accompany the motion. All motions and accompanying documentation shall be in English.

A4 Any motion that fails to meet all the requirements of A2 and A3 above shall be deemed invalid.

A4.1 Fair procedures shall apply to the consideration of any motion to terminate membership.

A4.2 Where a termination motion is received by the Secretary of the Coalition he shall, not less than five days after receipt, notify the member organisation which is the subject of the termination motion and provide them with all documents furnished in support of the motion which shall be in English.

A4.3 The Secretary shall inform the said member organisation that they may submit a response to the motion by letter, email or text, in English not later than a full seven days before said General Assembly or Special General Assembly.

A5 The Secretary shall furnish to all accredited delegates the terms of the motion and the documents furnished in support and the response of the member organisation not later than five days before the date of any General Assembly or Special General Assembly.

A6 At the Assembly, General or Special General, the Board shall timetable the consideration of the motion providing not more than 30 minutes for the proposer of the motion to set out their reasons for their motion.

A7 Immediately after the motion's proposers have presented their case the member organisation which is the subject of the motion shall have not more than 30 minutes to reply to the motion and the accompanying presentation.

A8 With the permission of the Chair of the meeting, the proposers or respondents may have one or more speakers provided the time limits in A6 and A7 are not contravened.

A9 At the conclusion of the presentation by the respondents, the proposers of the motion will have not more than 5 minutes to reply and respondents will then have not more than 5 minutes for a final comment.

A10 Following the conclusion of the presentations and responses the Chairman shall proceed to a vote of the accredited voting delegates and representatives. A simple majority of votes cast is required to decide whether the motion is carried or not.

Bye-Laws Appendix B

Articles 8.2 & 10.2 Conflicts of Interest of Voting Delegates or Board Members

These provisions shall apply to Voting Delegates per Article 8.2 and to Members of the Board per Article 10.2

B1 Where major conflicts of interest occur these shall prohibit participation in a General Assembly as a Voting Member and membership of the Board of Europa Uomo.

B2. A major conflict of interest is deemed to occur where a person:

B2.1. Was previously employed by a pharmaceutical company or holds or has held shares in a pharmaceutical company or a company which has material control of a pharmaceutical company within the previous five years, or a person who profits directly or indirectly from relations with the pharma industry.

B2.2. Is a close relative* to a person working for or having shares in a pharmaceutical company.

B2.3 Having served as a paid advisor, or consultant, to a pharmaceutical company within the previous five years.

B2.4. Has been paid or was granted any emolument, for whatever reason, by a pharmaceutical company.

B2.5. Has a patent on a pharmaceutical product or process or has held such patent within the past five years.

B3 A minor conflicts of interest is deemed to occur and must be declared if a person is to be involved in a Europa Uomo project or where a relevant item is on the agenda for a meeting. Where such declaration is made the meeting shall determine whether the person concerned shall participate further, in whole or in part.

B3.1 Minor conflicts of interest are deemed to be where the person:

(a) has participated in trials/studies with a pharmaceutical company as the main sponsor

(b) has received money or other emolument in a personal account for speaking at a conference or any other occasion sponsored by a pharmaceutical company.

**A close relative is a spouse, life partner, sibling, father, mother, aunt, uncle or first cousin or other first grade relative*

Appendix 3: Statutes Europa Uomo



STATUTES OF EUROPA UOMO

A non-profit association according to Belgian Law

Adopted by the General Assembly of Europa Uomo, London, 2014.

These Statutes replace those previously registered in Milan, Italy
and have been registered under Belgian Law No 556-724-867

Chapter I - Legal form – name - registered office - objectives and goals - duration

Art 1 Legal form – name

With this a national not-for-profit association with the name “Europa Uomo”, also called “The European Prostate Cancer Coalition”, EUomo or the Coalition is created.

The association is created in accordance with Belgian law (27 June 1921) on not-for-profit associations, international not for profit associations and foundations in this the NFP law.

Art 2 Registered office

The registered office of Europa Uomo is Lange Gasthuisstraat 35-37, 2000 Antwerp, Legal district Antwerp. The Board can create administrative or added offices when and where it sees the need to do so both in Belgium or abroad on condition that it takes into account the laws and language decrees of application.

Art 3 Objectives and goals

The principal concerns of Europa Uomo (the Coalition) are prostate cancer and prostate related conditions.

Europa Uomo aims to give support and solidarity to men and their families throughout Europe, by calling for greater information and awareness by public and health operators about prostate cancer and its prevention and treatment, to increase general awareness of the importance of this disease and foster greater collective commitment to research, prevention, early diagnosis and treatments.

