



The Voice of Men with Prostate Cancer in Europe

**Annual Report
of the Board
2017/18**

1. Chairman's Note

The adoption of this third Annual Report for Europa Uomo at the 2018 General Assembly near Dublin, will mark the conclusion of my two three-year terms on the Board. The past six years serving the membership in various offices of Europa Uomo have been both an honour and privilege. My thanks go to all of you, and your colleagues at home for their support.



When I came onto the Board in 2012, my basic objectives were the same as with my work for Tackle in the UK, viz., to improve the way we work as an organisation and to continue to work so that men get the right treatment at the right time. As I review these past six years I recall how we struggled, through much debate and confusion, to get our statutes into sufficient order to finally get ourselves legally registered as a Belgian not-for-profit. I was Treasurer for a time and being then responsible for our funding arrangements, I was concerned at how the lack of a business plan might hamper us, financially and organisationally, in the future. There were also issues associated with our handling of the transition from the founders who built the organisation since 2003.

I had to come to terms with the fact that we are all volunteers and that a small Board could not do it all. To manage the change process, we needed to be open and transparent with our members and our stakeholders. Our relationships with some of our stakeholders was mixed. It took some years of patient diplomacy to ensure that we improved and developed our relations with the likes of the urologists (EAU), the medical oncologists (ESMO), the big patient groups like ECPC, the intergovernmental bodies like ECCO, and of course one of our most important links: the European Medicines Agency (EMA). With these and

others we continue to forge our links and to make for a more meaningful relationship on behalf of prostate patients.

The other side of the coin was to improve our internal working. This meant examining honestly our strengths and weaknesses by means of a far-reaching review. This led to a strategic plan adopted by the 2016 GA and we are now well advanced on its implementation. Within our democratic structures, we also must give consideration to orderly succession planning in the same way as we do financial planning. It has been my good fortune to work with a Board who have been prepared to face the challenges, including its own renewal.

With a part-time Board of volunteers, it all takes time and effort, but I hope you are beginning to see the fruits of this. In the coming months we are putting in place a development programme for eastern Europe with an appointment in Warsaw, and which I think will raise our visibility and help grow our organisation in that part of Europe. We are also beginning to introduce new branding.

In addition to all these organisational matters, the reasons for our existence have to be kept to the foreground. With our increased access to policy and decision-makers we constantly raise our concerns about the inequality of treatment across the continent, and the wide variation in the access to drugs. While this has been one of my personal concerns, I have also sought to encourage our member organisations to better prepare themselves to deal with issues that are facing them in their own countries, I sought to give more people insight into the work of our organisation through the introduction of Liaison Officers. And we move another step forward with the development of our own training programme, a pilot for which will be tried out at this GA in Dublin. Some

of our members do this already, but at the Coalition level we must do more.

Improving communications was high on my agenda and dealing with it took longer than I would have liked. Although we do our business through the medium of English, it is not easy to communicate in written form with so many for whom reading and writing in English can be done only with difficulty. We consulted in 2016 with members and one result was the weekly *Update* which commenced in February 2017 and which has drawn very favourable comment from stakeholders. But this was only one step. We also commissioned a more far-reaching review, the results of which are currently under consideration by the Board.

Raising awareness of prostate disease, especially prostate cancer is one of our core activities. It is vital that we eliminate the spectre of so many men being diagnosed with advanced prostate cancer. It is not necessary, it is preventable, and a large proportion of prostate cancer deaths are avoidable.

Europa Uomo is now recognised as the voice of prostate patients in Europe. Our national member organisations continue to grow in influence in their home countries. Prostate patients are now experiencing a greater involvement at all levels. In Europe much of the patient involvement is unseen, but patients now participate, not only in the important committees of the EMA and EAU, but also in the work of committees that review applications to market new drugs, applications from pharma seeking advice from the EMA on matters that have not yet reached marketing application stage, competitions for research funding, guidelines for prostate cancer diagnosis and treatment, and many others. I am confident that all this work is a reflection of our growing expertise as patients and for that I thank you all.

This third Annual Report tells the story of our work over the year on behalf of patients. It reflects our commitment to the next generation of prostate patients, it is testimony to our flexibility and to our drive to increase awareness in others and to improve ourselves by training and development. This Report also gives a more detailed account of the way we are trying to take forward the projects approved by the 2017 GA.

My thanks to all our sponsors for their funding, thanks also to Anja Vancauwenbergh and Brigitte Dourcy-Belle-Rose for their support to the Board. Working in partnership with all stakeholders is the way forward for our organisation and with this in mind my thanks also go to the EAU represented by Prof. Hein van Poppel, Dr. Alberto Costa of the European School of Oncology, and also to Prof. Louis Denis and Dr. Luc De Wilde of OCA.

The challenges ahead in the areas of funding, development of our membership and role in our European family are considerable. The Coalition will have to deal with the inequalities of access to treatment and drugs. These new treatments and drugs, which are now coming to market, come at a real cost to the health budgets in all countries and we must strive, with our stakeholders, to ensure that this issue will be tackled fairly among future prostate cancer patients.

Finally, my thanks go to the officers, the Board, to 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. The current Board, working together, have endeavoured to move Europa Uomo into the next phase as the voice of all prostate patients in Europe.

I wish the next Board all the best for the future and in the fight for prostate patients. For myself I will continue the fight as a member of the Board of ECPC.

Ken Mastris

Chairman

2. Executive Summary

- ❖ **Board Meetings:** The Board met seven times since the last General Assembly. These meetings are listed in Section 3, p.9
- ❖ **Strategy:** The Board sought to implement the Strategy adopted by the GA in 2015/16 as modified by the GA in 2017. The key developments have been the steps taken to realise the development of the organisation in eastern Europe and the implementation of a training programme. [Section 4, p.11]
- ❖ **Projects:** A number of projects have been planned and initiated, aimed at increasing awareness, communication, representation, broadening our membership, training and auditing of specialist units. [Section 5, p.18]
- ❖ **Funding and Financial Report:** In keeping with the changes last year in presentation of the financial report, the Board has continued to recast expenditure to support the shift to project-based activity. The report also includes the audited Balance Sheet for 2017 and the Actual Outcomes against Budget for 2017, as well as the projected Outturn 2018 and an Outline Budget for 2019. [Section 6, p.24]
- ❖ **Liaison Officers:** The role of Liaison Officers was co-ordinated by Ken Mastris. [Section 7, p.31]
- ❖ **EPAD:** The Board staged a joint event with the EAU for European Prostate Awareness Day. A seminar was held on 27 September in the European Parliament in Brussels. [Section 8, p.31]

- ❖ **Meeting Reports:** Board members attended a number of conferences and meetings [Section 9, p.31; see also Appendix I, p.37]
- ❖ **Patient Seminar:** In June 2017 a patient seminar was hosted by Ekke BÜchler in Vienna. [Section 10, p.33]
- ❖ **European Medicines Agency:** The EMA has been at the forefront of involving stakeholders, including patients, in its regulatory work. Europa Uomo has been among the patient representatives present on the scientific committees and in working parties. [Section 11, p.34]
- ❖ **Membership:** 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 Europe. [Section 12, p.35]
- ❖ **Communications:** The Board took a number of initiatives to make its communication strategy more focussed and effective. These will be implemented over the remainder of the year. [Section 13, p.35]
- ❖ **Appendix I:** Europa Uomo Activities (June 2017 – May 2018), p.37
- ❖ **Appendix II:** Reports of Meetings and Conferences, p.41

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 2017, Vice-Chairman Ekke Büchler stepped down, having completed two terms on the Board. This meant there was one vacancy occurring on the Board. There were originally two candidates nominated, but one withdrew their nomination before the election. One candidate stood for election and Pentti Tuohimma (Finland) was elected in accordance with the Bye-Laws.

