

EUROPA UOMO 

The Voice of Men with Prostate Cancer In Europe

**Annual Report
of the Board
for 2019/20**



Above: Photo by Erik Briers of the **Delegates in Birmingham GA2019**

1. Chairman's Note

Dear Reader,

Who could imagine three months ago that a virus named Covid-19 would disturb our lives so much and change our behaviour so drastically?

I am writing this foreword to our annual report and preparing for our general assembly in a different world than the one that existed at the same time last year.

My thoughts, and those of the Europa Uomo Board, are with all prostate cancer patients and their families who in the last months:

- Lost their fight against PCa not properly supported by their loved ones
- Lost relatives due to Covid-19
- Suffered a delay in diagnosis
- Could not receive necessary treatments.



While we all hope that matters are soon back to normal, we also realise that it may take time and that we need to adapt our behaviour.

Needless to say, the Covid-19 pandemic has drastically interfered with the planning of our activities. So this annual report gives you an overview of our activities before the pandemic and our best guess as to what will be possible for the rest of the year.

In the last quarter of 2019 we launched our EUPROMS survey to measure the quality of life of prostate cancer patients after treatment. As you are well aware, it was a great success thanks to nearly two years of preparation and the support of all our member organisations. Nearly 3000 patients took time to answer the questions and share their experiences.

Their efforts have generated an incredibly rich database. In this report you can read the first results and our plans to disclose further analysis. For the first time in history, we are able to give patients and their families, health care professionals and the general public, a “snapshot” generated by patients of what happens to quality of life after prostate cancer treatments.

The results underline once more that our strategy of awareness, early detection and treatment in cancer centres is the right way to tackle the challenges of prostate cancer. There is now no excuse not to adopt this strategy immediately.

At our virtual general assembly we will launch our new website. We believe that communication and providing information is an important tool to achieve our goals. Therefore, we have invested in creating an up-to-date and attractive site

where you can find the latest news and information in a stimulating format. I invite you to visit the site on a regular basis. Alongside our newsletter, it is an important way we can connect with you.

In order to protect the health of our member representatives, we will hold our general assembly as a “virtual meeting”. This will be a very new experience for our organisation and our delegates. We will miss the hugs and handshakes, the sharing of experiences and ideas in the bar or during meals, the training sessions and so many other good things that lead to unforgettable memories. I would like to thank our friends in Cyprus, who were so kind as to offer to host the general assembly, for all their preparation for the event before we were forced to cancel.

I would also like to thank everyone who has this year contributed to the goals of Europa Uomo and its members, to the benefit of prostate cancer patients and their families.

André Deschamps

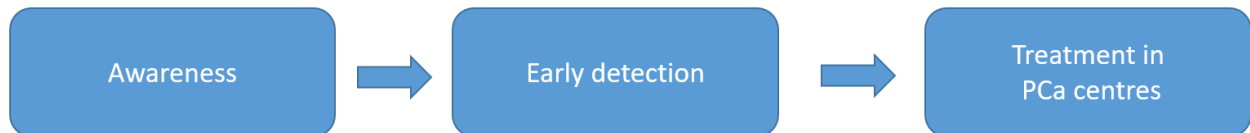
Chairman

Europa Uomo

2. Europa Uomo strategy and projects

2.1. Unchanged strategy

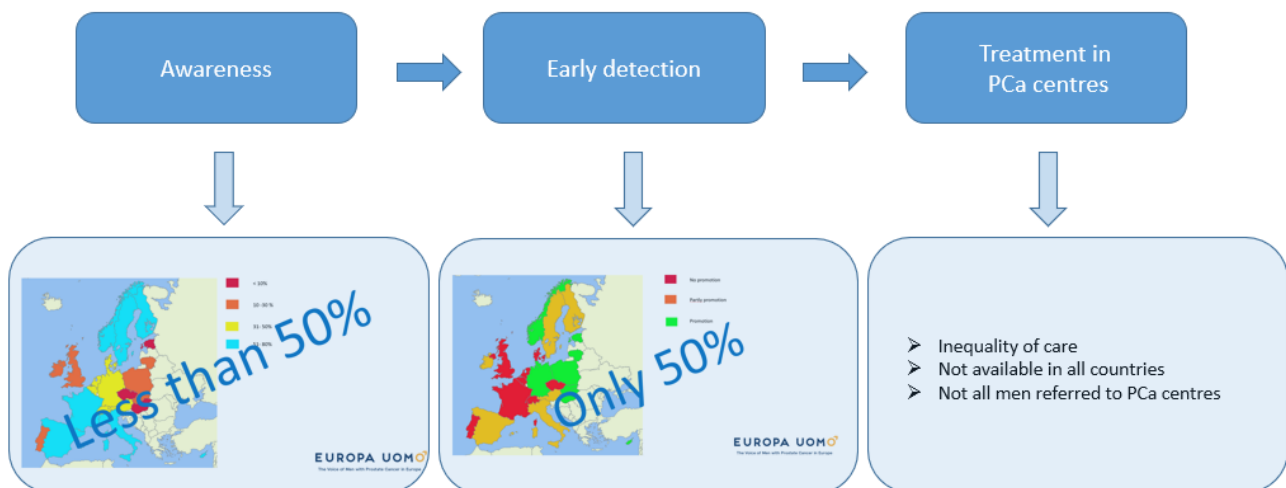
We still believe that the best care for PCa patients can be realised based on three pillars.