Europa Uomo shall promote initiatives to give appropriate priority to the problem of prostate diseases in general and prostate cancer in particular, as a European health issue, with full respect for cultural diversity in each country.

Such aims shall also be pursued by organising international campaigns at European level, involving conferences, publication of journals and other information material, research, exchanges and seminars.

Europa Uomo may take part in any discussion or activities at EU and international level on any matters that may involve patients, their treatments and rights, to take positions on these and communicate them to the appropriate parties. As such, Europa Uomo can take part in any multi-stakeholder organisation to defend the position of its membership without giving up its independence. Also Europa Uomo may take up representation at European or international level organisations.

Europa Uomo shall also assist its affiliate members, active within their national boundaries, to obtain the same exposure and awareness by organising advocacy training, providing basic information tools (brochures, web site materials etc) that can be used by the affiliate members.

Europa Uomo shall serve to promote quality of life for prostate patients and their families, and shall use all possible means to help this promotion.

Europa Uomo may acquire assets of any kind and enter any agreements, including commercial contracts that may become necessary for or useful to the pursuit of Europa Uomo’s corporate purposes.

Art 4 Duration

The association is created for unlimited duration.

Chapter II – Membership

Art 5 Members

The association has two categories of membership: Full Members and Other Members. In the category of Other Members we make a distinction between Associate Members, Supporting Members and Honorary Members. The association must have a minimum of three full members with all the rights as described for members in the NFP law. The founders are the first full members. Full members have all the rights and obligations that are listed in the NFP law and in these statutes. Other members have only those rights and obligations that are listed in these statutes. Other members have no voting rights.

In general, patient associations that wish to become a member of Europa Uomo cannot use this name unless it is followed by a designation of a location such as a country.

5a Full members

Freely established patient-led [having a governing body with a majority of patients] prostate cancer patients' supporting associations subscribing to the objectives of Europa Uomo, while enjoying full administrative and organisational liberty and autonomy, may apply for full membership. Member organisations are completely free to organise their association in accordance with the legal and practical possibilities of their country.

5b Associate members

Freely established patient-led [having a governing body with a majority of patients] patient organisations that deal with patient support in general and issues in cancer in particular and subscribing to the objectives of Europa Uomo, while enjoying full administrative and organisational liberty and autonomy, may apply for associate membership. Associate member organisations are completely free to organise their association in accordance with the legal and practical possibilities of their country.

5c Supporting members

Organisations that subscribe to the objectives of Europa Uomo and have administrative and organisational liberty and autonomy may apply for supporting membership. Supporting membership may also be offered to organisations that can help to realise the objectives and goals of Europa Uomo.

5d Honorary members

Individuals may be offered honorary membership of Europa Uomo as a reward for services rendered to Europa Uomo.

Art 6 Membership, acceptance, exclusion, resignation

Any organisation that wishes to apply for membership under 5a, 5b or 5c, must file an application for membership with the secretariat of Europa Uomo. In this application, the candidate member must submit all necessary information (statutes, governing body composition, budget, working report for the previous year and funding sources) in order for the Board of Europa Uomo to judge the eligibility of the applicant. Based on the consideration of the application the Board shall make a proposal to the next General Assembly where a majority vote shall decide on the application.

Where an application for "full" membership is not accepted the applicant may, at the discretion of General Assembly, be offered "associate membership".

At Europa Uomo General Assemblies only full members may vote under the following conditions:

- for each country with at least one full-member there will be one vote.
- If there is more than one full-member in a country, it shall be a matter for
- these full-members to decide who will have their national vote.
- If the full members of a country cannot decide by a majority vote who shall
- exercise the national vote they shall forfeit the national vote at the upcoming
- General Assembly.
- A full voting member shall be nominated for each General Assembly.

Candidates for the status of supporting members and honorary members may be proposed by the Board to the General Assembly which shall decide by simple majority on the candidature of these members.

Membership shall become effective only after a positive decision of the General Assembly, subject to the provisions of Article 6 of the statutes.

At General Assemblies all members may participate, but only one full-member [the voting delegate as defined in this article] per country may vote and all others may be present as observers and may give opinions and advice.

Any member organisation may submit its resignation by a registered letter together with a copy of their organisation's Motion to that effect signed by both its Chairman/President and its Secretary, to the secretariat of Europa Uomo.

Membership shall cease on receipt of the resignation letter. Any resignation shall be reported the next General Assembly.

Membership may be terminated by decision of the General Assembly for failure to fulfil the criteria of active membership. Such termination must follow proper fair procedures.

“Full” and “Associate” members shall be invited every three years to submit documents to prove that they are still in compliance with the criteria for membership.