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

The full Board for 2017–18 was:

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

Ex-officio members:

Partner nominated:	Prof. Hein van Poppel (EAU), Dr. Alberto Costa (ESO), Prof. Louis Denis (OCA).
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The current Board met in July (Antwerp), September (Brussels), November (Barcelona), January (Antwerp), March (Copenhagen), May (Antwerp) and our final meeting is due in June (Malahide).

In addition to the responsibilities in the statutes for Chairman, Treasurer and Secretary, it is now customary for other Board members to take on particular portfolios. Stig Lindahl, assisted by Pentti Tuohimäki have been developing our relations with our eastern European members. In addition to his Treasurer duties, André Deschamps has focused on the implementation of the organisation's strategy. Our Secretary, John Dowling, continued to deliver on the editorial role for the weekly *Update* and, with Roger Wotton, to develop a pilot training programme. Ken Mastris acted as co-ordinator of LOCs.

The Board is very grateful to our *ex-officio* members for their assistance and advice during the year. Prof. Louis Denis has been able to attend most of our Board meetings and Prof. Hein van Poppel attended our January Board meeting to brief us on the EAU's new Patient Office.

This year there are three Board positions about to become vacant, where the incumbents have reached the end of their 3-year terms. In one case, the member concerned, Ken Mastris, has completed two terms and is not allowed to stand again. The other two Board members, André Deschamps and John Dowling, are eligible for re-election.

The election of Board members is undertaken by the Voting Delegates at the General Assembly.

4. Europa Uomo Strategy – Goals

The Strategy was adopted by the General Assembly in June 2016.

Goal 1: Early Detection

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 show a reduction in mortality rates upon PSA utilisation for 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.
- ❖ Meanwhile the search goes on for an effective and economic alternative to the dependence on the PSA test, which is not a test for prostate cancer.
- ❖ The widespread overtreatment of prostate patients who have very low-risk tumours is gradually being eased with the greater use of active surveillance.
- ❖ The USPSTF has recently modified its stance on the use of screening.

As part of its implementation programme the Board had a joint event with the EAU in the European Parliament on 27 September 2017 to mark EPAD (European Prostate Cancer Awareness Day) [see Section 8, p.31].

Goal 2: Help establish Prostate Cancer Centers and raise quality to best international 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 agreed and published.
- ❖ ICHOM PROs added to prostate cancer treatment guidelines and reports of certified prostate cancer centers, Germany.
- ❖ PROs for advanced prostate cancer agreed and published; Prof. Denis co-authored the ICHOM dataset for advanced prostate cancer.
- ❖ EAU will take the lead in establishing a limited number of expert PCUs in different countries.
- ❖ In some EU states prostate cancer centers are already in existence.
- ❖ Europa Uomo (with the financial support of ESO) has undertaken its first audit of a PCU from a patient point-of-view. At least two further audits are planned for later in 2018.

The European School of Oncology (ESO) has long promoted the concept of multidisciplinary specialized prostate cancer units (PCUs), which observe optimal throughput and an appropriate mix of clinical skills. The ESO has also advocated that a patient review of the PCUs should be considered an integral part of the approach. Europa Uomo has been asked by the ESO to participate in an exercise to evaluate the quality of the patient experience in these PCUs.

In keeping with this the ESO and Europa Uomo last year visited a specialist cancer hospital and research centre in Lisbon. The Champalimaud Foundation's Centre met all criteria from both a

professional and patient perspective and was heartily approved. The visiting team were Dr. Costa and Roberta Ventura from ESO, together with André Deschamps, Joaquim de Cruz Domingos and John Dowling from Europa Uomo. See Appendix II [p.42] for the full report.

Goal 3: Therapy guidelines and patient information in all European States based upon best evidence

This goal includes three elements:

- I. Europa Uomo representation in the EAU guidelines working group
- II. To have in place up-to-date medical, scientific guidelines and patient guidelines in all European states
- III. Evidence of the application of those guidelines

Current situation:

- ❖ EAU guidelines and patient information sheets have been developed and are available in 14 languages.
- ❖ Europa Uomo representatives are members of the prostate guidelines committee.
- ❖ Those guidelines are used as an input for guidelines in individual countries. For a variety of reasons the country-specific guidelines are not always identical to the EAU guidelines.
- ❖ EAU has begun an initiative to establish a 'Patient Office'. Europa Uomo is represented in the steering group.

The EAU operates a range of guidelines committees, of which the prostate cancer committee is one. The Europa Uomo representatives Erik Briers and Paul Enders continue their work in this regard. The EAU Guidelines are reviewed continually and regularly updated.

The development of professional education in prostate cancer has taken a major step forward with the EAU's launch last year of the PCa17 meeting, held in Vienna. There were two days of intensive workshops and plenary sessions attended by more than 200 urology specialists. Ken Mastris, Ekke Büchler and John Dowling attended as patient representatives. A brief report of the Europa Uomo experience at PCa17 is included in Appendix II [p.41]. The PCa18 meeting will take place in September this year in Milan.

The EAU decided in October 2017 to establish a Patient Office, headed by Prof. Hein van Poppel. The Board was briefed by Prof. van Poppel in January on the intended role of the Office and it responded to his invitation to provide a patient representative on a steering group that he was establishing. Louis Denis accepted the nomination of Europa Uomo as patient representative on the steering group.

Goal 4: Encourage new support groups in European States

Current situation:

- ❖ There is a gap in the provision of support for prostate patients between the "richer States" and the "poorer States".
- ❖ Europa Uomo encourages and supports patient groups in any and all European States.
- ❖ Estonia formed a patient group with Europa Uomo assistance and in 2016 the GA accepted them as a member. After a set-back due to the untimely death of their founding President, during the last year the organisation has regrouped and become active again.
- ❖ The appointment of a Prostate Cancer Patient Officer, based in Warsaw, took effect in March 2018.
- ❖ Contacts have been developed in Latvia and Armenia, and it is hoped that these develop further in the coming year.

The provision of effective patient support organisations is very uneven, particularly in eastern European states. There are active organisations like Gladiator in Poland and the Lithuanian Prostate Patient Organisation, but over the region as a whole, the picture is very uneven. For the past few years Europa Uomo has been seeking to establish an active presence in the region which would improve the provision for prostate patients, and to build appropriate relations with professional groups in these countries.

With the active assistance of our Gladiator member organisation in Poland the Board was able to make a significant step forward in the past year with the recruitment of a Prostate Cancer Patient Officer, Izabella Pawłowska, who is based in Warsaw. This post has been effective since the beginning of March 2018.