- Awareness of PCa is key and we must change perceptions and “taboos”.
- There is scientific evidence that early detection saves lives and improves the quality of life of patients and partners.
- Treatment in cancers centres must be the norm in order to assure equality of care and avoid overtreatment.
- All 3 elements are equally important and one does not work without the others.

2.2. Where are we today?

Unfortunately, we are far from where we like to be.

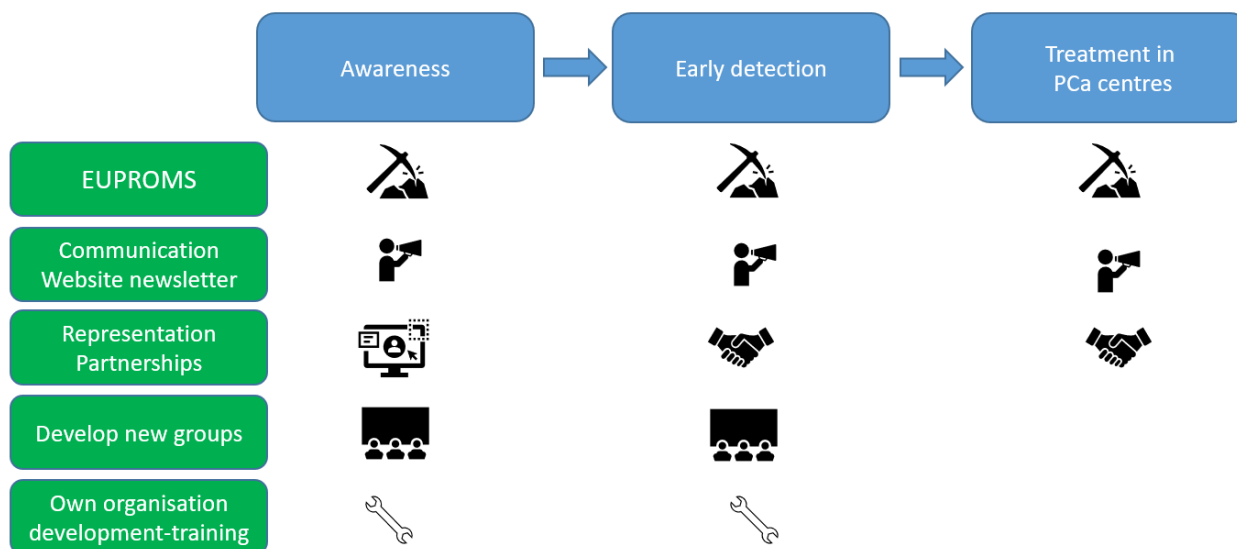


But, fortunately, there have also been hopeful signs developing over the past year: We were very happy to work with the European Association of Urology (EAU) on two documents , a reviewed [white paper on prostate cancer](#) and a [document on early detection](#). It is scientifically proven that early detection leads not only to better survival but also to a big gain in quality of life. As you will see when we publish the full results of our EUPROMS study, there are severe effects on quality of life whatever the treatment for PCa. But it is also very clear that the further the cancer spreads, the bigger the effect on quality of life.

Finland changed its approach and has chosen to promote early detection. Other countries are about to do the same.

2.3. Promoting our strategy through projects

The link between our strategy and this year's projects can be seen in the following figure.



2.4. EUPROMS project

- The survey was a success thanks to the efforts of all members and Board.
- The dataset is very rich and presents possibilities for further analysis.
- The survey has attracted a lot of attention.
- Distribution of results:
 - In the medical world: ESOU January 2020, EAU July 2020, ESMO September 2020, EMUC November 2020
 - To patients: annual report, mailing after EAU July 2020, newsletter, website
 - To the general public (linked with an awareness campaign): to be decided.

2.5. Communication, website and newsletter

Communication is key in these COVID-19 times. We have renewed our website and made it more up to date, functional and attractive.