Art 7 Annual dues

The General Assembly shall decide on annual dues per member category on a proposal by the Board. At the commencement of these statutes the annual dues are set as follows:

Full-members and associate members: 100 Euro

Supporting members: a donation agreed with the Board

Honorary members: no dues

The Board, at its discretion, may recommend the General Assembly a waiver of dues from new members subject to such waiver not exceeding three years.

Chapter III - General Assembly

Art 8 General Assembly

8.1 Powers of the General Assembly

The following powers are exclusive to the General Assembly:

- [a] Changing the statutes
- [b] Appointing the Board by election and, if appropriate, Commissioners
- [c] Approving the budget and annual accounts
- [d] Giving discharge to Board members and, eventually, Commissioners
- [e] Dissolve Europa Uomo by its own decision
- [f] Acceptance or exclusion of a member
- [g] Acceptance of house rules or bye-laws and their alteration

8.2 Composition

The General Assembly shall comprise all members of Europa Uomo. As set forth under Art. 5 and 6 of these statutes, the “Full” members delegates from each country shall decide in advance on the delegate who will have the voting rights for their country. This delegate will be called the “voting delegate”.

The voting delegate shall declare that he or she has no conflict of interest on any point of the agenda. Should a conflict of interest be declared than the delegate shall leave the assembly during deliberations and votes on agenda points on which he or she has declared a conflict of interest.

8.3 Assembly and invitation

The General Assembly shall meet in plenary session; voting shall be on a country basis by the Voting Delegates only.

The General Assembly shall meet under the Chairman/President of Europa Uomo, at least once every year. The meeting shall be convened by letter, fax, text message or e-mail sent not less than 30 days in advance of the date of the meeting.

8.4 Voting, deciding

The quorum for an ordinary General Assembly meeting is fifty per cent (50%) of countries represented in the Coalition plus one. Representation by proxy is permissible by simple letter, fax or e-mail to the secretariat. No proxy holder may hold more than one mandate.

If there is no quorum, a second ordinary Assembly may be convened in accordance with Art. 8.3 and shall be legal whatever the number of Voting Delegates present or represented. Only voting-delegates may act as proxies and no voting delegate may exercise a proxy for more than one other.

The members of the Board have no voting rights.

All resolutions shall be decided by simple majority unless specified otherwise in these statutes and the NFP law. Resolutions shall be minuted in a record signed by the Chairman/President and the Secretary of Europa Uomo and kept in the registered office of Europa Uomo. Amendments to these Statutes and to the bye-laws of Europa Uomo may be decided by ordinary General Assembly meetings provided that the contents of such amendments are clearly indicated in its agenda and in accordance with art. 8.

Should Europa Uomo need to be legally represented, the Board shall decide for each case separately who shall represent its interests. On all legal actions both as plaintiff or defendant, the Board shall report progress and outcome to the General Assembly.

Art 9 Change of Statutes

Change of Statutes, notwithstanding the application of the laws on not-for-profit associations, international not-for-profit associations and foundations, any proposal for a change in the statutes or the dissolution of Europa Uomo shall not be considered unless it has the support of at least one fifth [20%] of countries having “full” membership of Europa Uomo.

The Board, on receipt of such proposal, shall decide whether the proposal shall be considered at the next ordinary General Assembly or should be considered at a Special General Assembly.

Such General Assemblies may only decide on any change in the statutes if two-thirds of the voting-delegates are present or represented by proxy.

A proposal to alter these Statutes shall have effect only if carried by three-quarters of the votes cast.

If the required quorum is not reached a new assembly may be called to meet not less than 15 days after the inquorate meeting and shall decide by a three quarters majority of those present or represented whether to disregard the quorum requirement.

Chapter IV - Board

Art 10 Board

10.1 Powers of the Board

The powers reserved exclusively to the General Assembly are set forth under art 8.1 or in accordance with the NFP law.

The Board shall be responsible for all matters of administration and management necessary to realise the goals and objectives of Europa Uomo.

The Board may decide to delegate the day-to-day management of Europa Uomo to one or more of its members or other persons. The Board shall decide on the powers of such executive management.

10.2 Composition

The Board shall consist of maximum 7 members elected from a list of persons proposed by the “full” members. At all times, the number of board members has to be lower than the total number of full members, and minimum three.

Board members may be elected for a term of three years and upon completion of such term are eligible to be immediately re-elected for a further term of three years after which they shall stand down for at least three years before being eligible for re-election. Board membership is personal to the Board member and not for the “full” member.