Two Board members, Stig Lindahl and Pentti Tuohimma, will be working with Izabella. For the moment, effort is being concentrated in Estonia, Latvia and Armenia. Other leads are also being followed up for later development. The Board is particularly grateful to Dr. Roman Sosnowski and his colleagues in Poland for their support in this project.

Goal 5: Develop Europa Uomo organizations, staff and funding

Current situation:

- ❖ Local Organising Committee (LOC) strategy developed.
- ❖ Statutes and Bye-laws restructured and adopted by GA, registration in Belgium completed.
- ❖ EPAD events were organized and will be repeated when appropriate.
- ❖ New website launched.

- ❖ E-mail-based Newsletter launched.
- ❖ First patient representative training at GA to be piloted this year.

The Board is seeking to provide assistance where requested. This has sometimes been modest financial support for specific projects. The development of a training provision within the organisation is also seen as an aid to members.

Goal 6: Support a co-ordinated European research program with patient advocate representation

This goal includes 4 sequential elements:

- I. Obtain the support of the EU Parliament and EU Commission for co-ordinated research in Europe
- II. Obtain the support of the EU Parliament and EU Commission for the registration and reporting of all clinical trials in Europe
- III. Representation of Europa Uomo in EMA work groups and commissions such as the Committee for Medicinal Products for Human Use (CHMP), the Committee for Advanced Therapies (CAT), the Clinical Trial Facilitation Group, etc...
- IV. The organisation of co-ordinated prostate cancer research for faster and better results, and including patient representation and input

Current situation:

- ❖ Within the European Union health matters are the responsibility of individual nations.
- ❖ Parliamentary support has been achieved in the research funding program Horizon 2020, however this is but the first modest step towards the co-ordination of research (at least 3 independent

organisations from different EU countries are required in each collaborative project).

- ❖ Registration and reporting of all clinical trials in Europe has been achieved, but the EUdraCT register of clinical trials is only available in English.

<http://www.eudrapharm.eu/eudrapharm/clinicaltrials.do>

- ❖ Europa Uomo has representatives in EMA in a variety of committees and working groups. The reports of those work groups are available on the EMA website.

5. Projects

In order to achieve our goals, we have developed several large projects. Each project has its own schedule and assigned budget. Some projects are linked to one specific goal, others are linked to more than one goal. The table below shows the links between goals and projects.

Project	Goal 1 Awareness	Goal 2 PCUs	Goal 3 Guidelines	Goal 4 New groups	Goal 5 Organization	Goal 6 Research
Awareness campaign A tough nut to crack	★					
Representation at EU-level meetings	★	★	★	★	★	★
New member states				★		
Website and new media communications	★	★	★	★	★	★
Training patient advocates	★	★	★		★	
Audits in PCUs		★				
Early diagnosis in all states	★					

Project 1: Awareness campaign: a tough nut to crack

Project Description		Publish adverts in different media
Project timing	Start date	11/2016
	Finish	12/2019
Project financing	Total amount	€5,000 per year
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
- ❖ Publication in several local publications

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

Project Description		Send representatives to EMA, ESO, steering committees, EU task force, ECPC, EAU congress and PCa18
Project timing	Start date	01/2017
	Finish	12/2020
Project financing	Total amount	€30,000 per year
Project deliverables		List and reports of meetings where we were represented, reports to Board

Achieved so far:

- ❖ See list of attended meetings attached in Appendix I, p.37.

Project 3: Initiatives in certain states in eastern and southern Europe

Project Description		Develop activities specific for eastern states: training, awareness, new patient groups
Project timing	Start date	10/2017
	Finish	12/2019
Project financing	Total amount	€20,000 per year
Project deliverables		Training sessions Dedicated personnel Patient sessions

Achieved so far:

- ❖ Information session for 70 Polish prostate cancer patients during EPAD in Krakow
- ❖ With the support and co-operation of the Gladiator organisation, the Polish Hub was established in March 2018 with the employment of our first 'Patient Officer' Izabella Pawłowska
- ❖ Training session in Vienna, June 2017 for 40 prostate cancer patients from Slovakia and Poland
- ❖ Progress reported on the re-activation of the Estonian prostate patient organisation
- ❖ Preparatory work underway in Latvia to establish an organisation for prostate patients
- ❖ Discussions have taken place with patient and medical representatives in Armenia about establishing an organisation there. Due to the current political situation, initial meetings have been postponed until autumn 2018
- ❖ ProstaBus proposal by Dr. Roman Sosnowski to be developed – first for Poland and then in adjoining states

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

Project Description		In order to inform all stakeholders ensure website and social media content is up-to-date and easy to access
Project timing	Start date	05/2017
	Finish	12/2020
Project financing	Total amount	€10,000 per year
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 added on website to support awareness campaign
- ❖ Twitter account and Facebook account established



- ❖ New Europa Uomo graphics to be implemented on website
- ❖ Board to focus on developing website homepage this year
- ❖ Feasibility of offering sub-sites on the Europa Uomo website is being examined. Member organisations without the resources to maintain their own website might wish to avail of a sub-site

Project 5: Training patient advocates

Project Description		Develop two-day training course for patient advocates, involving organisational and travel costs Day 1: Training on PCa; Day 2: Patient advocate skills
Project timing	Start date	03/2018
	Finish	12/2019
Project financing	Total amount	€65,000
Project deliverables		Training session; programme to be arranged

Achieved so far:

- ❖ Pilot training course to be trialled at GA 2018
- ❖ Rollout of training programme will be subject to evaluation of pilot
- ❖ Extensive training programme to be developed in 2018-19

Project 6: Auditing PCUs

Project Description		ESO asked us to be involved in PCU audits. Successful 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	€5,000 per year
Project deliverables		Patient recommendation for PCU

Achieved so far:

- ❖ This project is supported and sponsored by ESO

- ❖ First audit was carried out in Lisbon at the Champalimaud Cancer Foundation in November 2017 [see report in Appendix II, p.42]
- ❖ A minimum of two further audits planned in late 2018

Project 7: Early diagnosis in states with poorer healthcare systems

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		Documents in local languages and increasing early diagnosis in developing countries

Achieved so far:

- ❖ This project will end and be integrated into project 3

6. Funding of Europa Uomo and Financial Report

Summary:

- ❖ This report is based on our audited accounts, as required by Belgian law
- ❖ No discrepancies were found during audit
- ❖ This represents the first attempt to distribute some costs to projects
- ❖ Income more or less equals spending
- ❖ Extra spending incurred on two important projects

The funding of Europa Uomo comes from small contributions from member organizations through their annual dues, contributions from partner organizations, especially the European Association of Urologists (EAU) and the European School of Oncology (ESO), a number of pharmaceutical companies and reimbursement of costs, where board members or LOCs have attended meetings.

Compared to the budget presented in our previous annual report, some projects were launched more slowly than expected – hence the lower spending and lower income in the actual budget comparisons.

As we like to be cautious, our budget for 2018 and 2019 again shows the most ambitious spending and income. The Board has the task of aligning income and expenditure.

The Board has also decided to launch two major initiatives in 2017–2018 [see Section 5: Projects, pp.18–23]. This will result in more spending than income in 2018. There are sufficient cash reserves available.

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 on our sponsors.

Open bookkeeping will be the key to our further success. That is why we distinguish in our budgets and reports the sponsorship given for our core activities and those for projects.