- It will have an interactive function with our newsletter.
- It is readable in all European languages using "Google Translate" technology.
- Members have a higher profile, and are encouraged to share their news.
- It promotes Europa Uomo better, with more accessible resources and information



We are a European advocacy movement for men with prostate cancer, representing 27 national patients' groups

OUR PRIORITIES

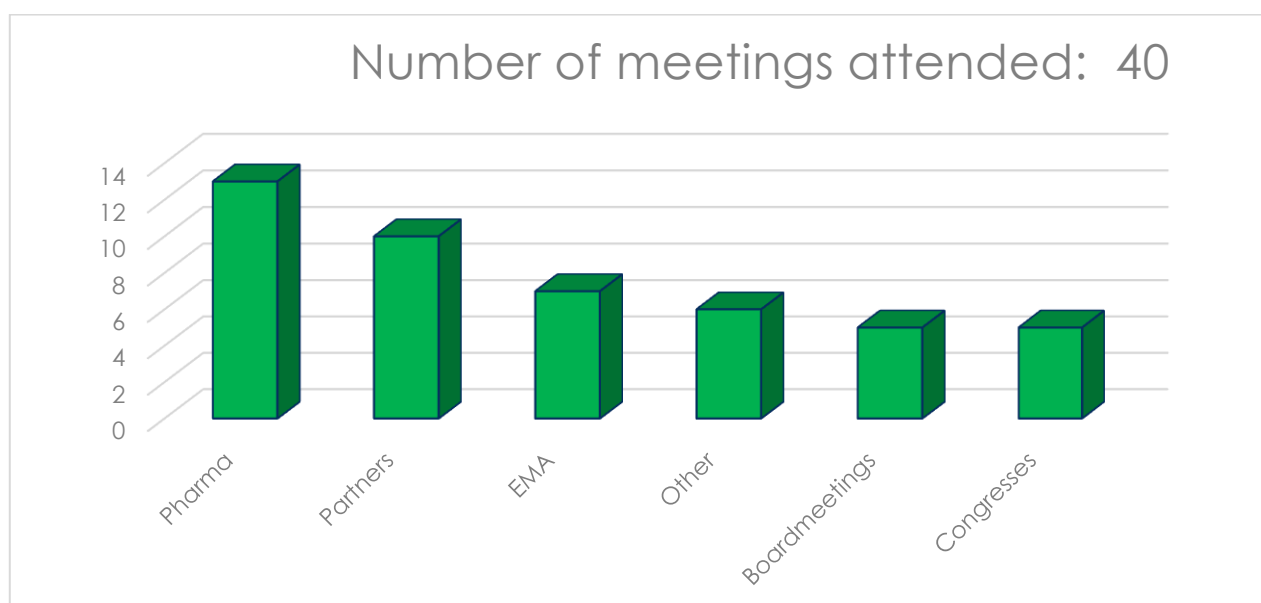
- > Better quality of life
- > Prostate cancer screening programmes
- > Better treatment and awareness