As a matter of law board membership ceases on death, resignation, incapacity to participate at Board meetings (as decided by the other Board members), a decision to withdraw membership by the General Assembly, loss of civil rights, or the said member being declared unfit to hold the position because of conduct considered by the General Assembly unbecoming a Board member. Or by his own national full member organisation.

Board members shall declare that he or she has no conflict of interest on any point of the agenda. Should a conflict of interest be declared then the Board member shall leave the meeting during any deliberations and votes on agenda points regarding which he or she has a conflict of interest.

Board members may at all times be removed from the Board by a decision of the General Assembly for stated cause by a two/third majority. Such removal must follow proper fair procedures.

Should a Board member cease their tenure as a Board member for whatever reason, the position shall be filled, by an election at the next general assembly.

The Board shall elect from its membership a Chairman (also Chairman of Europa Uomo the legal representative of Europa Uomo), a secretary (also Secretary of Europa Uomo) a treasurer and two Vice-Chairmen. Any outgoing Chairman shall be available to the Board if so required.

All decisions on the appointment and changes in the composition of the Board shall be published according to Belgian law.

10.3 Meeting of the board, invitation

The Board shall meet at least twice a year. Meetings shall take place in response to an invitation by mail, fax, electronic means by the Secretary and sent at least fifteen days before the meeting date. The Board can also be convened whenever the President or the Secretary consider it necessary or when a minimum of three members of the Board requires so in writing.

10.4 Decisions

Resolutions shall be decided by simple majority provided that a majority of members are present. If there is a tied vote, the chair of the meeting shall have both a deliberative and casting vote.

10.5 Register of resolutions

The resolutions of the Board shall be written in a record signed by Chairman/President and Secretary.

Should the need arise, the Board may employ and pay a person or persons qualified to organise and carry on the work of Europa Uomo. The terms and conditions of employment of any employees will be set by the Board and the employment shall be subject to the laws of the country in which they are employed.

Art 11 Legal representation and third parties

Any document that binds Europa Uomo may be signed by any two Board members who have been given this authority by the Board. These representatives do not have to prove their status.

The Board exercises all the legal rights of Europa Uomo and in such an event may be legally represented by two Board members, its President, Secretary or any executive charged with such by the Board.

Any decision on the appointment or termination of persons qualified to commit Europa Uomo shall be published according to Belgian law.

Chapter V - Budget and accounts

Art 12 Annual Report, Budget and Accounts

The financial period shall end each year on 31 December.

The Secretary shall prepare the Annual Report and the Treasurer shall prepare the balance sheet for the closing financial period and the budget for the opening of the next Financial year. All such documents shall be submitted for approval to the General Assembly and as such distributed to the membership. The General Assembly shall decide on the nomination and appointment of an independent auditor in Belgium.

After the approval of the annual accounts and the budget the general assembly shall vote on the acquittal of board members and commissioners if there are any. The Board shall be responsible for the publication of the annual accounts according to Belgian Law.

Chapter VI - Dissolution - liquidation

Art. 13 Dissolution:

Europa Uomo may be dissolved by a resolution supported by not less than two-thirds of the voting delegates meeting for this purpose. A resolution to dissolve Europa Uomo must be notified to all assembly members not less than 45 days before the proposed General Assembly or special General Assembly.

A resolution to dissolve Europa Uomo may be tabled by (a) the Board having so decided by simple majority or (b) by at least one third of the Full Members of Europa Uomo.

A resolution to dissolve Europa Uomo must be approved by not less than four-fifths [80%] of the voting-members present or represented at the General Assembly or Special General Assembly convened for this purpose.

Art.14 Liquidation, assets

Should the proposal to dissolve Europa Uomo be carried, the net assets of Europa Uomo shall be transferred to a similar not-for-profit association.

Chapter VII - General statement

Art 15 General statement

For any matter that has not been mentioned in the above statutes Europa Uomo shall act in accordance with The NFP law.

Thanks to our sponsors



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A TOUGH NUT TO CRACK

*A man's prostate may be as small as a walnut,
but that doesn't mean it should be ignored*

It is estimated that one in seven men will face some form of prostate cancer over their lifetime.

The majority of these prostate cancers are low risk, evolving slowly and rarely needing treatment or become life threatening. However, medium and high-risk cancers require immediate attention as soon as they are discovered. Early treatment is essential before they progress into metastasis, which can have fatal consequences. These early forms of cancer can often be symptomless, so it is essential to be vigilant. All men from the age of 45 should ask their doctor about a PSA blood test. The result can provide indication of their prostate's health and whether further testing is needed.

www.europa-uomo.org/awareness



Europa Uomo, the European Prostate Cancer Coalition is the umbrella organization for prostate cancer patients with members in 24 countries.