Our accounts have been audited and no issues were found. The statements underneath are a true and honest account.

In accordance with Belgian law for not-for-profit organizations 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 recognized patient organizations in terms of the number of pharma companies from whom it draws financial support and the requirement that it is not more than 50% dependent on any one source.

Balance Sheet at December 31, 2017 (in Euro €)

ASSETS:

Bank accounts:

Business Compact account

151,778.88

Savings account

50,314.34

Amounts receivable:

Grant Pharma

17,500.00

Deferred expenses:

IBIS hotel

170.00

Total assets:

219,763.22

LIABILITIES:

Deferred income and accrued expenses:

Yearly accountancy costs

151.25

Website maintenance

405.00

Refund travelling expenses

1,472.69

Capital of the association

Balance at 31/12/2016

221,597.55

Result 2017

-3,857.27

Total liabilities:

219,763.22

Accounts audited by Guido Smet

Income 2017 budget - Actual

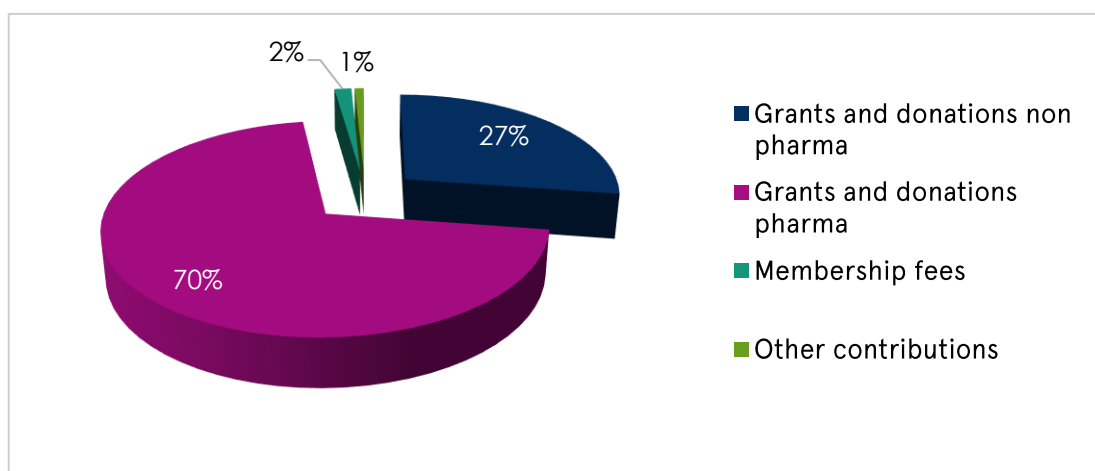
	Budget €	Actual €	Delta €
	2017	2017	2017
Grant European Urological Found - Arnhem	25 000	25 000	0
Support European School of Oncology	5 000	15 800	10 800
Total grants and donations (non-Pharma)	30 000	40 800	10 800
Grant Amgen (Europe) GMBH	15 000	15 000	0
Bayer Corporation Pittsburgh	50 000	50 000	0
Grant Janssen Pharmaceuticals	25 000	25 000	0
Total grants and donations (Pharma non-project-based)	90 000	90 000	0
Ferring	15 000	0	-15 000
Sanofi	25 000	0	-25 000
Grant Ipsen Pharma	25 000	15 000	-10 000
Astellas	25 000	0	-25 000
Total grants and donations (Pharma project-based)	90 000	15 000	-75 000
Annual membership fees 2017	2 100	2 200	100
Income other	3 000	1 184	-1 816
Total income	215 100	149 184	-65 916

Expenditure 2017 budget - Actual

	Budget €	Actual	Delta €
	2017	2017	2017
Secretariat	50 000	50 000	0
Other secretarial costs	1 000	466	-534
Project 1: Awareness	7 000	0	-7 000
Project 2: Attendance to meetings	30 000	32 040	2 040
Project 3: New member states	10 000	5 800	-4 200
Project 4: Website and communication	10 000	4 993	-5 007
Project 5: Training session advocates	7 000	7 185	185
Project 6: Audit PCU units	5 000	2 700	-2 300
Internet	200	0	-200
Audit fee + tax return fee	2 500	2 329	-171
Legal publications	150	127	-23
Insurance	600	525	-75
Memberships	300	0	-300
Refund travelling costs to meetings	30 000	9 477	-20 523
Other meeting costs	55 000	36 838	-18 162
Bank charges	250	190	-60
Tax on assets (non-profit organisations)	500	372	-128
Contingency	5 000	0	-5 000
Total expenditure	214 500	153 042	-61 458

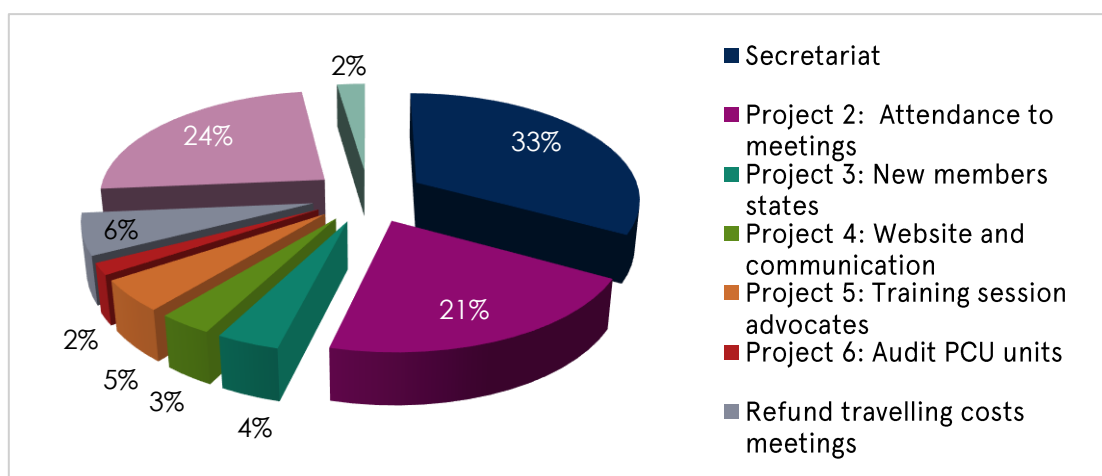
Result	600	-3 858
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Income distribution:



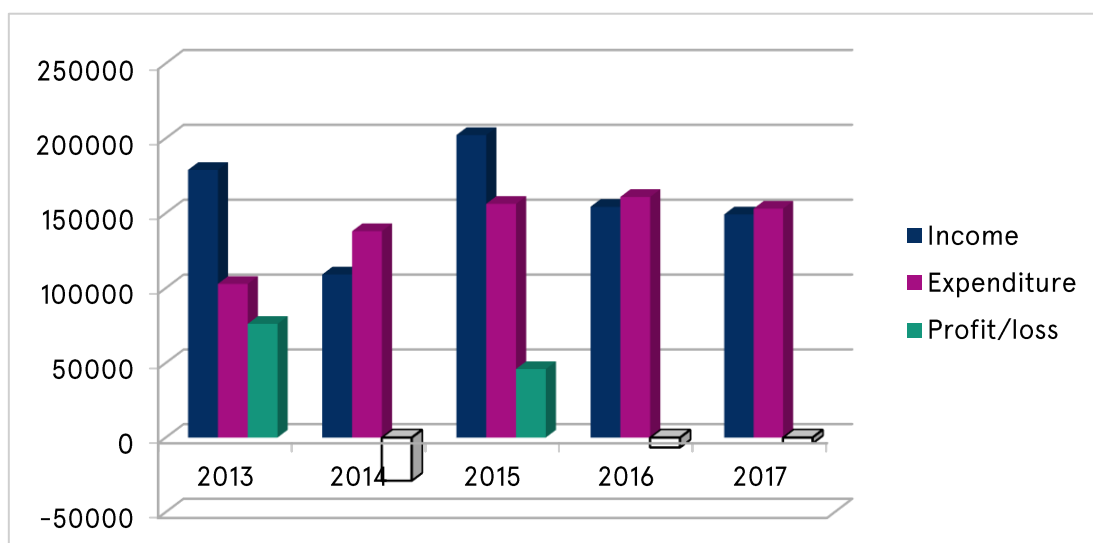
Grants and donations (non-Pharma)	27.35%
Grants and donations (Pharma)	70.38%
Membership fees	1.47%
Other contributions	0.79%

Expenditure distribution:



Secretariat	32.98%
Project 2: Attendance at meetings	20.94%
Project 3: New member states	3.79%
Project 4: Website and communications	3.26%
Project 5: Training session advocates	4.69%
Project 6: Audit PCU units	1.76%
Travelling costs to meetings	6.19%
Other meeting costs	24.04%
Other costs	2.32%
Other contributions	0.79%

Difference income - expenditure over the past 4 years:



Budget 2018 and 2019:

Income

	Budget €	Budget €	Budget €
	2018	2019	2020
Grant European Urological Found – Arnhem	25 000	30 000	30 000
Support European School of Oncology	10 000	15 000	15 000
Total grants and donations (non-Pharma)	35 000	45 000	45 000
Grant Amgen (Europe) GMBH	15 000	15 000	15 000
Bayer Corporation Pittsburgh	50 000	50 000	50 000
Grant Janssen Pharmaceutica	25 000	25 000	25 000
Total grants and donations (Pharma non-project-based)	90 000	90 000	90 000
Ferring	10 000	10 000	10 000
Sanofi	25 000	25 000	25 000
Grant Ipsen Pharma	15 000	15 000	15 000
Astellas	0	0	0
Grant Janssen Pharmaceuticals	15 000	15 000	15 000
Non-specified project-based income	10 000	10 000	10 000
Total grants and donations (Pharma project-based)	75 000	75 000	75 000
Annual membership fees 2018	2 200	2 100	2 100
Income other	2 800	3 000	3 000
Total income	205 000	215 100	215 100

Expenditure

	Budget €	Budget €	Budget €
	2018	2019	2020
Secretariat	60 000	50 000	50 000
Other secretarial costs	1 000	1 000	1 000
Project 1: Awareness	2 000	5 000	5 000
Project 2: Attendance at meetings	30 000	30 000	30 000
Project 3: New member states	20 000	20 000	20 000
Project 4: Website and communication	10 000	10 000	10 000
Project 5: Training session advocates	15 000	25 000	25 000
Project 6: Audit PCU units	5 000	5 000	5 000
Internet	200	200	200
Audit fee + tax return fee	2 500	2 500	2 500
Legal publications	150	150	150
Insurance	600	600	600
Memberships	300	300	300
Refund travelling costs to meetings	10 000	10 000	10 000
Other meeting costs	50 000	50 000	50 000
Bank charges	250	250	250
Tax on assets (non-profit organisations)	500	500	500
Total expenditure	207 500	210 500	210 500

Forecasted result	-2 500	4 600	4 600
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7. Liaison Officers

The Board wishes to acknowledge the contribution made by the LOCs during the past year. LOCs will be deployed on behalf of Europa Uomo and comply with reporting arrangements when they represent the organisation at meetings and conferences. Ken Mastris acted as co-ordinator for LOCs.

The Liaison Officers in 2017-18 were: Paul Enders, Erik Briers, Roger Wotton, Maria Louisa Domingos, Brigitte Dourcy-Belle-Rose, Joaquim Domingos.

8. European Prostate Awareness Day (EPAD) – European Parliament, Brussels, 27 September 2017

In conjunction with the EAU an EPAD was held in the EU Parliament Building in Brussels. Two MEPs co-chaired the meeting in a very disciplined manner – Marian Harkin (Ireland) and Alojz Peterle (Slovakia). There were 17 short presentations with Q & A sessions. Ken Mastris and Paul Enders were the prostate patient presenters. The meeting was also addressed by Vytenis Andriukaitis, EU Commissioner for Health and Food Safety, and Chris Chapple, Secretary-General of the EAU. A high-powered array of clinicians and researchers were led off by Prof. Bertran Tombal.

9. Conferences & Meetings Attended

Members of the Board and Liaison Officers attend a wide range of meetings on behalf of Europa Uomo. During the course of the year the meetings attended have been reviewed and from now on the Board will

only attend the following meetings as a Board: the EAU congress, EPAD meetings and the GA.

European Multidisciplinary Meeting on Urological Cancers (EMUC)

The EMUC meeting was held in November 2017 in Barcelona 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 significant areas of interest at the meeting, so it provided an excellent learning opportunity for Board members to hear leading clinicians and researchers present on the latest developments in prostate cancer research, diagnosis and treatments. A meeting of the Board was held during EMUC.

European Association of Urologists Congress – Copenhagen, March 2018

The EAU Congress is the biggest congress of its type in Europe with some 14,000 attendees – not only urologists but many scientists and clinicians in various fields associated with a wide 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 attended the Board meeting. Many pharma companies also attend and exhibit at the congress.

The occasion of the EAU Congress not only provided an opportunity for the Board to meet about its own business, but Board members, together with LOCs, had 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.

In addition, the occasion permitted the Board to arrange meetings with some of our sponsors. In Copenhagen, sit-down meetings were held with a number of our sponsors and possible new approaches were discussed.

A listing of meetings and conferences attended by Europa Uomo representatives in 2017-2018 is set out in Appendix I, p.37.



Delegates at the Europa Uomo General Assembly in Vienna, June 2017

10. Patient Seminar, Vienna, June 2017

The day after the GA in Vienna in June 2017, Ekke Büchler with clinician Prof. Shahrokh Shariat, MD, organised a formidable programme of experts, who provided a wide range of presentations on prostate cancer diagnosis and treatment topics. A group of Slovak patients also attended, for whom a translation service was provided. Reports of many of the presentations were published in the weekly *Update* in the weeks afterwards.

11. European Medicines Agency (EMA)

The Agency is an arm of the EU Commission that deals with the authorisation of new human and veterinary medicines and the monitoring of medicines already in use (pharmacovigilance). The EMA has been based in London for many years, but with the decision of the UK to leave the European Union, the EU Council of Ministers decided that the Agency would be relocated to Amsterdam in 2019.

The EMA has been active in promoting patient involvement in its workings. Europa Uomo was fortunate to have retained its representation on the Patients' and Consumers' Working Party [PCWP] last year, but as Ken Mastris, our representative since 2015, is stepping down from the Board in June, he will swap places on the PCWP with André Deschamps (who has been an Alternate member). Will Jansen will take over as the Alternate when the Agency moves to The Netherlands. Erik Briers continues to act as an Alternate member of the Committee on Advanced Therapies.