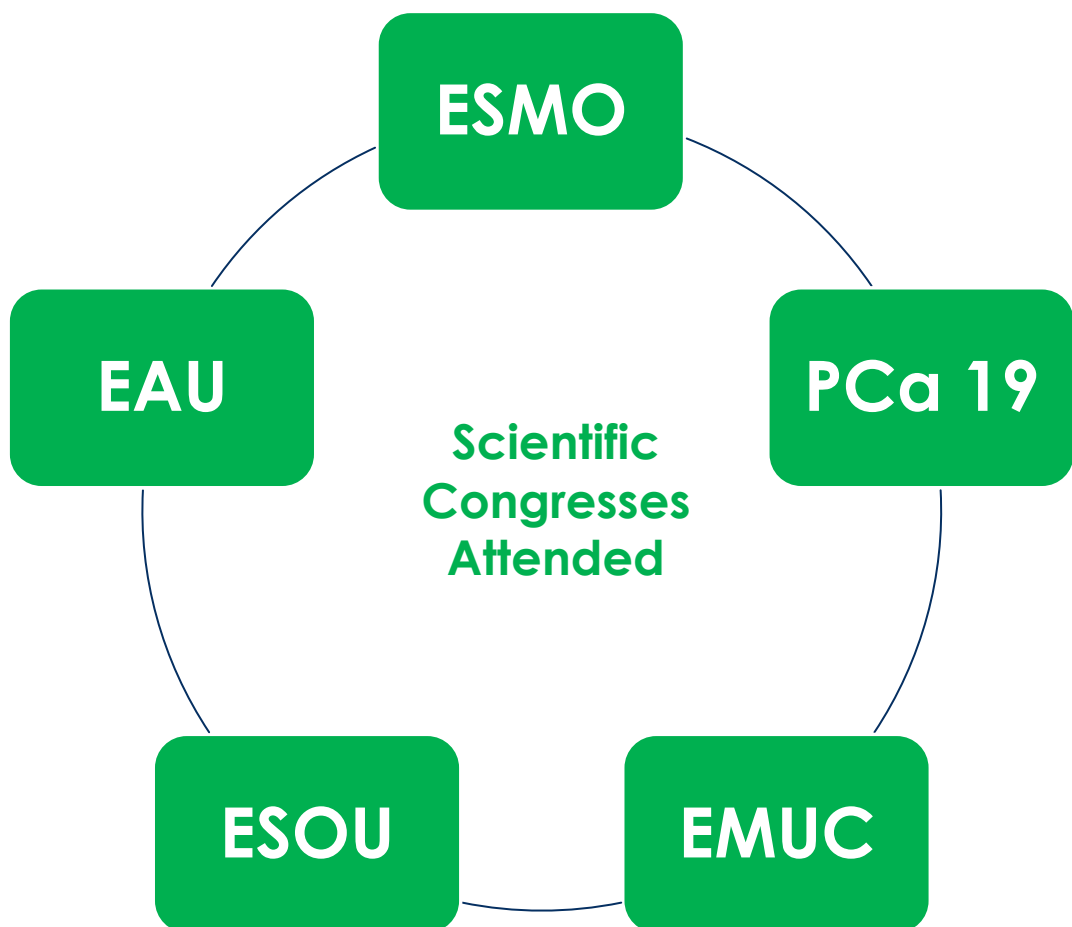
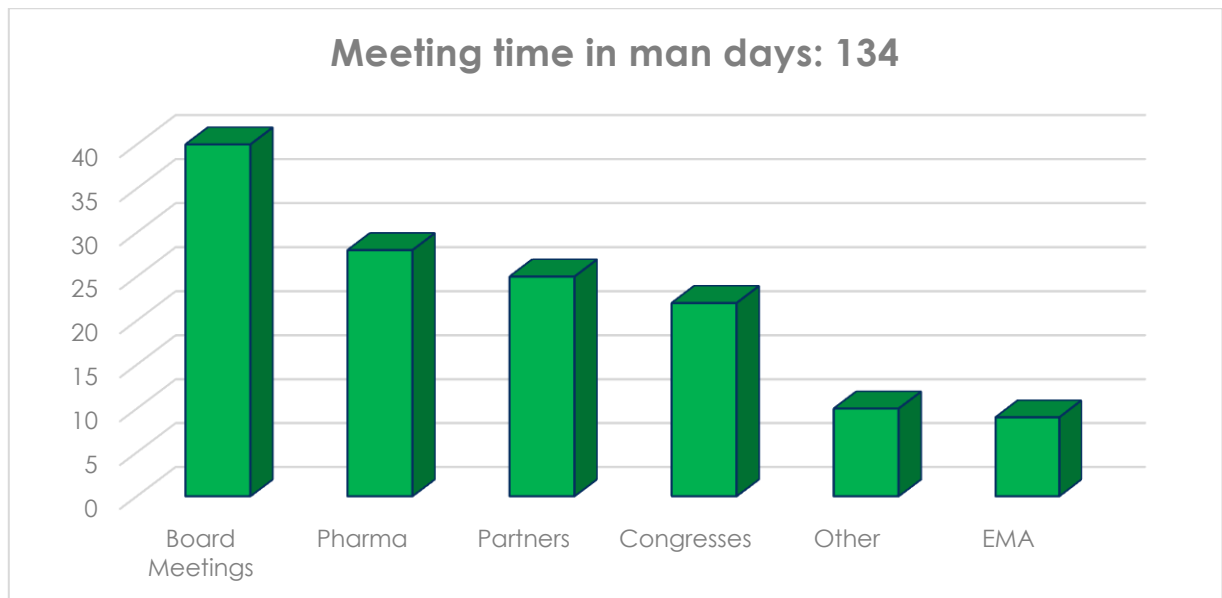
"Men with prostate cancer deserve to have a say"