During the year under review Ken Mastris and André Deschamps attended quarterly PCWP meetings. The annual Training Day in November was attended by André Deschamps and John Dowling. Europa Uomo has also provided representatives for various committees to review applications for marketing authorisation and for scientific advice.

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

12. Membership of Europa Uomo

Less than a year after joining Europa Uomo, our Estonian affiliate suffered the loss of its President. This was a difficult period for the organisation, but with the support of Board member Pentti Touhimma, the Estonian organisation is now resuming activity again. Vice Chairman Stig Lindahl has taken the lead in developing our project for eastern Europe. He has also been instrumental in the recruitment of our Patient Officer, Izabella Pawłowska, who took up duty at the beginning of March. Contacts have been developed with a number of countries, which it is hoped will bear fruit in the next year.

13. Communications

The Board has continued to review its approach to communications – with both internal and external parties. The developments of recent years, such as the revamp of the website, Facebook page and a more frequent newsletter needed to be developed further. The Board retained the services of a science writer and media consultant to review where we are now and where we should go next. His preliminary report was considered in March and a final report is with the Board at the time of writing.

The Board very much appreciate the work of our webmaster, Nancy Verbrugghe, for her efforts to keep the website current. Nancy has also developed our Facebook and Twitter accounts. The Board also appreciate the efforts of John Dowling and Anja Vancauwenburgh in producing the weekly *Update*. During Anja's maternity leave Judy Higgins has been deputising.

Back-issues of the *Update* are available on our website:

<http://www.europa-uomo.org/newsletters/>

Subscription to the *Europa Uomo Update* is free and can be found at:

<http://www.europa-uomo.org/newsletters/subscribe-update-mailing/>

14. Conclusion

The Board has adopted the tagline “The Voice of Men with Prostate Cancer in Europe”. This claim is a reflection of the continued and growing influence of Europa Uomo within the European-level institutions, patient organisations, professional organisations and industry supporters. As a confederation of prostate patient support organisations, we seek to build on the progress of the past 15 years, since our foundation. What has been achieved has been a result of the efforts of a relatively small cohort of volunteers, elected by successive General Assemblies, together with the Liaison Officers and our ex-*Officio* members.

We stated in the conclusion to last year’s report that “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.” The Board believe that their actions during this past year are a further step on this path. The Board wishes to thank all those who have made their effort to develop and further the organisation.

Approved by the Board May 2018

Appendix I: Europa Uomo Activities (June 2017 – May 2018)

E. Briers
**EMA Committee for Advanced
 Therapies (CAT) meeting**
 San Lawrenz, Malta
 1-2.06.17

J. Beresford
**Patient participation in a panel of
 experts for the EMA Scientific
 Advice/HTA procedure.**
 London, UK
 08.06.17

C. Arnold, E. Büchler, L. Denis, A.
 Deschamps, W. Jansen, K. Mastris,
 S. Lindahl, A. Vancauwenbergh
Europa Uomo Board meeting
(09.06.17)
General Assembly EUomo 2017
(09.06.17)
Seminar '360 Degree Prospective
on Prostate Cancer' (10.06.17)
 Antwerp, Belgium
 08-11.06.17

L. Denis, K. Mastris
Annual General Meeting European
Cancer Patient Coalition (ECPC)
 Brussels, Belgium
 16-18.06.17

J. Domingos, J. Graça
5th Global Congress on Prostate
Cancer
 Lisbon, Portugal
 28-30.06.17

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

Antwerp, Belgium
 05.07.17

E. Briers
EMA Committee for Advanced
Therapies (CAT) meeting
 London, UK
 6-8.08.17

J. Dowling
European Medicines Agency
 30.08.17

E. Briers, A. Deschamps, J.
 Domingos, K. Mastris
Annual meeting ESMO + booth
WECAN meeting (08.09.17)
 Madrid, Spain
 8-12.09.17

E. Büchler, L. Denis, B. Dourcy-
 Belle-Rose, J. Dowling, E.
 Kumhofer, K. Mastris
EAU Update on Prostate Cancer -
PCa17
 Vienna, Austria
 15-16.09.17

J. Dowling
Dinner Human Proteome
Organisation World Congress
 Dublin, Ireland
 16.09.17

K. Mastris
ONJ and Bone Health Workshop
(Amgen)
 Geneva, Switzerland
 22.09.17

C. Arnold, L. Denis, A. Deschamps,
 J. Dowling, W. Jansen, S. Lindahl,

K. Mastris, P. Tuohimaa, A.
Vancauwenbergh
Europa Uomo Board meeting
European Prostate Awareness Day
(European Parliament)
Brussels, Belgium
27.09.17

J. Dowling
ESMO Workshop on Science for
Advocates
Munich, Germany
13-15.10.17

F. Brennan, J. Dowling
2nd National Patient Safety Office
Conference
Dublin, Ireland
25-26.10.17

A. Deschamps, J. Domingos, J.
Dowling
PCU site visit
Lisbon, Portugal
3.11.17

K. Mastris
EAU Prostate Cancer Centre
Consensus Meeting (EPCCCM)
Barcelona, Spain
16.11.17

C. Arnold, E. Briers, L. Denis, A.
Deschamps, J. Domingos, J.
Dowling, W. Jansen, S. Lindahl, K.
Mastris, P. Tuohimaa, A.
Vancauwenbergh, R. Wotton
Europa Uomo Board meeting
9th European Multidisciplinary
meeting on Urological Cancer
(EMUC) + booth
Barcelona, Spain
16-19.11.17

J. Dowling
Lunch meeting Dr. A. Costa
(17.11.17)
Europa Donna Advocates Training
Course
Milan, Italy
17-19.11.17

J. Dowling
Meeting Rachel Fingleton (graphic
designer)
London, UK
20.11.17

A. Deschamps, J. Dowling
EMA annual training day (21.11.17)
PCWP/HCPWP training session
(21.11.17)
PCWP plenary meeting with all
eligible organisations (22.11.17)
London, UK
21-22.11.17

J. Dowling
1st European Alliance for
Personalised Medicine congress
Belfast, Ireland
27-30.11.17

A. Deschamps, K. Mastris
Telephone Conference Gunnar
Schroefel (Bayer)
29.11.17

J. Dowling, S. Lindahl
Meeting with Gladiator
representatives and Izabella
Pawlowska (Polish Hub)
Warsaw, Poland
18.12.17

C. Arnold, L. Denis, A. Deschamps,
J. Dowling, W. Janssen, S. Lindahl,
K. Mastris, P. Tuohimaa, A.
Vancauwenbergh, H. Van Poppel
Europa Uomo Board meeting
Antwerp, Belgium
17.01.18

K. Mastris
**ECCO-ESO working group on
prostate cancer meeting**
Milan, Italy
22.01.2018

E. Büchler, A. Deschamps, R.
Wotton
**PCa Europe 2018 Roundtable
(International Center for
Parliamentary Studies)**
Brussels, Belgium
23.01.18

K. Mastris
ECPC Board meeting
Brussels, Belgium
06.02.18

S. Lindahl, K. Mastris, P.
Tuohimaa, R. Wotton
**3rd ESO Masterclass in Cancer
Patient Advocacy: Working
Towards Stronger and more
Effective Advocacy in Europe**
Lisbon, Portugal
23.25-02.18

K. Mastris
WECAN meeting
Lisbon, Portugal
25.02.18

L. Denis, W. Jansen

**Inaugural Lecture Prof. Monique
Roobol**
Rotterdam, The Netherlands
02.03.18

E. Briers, C. Arnold, L. Denis, A.
Deschamps, J. Dowling, W.
Janssen, S. Lindahl, K. Mastris, I.
Pawlowska, N. Saard, P. Tuohimaa
**5th ESO Prostate Cancer
Observatory (16.03.18)
Meeting Janssen (N. Buhl)
(16.03.18)
Europa Uomo Board meeting
(17.03.18)
Meeting Bayer (Gunnar Schroefel)
(17.03.2018)
33rd Annual Meeting European
Association for Urology 2018
Copenhagen, Denmark
16-20.03.18**

K. Järvinen, M. Kivi, V. Pulp, K.
Roomus, N. Saard, P. Tuohimaa
**Estonian Prostate Cancer Patient
Organisation Meeting**
Tallinn, Estonia
12.04.18

E. Briers
**EMA Committee for Advanced
Therapies (CAT) Meeting**
London, UK
18-20.04.18

K. Mastris
**ECCO-Patient Advisory
Committee Meeting**
Brussels, Belgium
09.04.18

K. Mastris
ECPC Board Meeting

Brussels, Belgium
18.04.18

C. Arnold, S. Crompton, L. Denis,
A. Deschamps, J. Dowling, J.
Higgins, S. Lindahl, K. Mastris
Europa Uomo Board Meeting
Antwerp, Belgium

03.05.18

A. Deschamps, J. Dowling, K.
Mastris
Meeting Janssen
Brussels, Belgium
22.05.18

Appendix II: Reports of meetings and conferences

1. Report PCa17 Conference Vienna 15/16 September:

By John Dowling

This conference was described by the EAU as an Update on Prostate Cancer. This may be the first of a series. About 300 urologists/EAU members attended. Ken Mastris, Erik Briers, Ekke Büchler and myself were the patient representatives in attendance. From this patient's viewpoint, the meeting was an outstanding success. On the basis of this initiative PCa18, PCa19 and so on should follow.

The format included several plenary sessions with all attendees who were then assigned to specific breakout groups. The plenary session speakers and other faculty members then rotated through the four breakout groups to lead treatment discussions on the cases presented. Attendees were asked to use the EAU App to vote on the various treatment options for each case. The divergence among urologists on best treatments was sometimes extensive. Discussion and intervention was encouraged, however, and our small patient cohort frequently availed of this opportunity. One little niggle was that three of the four patient reps were assigned to the one group.

Urologists are specialists in a wide range of areas to do with kidney, bladder and genital functions as well as prostate-related issues. But urologists are first and foremost surgeons, and it would be surprising if some did not have some difficulty in adjusting to the impact on their profession of the changes now underway and in prospect. The advent of genomic medicine and the prospect of personalised care may detract from the usual pre-eminence accorded to surgeons. Some may be fearful of what the future holds for the urologist and wonder how they might best respond. A clear take-away message from trial results on PCa issues, the EAU practice guidelines and conferences such as PCa17 is that the profession must stop overtreating prostate patients – this, of course, will mean less surgery and all that follows.

It is clear, that the EAU wishes to embrace the opportunities these new fields are opening up. The PCa17 initiative was an indication that the EAU is seeking to offer positive leadership to its members which will secure the urologists' role in prostate cancer through a dramatic "up-skilling" of the surgeon for the modern genomic and robotic age.

2. Prostate Cancer Unit (PCU) Patient Audit No. 1 – Champalimaud Clinical Centre (CCC). Report of Meeting between representatives of European School of Oncology (ESO), Europa Uomo & CCC, 3rd Nov 2017

- The Europa Uomo (EU) representatives met with two former/present patients **before** the meeting with the CCC team.
Patient No. 1 is a 60-year-old man who had a significant cardiac co-morbidity. He had surgery and had a good experience of the hospital and in the aftermath of his operation.
Patient No. 2 is 63 and otherwise without co-morbidity. He had attended another facility in Portugal where he was informed of his diagnosis: that he had low risk prostate cancer with a Gleason score of 3+3. He was also informed that his treatment options were radical surgery or radiation. No mention was made of active surveillance (AS). He came to Dr. Jorge Fonseca (JF) for a second opinion and learned **for the first time** of AS. He has remained on AS for 4 years. He is very happy with the way the CCC treated him and with his continuing treatment with AS.
- A separate note on these interviews, which were conducted separately and in Portuguese in the presence of only André Deschamps (AD), Joaquim da Cruz Domingos (JCD) (interviewer) & John Dowling (JD) is attached to this report.
- The opening cordial exchanges were led by Dr. Alberto Costa ESO, who described our mission as inspecting the facility from the standpoint of the patient, to see if it was a place you would recommend it to a friend who might require a prostate review and possible treatment – “a PCU TripAdvisor” as he termed it. AD explained that the three EU reps had earlier met with two prostate patients of the CCC. He impressed upon the CCC Team that the EU concerns were with the patient experience of the CCC, this included the run-up to the diagnosis, through treatment and, very importantly, after primary treatment. We (EU) were not there to interfere with the technical criteria outlined in the ESO criteria, unless the CCC wished to raise an issue on any of them.
- JF (CCC Head of Urology Dept.) outlined how he proposed to address the ESO criteria. On twin projection screens he juxtaposed the ESO criteria on the left screen and the actual CCC provision on the right-hand screen. In this way, as he reviewed the ESO criteria point by point, he was able to satisfy the EU & ESO representatives that CCC fully meets the criteria for accredited PCUs. AD reported to the meeting that the patients interviewed

earlier had expressed themselves as being very satisfied with their treatment and overall care. The Clinical Director of the CCC gave a short account of the history of the development of the CCC as a Not-For-Profit which benefitted from a substantial bequest from Señor Champalimaud, who himself suffered from and succumbed to prostate cancer.

- AD referred to the gap in understanding between patients and their treating doctors generally in Europe. By way of example, he cited the criteria used by many urologists that if a man uses one or less continence pads per day he is to be regarded as continent, whereas, the patient regards the need to use **any** continence pad as indicative of **incontinence**. He also instanced the gap in patient/doctor perceptions regarding post-treatment sexual functioning criteria.
- JF said that in CCC most patients don't lose urine after the first day. The CCC has pioneered a new technique in Europe, which was first done in 2010. There have been 6 papers reporting on continence performance after treatment. Since January 2017 the CCC had used this surgery technique in 40 patients – all of whom are continent. JF does admit that the patients are selected for this procedure. Many patients when they first present at the CCC are already incontinent.
- JF said the CCC used a robust multidisciplinary approach. He later introduced the members of the multidisciplinary team (MDT).
- **Staffing and Beds:** The CCC has a research staff of 300, the medical and other professional staff in the hospital facility number a further 300. There are also essential administrative and support staff. The CCC has 30 beds – more than half of the beds are situated adjacent to the three operating theatres, the remaining beds are used for non-surgical patients.
- **Finance:** The CCC has a large endowment from the Champalimaud bequest which provides with an income of several million Euro annually. As a private not-for-profit hospital, it charges patient fees so that the in-patient and out-patient charges make the hospital part of the facility financially self-sustaining. The CCC patients are diverse, with a growing patient traffic from North and South America, but it is used mainly by Portuguese patients who have private or public insurance which reimburses them the treatment costs, or the greater part thereof. The CCC receives no direct State support other than the fees paid on behalf of certain civil servants and military personnel who have contractual terms which allow them to access the CCC as patients.