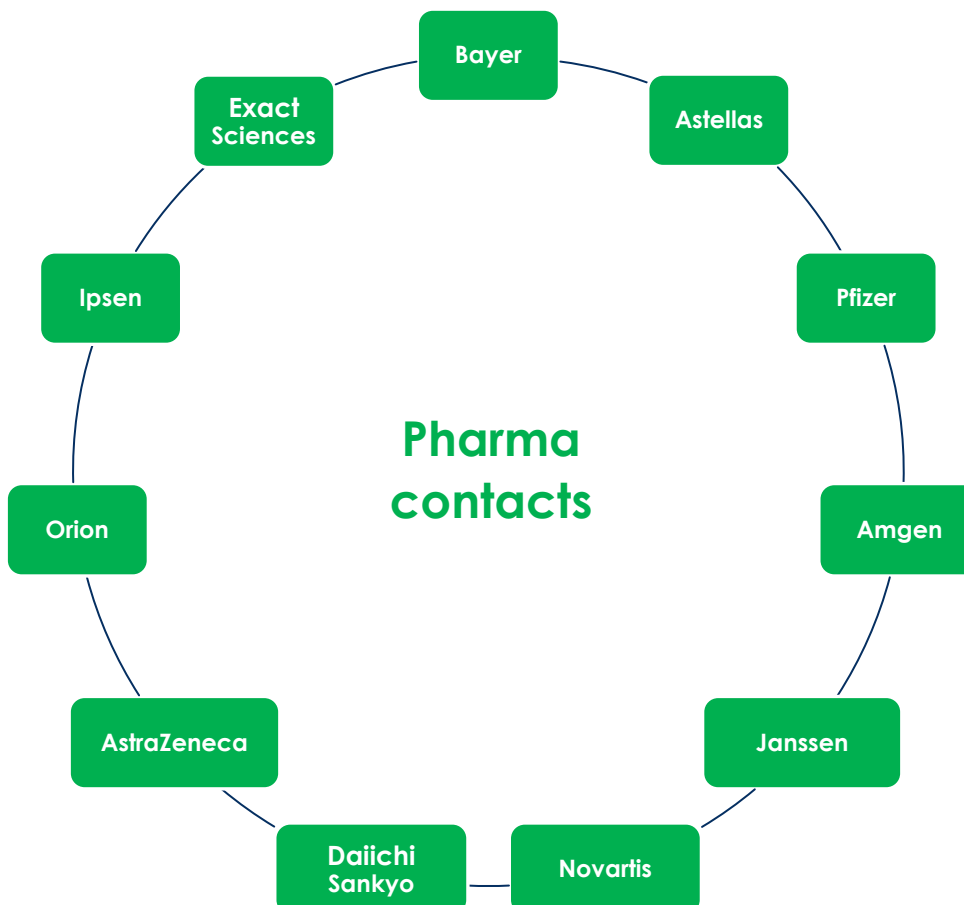
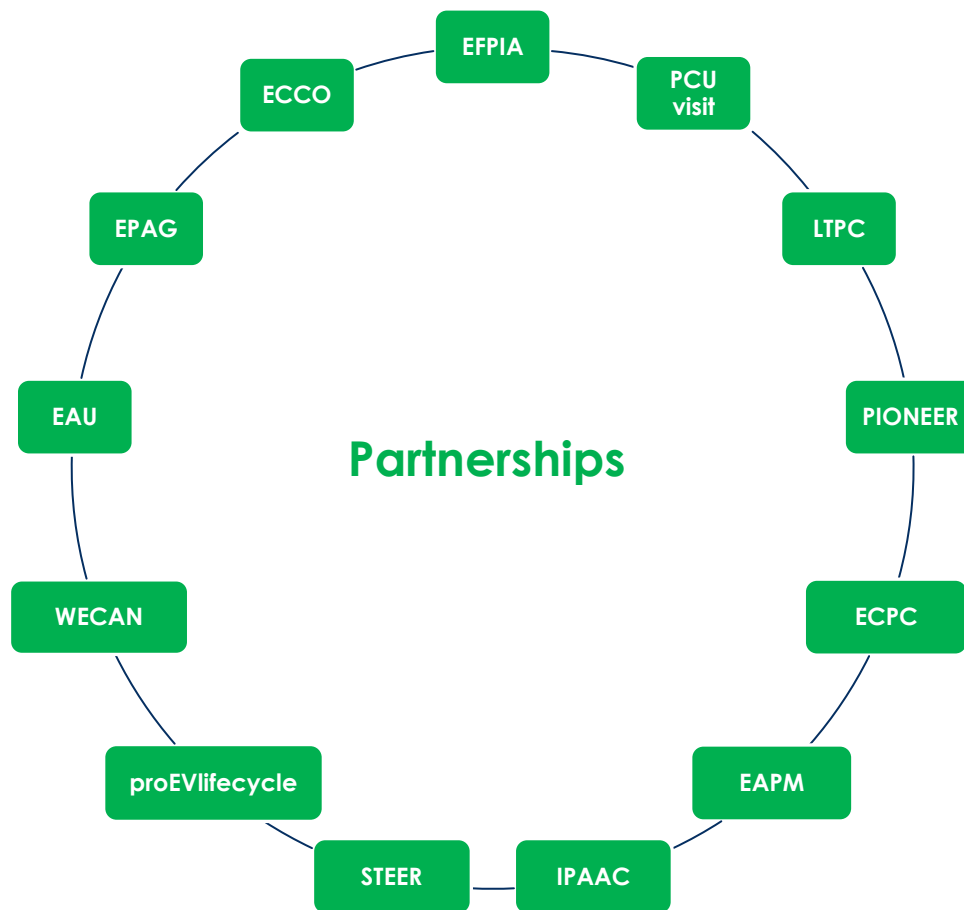
> More about us

2.6. Partnerships and attendance at meetings

Making partnerships and communicating our views are extremely important if we are to realise our ideas. Rather than providing a list of all our activities, the infographics below provide a summary.







2.7. Development and new groups

We have continued our efforts to encourage new patient groups both in the “Eastern Europe” area and the rest of Europe.

During our GA we will ask the membership to vote on whether to admit a second Spanish member, ANCAP .

We are also exploring active leads in Malta and Greece.

2.8. Own organisation development and training

Unfortunately, all plans for all in-person meetings had to be cancelled. Hence training or information sessions could not take place. That does not mean that activities have been stopped. Where possible, we communicate and inform “virtually”.

We follow closely the “softening of measurements” and will resume as soon as possible but safety for our members and patients is and will be the main driver.

3. Board Membership

The Board has seven members each elected by the General Assembly for a term of three years, renewable for a further term of three years. At the GA in 2019, Vice-Chairman, Stig Lindahl (Sweden), completed the first term of his membership of the Board and decided to step down. Will Jansen (The Netherlands) has also completed his first term, but, was re-elected. The newly elected member was Nils Petter Sjøholt (Norway).

The new Board met briefly before the end of the General Assembly at which the officers were elected. The full Board for 2019-20 was:

Chairman:	André Deschamps (Belgium)
Vice-Chairmen:	Guenther Carl (Germany) John Dowling (Ireland)
Treasurer:	Ioannis Vanezos (Cyprus)
Secretary:	Will Jansen (The Netherlands)
Other members:	Pentti Tuohimaa (Finland) Nils Petter Sjøholt (Norway)

Ex-officio members nominated by partners:

Prof. Hein Van Poppel (EAU)
Dr. Alberto Costa (ESO)
Prof. Louis Denis (OCA)

The Board met five times since the last General Assembly:

- 1) 03.09.19 Brussels
- 2) 10.10.19 Prague
- 3) 18.01.20 Dublin
- 4) 20.03.20 by Zoom
- 5) 04.05.20 by Zoom

In addition to the responsibilities set out in our Statutes for Chairman, Treasurer and Secretary, it is now customary for other Board members to take on particular portfolios.

4. 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
- The Board continues to distribute some costs to projects
- Income equals more or less spending

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 for costs where Board members or LOCs have attended meetings.

As with any organization, but especially in one run by volunteers, it is not always possible to roll out projects to the intended timeline. As was the case last year, when comparing the budget presented in our previous annual report, some projects which were launched more slowly than expected did not reflect the full financial provision made. Hence, we show less spending and less income in the actual –budget comparisons.

As we like to be cautious, our budgets for 2020 and 2021 again show ambitious spending and income. It is the Board's task to monitor and align income and spending.

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, for our sponsors.

Open bookkeeping is a 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 problems were found. So, the statements below are a true and honest account.

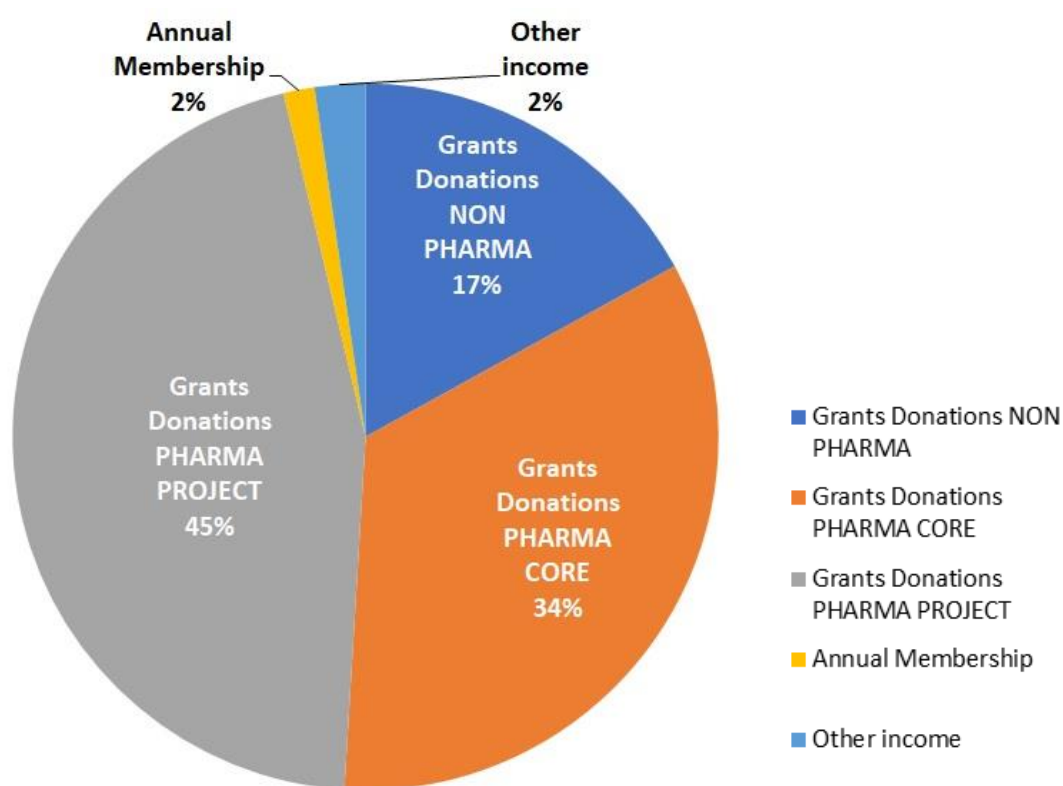
In accordance with Belgian law for not-for-profit organizations it is necessary that these financial reports be considered and approved by the General Assembly so that the Board may be discharged.

4.1 Balance Sheet at December 31, 2019

Accounts audited by Guido Smet

ASSETS		LIABILITIES	
Business Compact account	137.207,36	Balance at 31/12/2016	221.591,55
Saving account	50.134,34	Transfer of previous year	6.857,98
Receivables QoL project	25.000,00	Results 2019	-37.115,14
Deferred expenses	14.320,09	Deferred invoices	35.507,40
	226.841,79		226.841,79

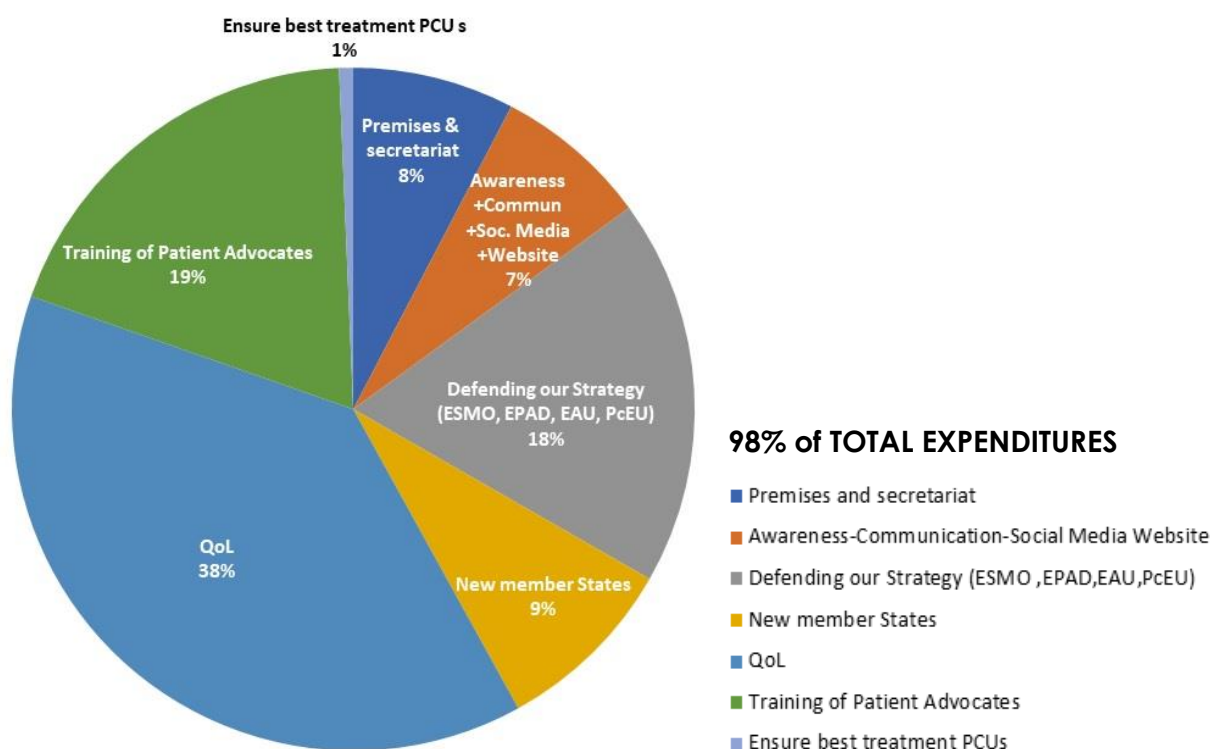
4.2 Income 2019 distribution



4.3. Income 2019 Breakdown

	Actual income	Budget
Grants Donations NON PHARMA	30.000,00	40.000,00
Grants Donations PHARMA CORE	60.000,00	75.000,00
Grants Donations PHARMA PROJECT	80.000,00	150.000,00
Annual Membership	2.500,00	2.200,00
Other Income	4.097,00	3.000,00
New Member Support		5.000,00
	176.597,00	275.200,00

4.4 Expenditures 2019 distribution

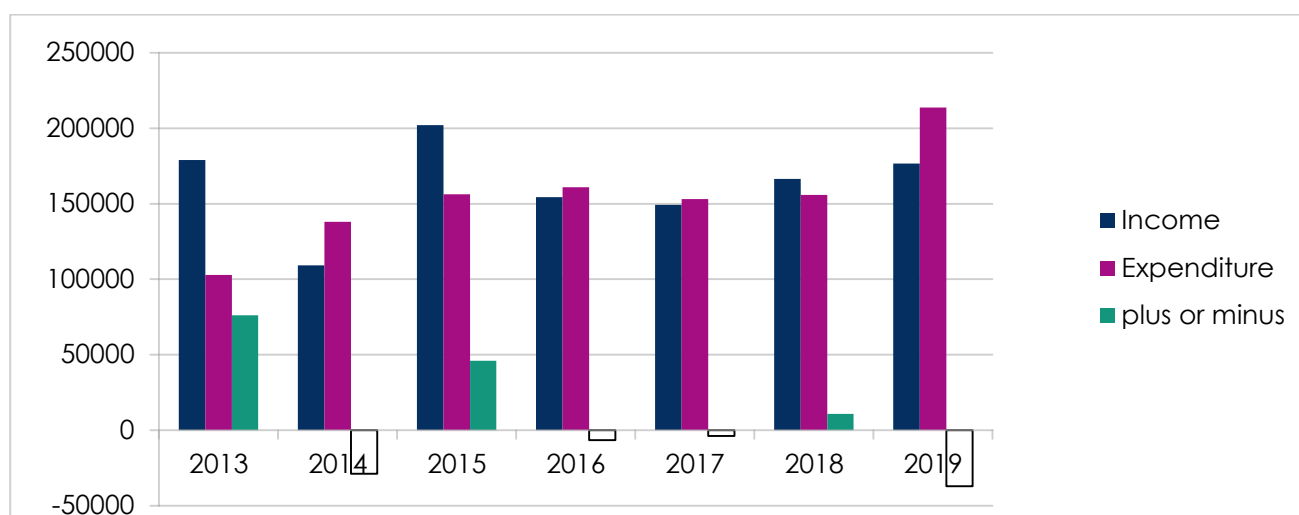


4.5 Expenditures 2019 Breakdown

	Budget 2019	Actual 2019
Premises and secretariat	16.000,00	16.000,00
Other secretariat costs	1.000,00	929,00
Awereness, Communication, Social Media	22.500,00	15.252,00
Defending our Strategy (ESMO, EPAD, EAU, EU)	40.000,00	38.230,00
New member States	16.500,00	18.156,00
QoL	75.000,00	80.155,00
Training of Patient Advocates	55.000,00	39.600,00
Ensure best treatment PCU's	44.000,00	1.400,00
Internet	200,00	
Audit fee and tax	2.500,00	920,00
Legal publications	150,00	135,00
Insurances	600,00	530,00
Memberships	300,00	100,00
Other meeting costs	11.000,00	1.830,00
Bank charges	250,00	390,00
Taxes on non-profit organsiation	500,00	85,00
Contingency	5.000,00	0,00
	290.500,00	213.712,00

4.6 Results for the years 2013-2019

	2013	2014	2015	2016	2017	2018	2019
Income	178875	109116	202150	154282	149183	166474	176596
Expenditure	102768	137989	156231	160867	153041	155759	213712
Result	76107	-28873	45919	-6585	-3858	10715	-37116



4.7 Budget and actual 2019

	Budget	Actual	%
Income	275.200	176.596	64,2
Expenses	290.500	213.712	73,5
	Expected and budgeted -15.300	Results in -37.116	

4.8 Income budget 2019,2020,2021

	BUDGET 2019	ACTUAL 2019	REVISED 2020	BUDGET 2021
GRANTS DONATION NON PHARMA	40 000,00	30 000,00	40 000,00	40 000,00
PHARMA CORE FUNDING	75 000,00	60 000,00	50 000,00	75 000,00
PHARMA PROJECT FUNDING	150 000,00	80 000,00	90 000,00	90 000,00
ANNUAL MEMBERSHIP	2 200,00	2 500,00	2 500,00	2 300,00
OTHER INCOME	3 000,00	4 097,00	13 500,00	13 000,00
	270 200,00	176 597,00	196 000,00	220 300,00

4.9 Expenses budget 2019,2020,2021

	BUDGET 2109	ACTUAL 2019	REVISED 2020	BUDGET 2021
Premises and secretariat	16 000,00	16 000,00	16 000,00	16 000,00
Other secretariat costs	1 000,00	929,00	1 000,00	1 000,00
Awareness+ Social Media	22 500,00	15 252,00	22 500,00	22 500,00
Defending our Strategy	40 000,00	38 230,00	35 000,00	40 000,00
New member States	16 500,00	18 156,00	16 500,00	16 500,00
QoL	75 000,00	80 155,00	25 000,00	12 000,00
Training	55 000,00	39 600,00	45 000,00	55 000,00
Ensure best treatment	44 000,00	1 400,00	22 500,00	44 000,00
Internet	200,00		200,00	200,00
Audit fee and tax	2 500,00	920,00	2 500,00	2 500,00
Legal Publications	150,00	135,00	150,00	150,00
Insurances	600,00	530,00	600,00	600,00
Memberships	300,00	100,00	300,00	300,00
Other meeting costs	11 000,00	1 830,00	11 000,00	11 000,00
Bank charges	250,00	390,00	250,00	250,00
Taxes	500,00	85,00	500,00	500,00
Contingency	5 000,00	0,00	1 000,00	5 000,00
	290 500,00	213 712,00	200 000,00	227 500,00

Thanks to our sponsors during 2019/20



This report is published by the Board of Europa Uomo.

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