- The organisational and professional management of the CCC hospital facility is focussed on specific cancer groups, or disease management teams (DMT) and the current CCC objective is to obtain a U.S. certification which gives it global status. Today, the CCC has this certification for Breast, Lung and GI treatments. The CCC has not yet acquired such certification for Genito-Urinary cancers [which would include prostate], but it is next on the list.
- The CCC is partaking in a number of clinical trials which also may involve both research and hospital oncology staff.
- Many patients come to the hospital for 2nd opinions and some of these revert to their original hospital and others avail of treatment in the CCC.
- **Statistics:**

2016	25K patients seen 56K consultations 500+ patients in Trials 300 professionals >50 publications
2017	estimate 20% increase

Innovations: [1] The hospital has been developing its expertise in an innovative surgical technique which literally comes at the prostate from a different direction, sparing totally the Retzius ligaments which are normally cut in prostatectomy operations. When compared with Robotic Assisted Radical Prostatectomy [RARP] the randomised clinical trial described recently in the EAU's journal *European Urology* 2017 volume 72, issue 5 pages 686-688 [see link to the full article below] shows a very distinct gain in both urinary continence (NO PADS) and an earlier and more rapid recovery of sexual function after the procedure.

[http://www.europeanurology.com/article/S0302-2838\(17\)30523-7/pdf](http://www.europeanurology.com/article/S0302-2838(17)30523-7/pdf)

Innovations: [2] The hospital has been developing a new way of using radiotherapy to undertake what they term a "virtual prostatectomy" by *radiosurgery*. Using a machine called EDGE [see link below], the radiation oncologist and the team prepare an individualised plan which is then verified by the software and the various imaging factors and sensors are deployed which allow for what the Head of the Radiation Oncologist Department term virtual surgery by radiation. The EDGE is a very sophisticated external beam accelerator which delivers "virtual surgery", with the machine's active component moving over the target tissue, like a scalpel, and delivering the normal dosage of radiation over five [5] treatment sessions instead of the standard 35 sessions.

<https://www.varian.com/oncology/products/treatment-delivery/edge-radiosurgery-system>

Each session takes only a few minutes, so the standard 35-day fractionation is reduced to a 5-day Mon-Fri procedure delivering the same radiotherapy punch in terms of total GRAY, but delivered more precisely and with much less damage or no damage at all to: (a) the urethra, (b) the nerve cells controlling sexual function, (c) the vascular tissue supplying the penis with blood supply for erections, and (d) the bladder and rectum which are protected.

According to the CCC, the continence and sexual function recovery rates are not only higher, but much sooner than in conventional IMRT and similar radiation treatments. In the view of the lead Radiation Oncologist this EDGE machine, its software and the procedure has rendered obsolescent brachytherapy, CyberKnife and several other RT techniques. In some cancer cases, the patient can be treated with a single 45 Gray dose – and the patient can go home with very little, if any, adverse effect on their quality of life. The EDGE machines come at a cost of €5-6m and the CCC has two of them. But the radiation room set-up times are much shorter, the number of sessions per patient is one seventh of that of standard treatment, all of which allows for greater throughput. The limiting factor is the time of the specialist staff who prepare the software and the patients for the personalised RT delivery – this is quite hungry in terms of people time – highly trained people time.

Innovations: [3] From the strictly patient experience of the hospital, an impressive innovation, at the CCC, allows all patients to be assigned to one of the Patient Managers. This is the single point of contact in the CCC for the patient about their appointments, about whom they should see, when, where, what information/papers/records they should bring. The Patient Manager ensures that the patient gets to see the right doctor or nurse at the right time. To achieve this the Patient Manager liaises closely with the doctors and nurses, as well as the patient. It is a system which the patient may perceive as a one-stop-shop, but like the duck gliding majestically across a pond, the patient may be totally unaware of all the paddling that is taking place on their behalf.

Innovations: [4] In the conventional hospital Out-Patient setting there is often considerable delay and anxiety on the part of the patient. CCC has sought to address this: when a patient arrives at the hospital for their appointment at the Out-Patient Department they are given a special cell phone for the duration of their visit. This will convey any appropriate messages concerning their visit and instead of waiting in the general waiting room for a doctor or nurse to eventually call out their name, in the CCC the patient awaiting a consultation or a procedure, such as a

chemotherapy session, is free to walk the grounds, to stroll along the harbour shore, to go to the excellent cafeteria, knowing that when they are required to physically attend to see the nurse or doctor or commence a procedure, they will receive a timely personal message on their hospital phone. Any delays due to unforeseen circumstances can be conveyed to the patient via their message phone. They feel that this not only relieves some of the anxiety that the patient feels but also that it maintains a certain level of privacy in that they are not called out loud by the doctor or nurse.

Almost every member of the team (about 20 staff) in the room made short presentations: doctors, nurses, psychologist, pathologist, oncology nurses, radiologist, surgical, radiotherapy and medical oncologists, researchers and others.

This is truly a “state of the art” facility in a beautiful location at the mouth of the Tagus river from redolent of Vasco da Gama, Magellan and others setting sail centuries ago on wonderous voyages of discovery. The building was designed by an Indian architect of Portuguese heritage [Goa – was a small Portuguese enclave on the Indian coast absorbed into the Indian republic at the end of the 20th century].

The footprint of the facility exceeds that of three football pitches. The views are truly spectacular – André Deschamps was in his element. The patient rooms are *magnificent* with beautiful, therapeutic views out to sea, many unique features in the fixtures, one could go on and on. Again, André was regretting he didn’t have a prostate any longer which would justify him booking in. A truly memorable day. Dr. Alberto Costa is a fiendishly clever man, for he must know that after this there is only one trajectory for subsequent visits to other PCUs. We have a template for PCUs and we have a standard in terms of patient care which others can be encouraged to emulate.

Finally, the only negative note is, even though it is a Not-For-Profit hospital – this is a private hospital with all that this implies. There is some interaction between the CCC and the public (State) hospitals in Portugal, but much of Portuguese culture is based on personal contact – so friends from medical school, from nursing school etc., refer patients and exchange advice with people they know personally – there are many personal networks rather than organisational networks. It was described to us as a very person-to-person orientated culture. Another cultural aspect referred to is the reluctance of men in Portugal to be seen to by a female nurse or doctor for prostate-related consultations and

procedures. DREs or TRUS examinations involving sticking things in the penis or rectum are not always readily received from a female professional. Younger men are said to be less fussy, but then prostate cancer is not usually a disease of young men.

André Deschamps
Joaquim da Cruz Domingos
John Dowling
November 2017

Thanks to our sponsors:

