

**EUROPA UOMO** 

**The Voice of Men with Prostate Cancer In Europe**

**Annual Report  
of the Board  
for 2020/21**

## 1. Chairman's Note

Dear Reader,

For the second year in a row COVID 19 is defining what we can and cannot do and needless to say the virus has changed our way of living far more and for far longer than we could have imagined a year ago.

For a second year we are forced to hold a virtual general assembly missing the exchange of ideas and experiences.

Although we all are used to virtual meetings and have very quickly learned to make the best out of it, we cannot deny that the lack of personal contact has an effect on us. This is also disturbing our normal cycle of Board membership as electing Board members and dividing responsibilities between them is a process that is facilitated by a live presence.

That is why the Board has asked the members to change the term of the Board exceptionally from 3 to 4 years and at the same time open up 2 extra board positions in order to assure a smooth transition in 2022. I like to thank our members who approved this proposal unanimously during our extraordinary GA in March 2021.

Europa Uomo was able to adapt very quickly to the "new normal". The new website, newsletter and our increased presence on social media, all launched during our GA in 2020, has enabled us to communicate very effectively in these COVID times. Just look at the list of our activities in this report to be convinced.

I am also very pleased with the numerous presentations, peer reviewed articles and abstracts communicating the results of our EUPROMS survey. This study has really changed the prostate cancer world. We had a lot of attention from healthcare professionals and decision makers. I even dare to suggest that the decision of the EU BECA committee to "study the possibility of early detection for PCa" has been influenced by EUPROMS.

We have also translated the scientific analysis in a presentation designed for patients and their relatives. This presentation is translated into 17 languages and freely available on our website.

In discussing the results of EUPROMS with many stakeholders, we found that in spite of the relevant results of EUPROMS, important questions on the quality of life after PCa treatments remain unanswered and this is why we have decided to launch a follow up survey in the last quarter of 2021, called EUPROMS 2.



Thanks to our sponsors we were able to secure the funding needed and I can assure you that the efforts of all patients answering EUPROMS 2 will pay off and force decision makers to finally give prostate cancer the attention that it deserves. The strategy of "Speak with facts" has proven to be very successful and we would like to continue along this path.

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

- Lost their fight against PCa and were not able to be properly supported in their final journey by their loved ones due to Covid-19 restrictions
- Lost relatives due to Covid-19
- Suffered a delay in the diagnosis of a condition
- Could not receive necessary treatments.

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**

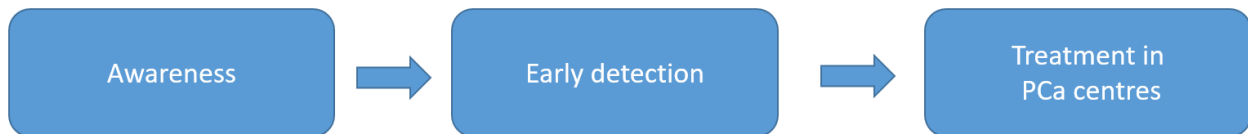
Chairman

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

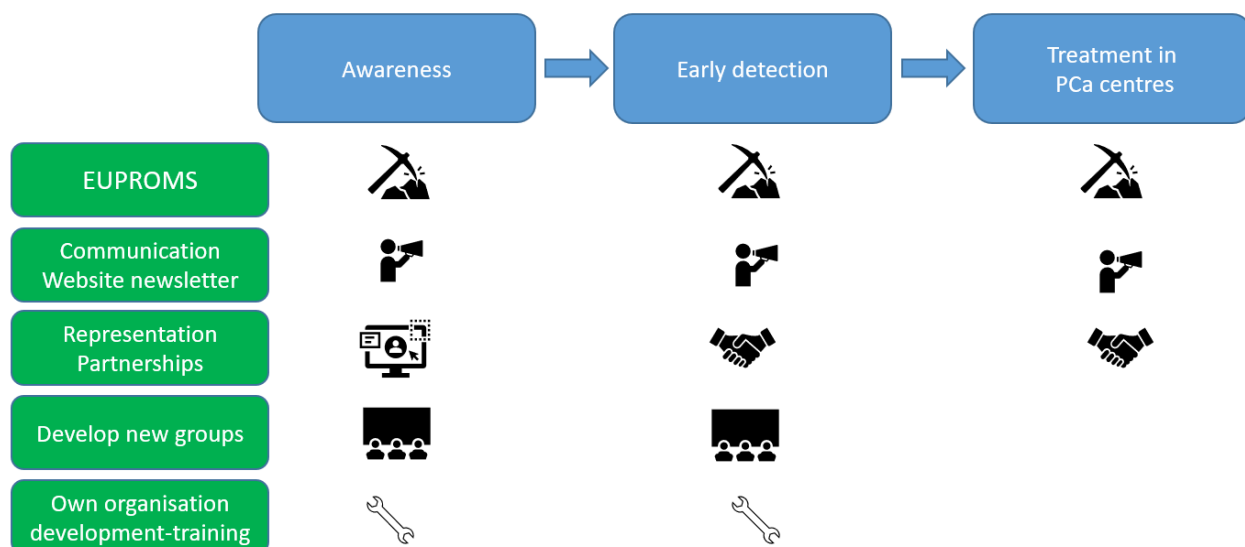
But there is also some good news.

In the beginning of this year Austria decided to support early detection for PCa. In may Norway decided to do the same and as you know Finland announced this policy last year.

The EU beating the cancer plan announced an evaluation of adding prostate cancer to the list of cancers for early detection. This decision will be made early 2022 by the BECA committee. It is our task to supply the patient view and the necessary data to prove our point. Building on the experience of EUPROMS 1, we will launch a new survey EUPROMS 2 especially to investigate the differences in quality of life with or without early detection.

### 2.3. Promoting our strategy through projects

The link between our strategy and our projects can be seen in the following figure.



## 2.4. EUPROMS project

EUPROMS 1 was a success thanks to the efforts of all members and Board. Over the last year the full analysis was completed, many presentations were given and different articles, posters and abstracts are published

Here is the list :

- ESOU 2020 (main session)
- EAU 2020 (game changing session)
- EPAD 2020 (main session)
- EMUC 2020 (main session)
- EORTC congress
- ESMO 2020 (2 abstracts)
- Europa Uomo general assembly
- Peer voice (United states)
- Movember prostate cancer meeting
- EAU 2021 (5 abstracts submitted)
- Presentations for sponsors (13)
- AUA 2021 (2 abstracts: a podium presentation and a moderated poster presentation)
- ISOQOL 2021 (1 abstract for post presentation)

We developed a presentation with the results especially designed for patients and their relatives. This presentation is downloadable at our website and is available in 17 different languages. Here is the link:

<https://www.europa-uomo.org/news/euproms-presentation-available-in-17-languages/>

As already mentioned above, the analysis of the results triggered many other questions regarding the quality of life of prostate cancer patients. Also some scientific data need to be clarified in order to draw even better conclusions. Therefore the board decided to initiate an EUPROMS 2 survey that will take place in the autumn of 2021

## 2.5. **Communication, website and newsletter**

In recent years, Europa Uomo has allocated significant resources to internal and external communications. To justify this expenditure etc., the Board has recognised that the communications role must be the subject of critical review and continuous development. This ensures that our organisation gets value for money in terms of letting the world know of our existence and our mission, as well as promoting events and particular issues, that are important to Europa Uomo: early diagnosis, organised screening, multidisciplinary treatment centres, quality of life and the importance of listening to the patients' voice.

Communications resources obviously requires, notwithstanding all the new technology we have available, a mainly human input. The outputs are the result of solid maintenance work done during the year as well as our participation in particular initiatives. As a result, we have been very busy as a European organisation despite the disruption of Covid-19. The public face of Europa Uomo has been very ably represented by our Chairman, André Deschamps, who has had an incredibly busy time, tirelessly explaining, to a multitude of virtual conferences and smaller on-line meetings, the lessons for patients and practitioners from our very successful EUPROMS study, now known as EUPROMS I.

André's determined work as public face of our organisation, has allowed us to expand and develop more extensive contacts and supports with the representative medical organisations such as EAU\*, ESMO\*, EORTC\* and last but not least EAON\* (whose members are very often the linch-pin between patient and specialist physician). In addition, we have made it a priority to continue to develop our inter-patient group contacts such as via ECPC, WECAN and, most recently, our joining of the European Patient Forum which we joined in April 2021.

In June 2019, the Board assigned Vice-Chairman, John Dowling, oversight of communications matters. He has had the invaluable services of our science writer and media consultant, Simon Crompton, and from within the Secretariat, Anja Vancauwenbergh, who works with Simon and John on the website and the production process that results in the *Update* newsletter, and making sure it gets to members and others on schedule.

The overall Communications Plan developed by Simon and John and approved by the Board in late 2019 was centred on a rebuild of the website and a new design to better present our message. Since he has taken on this portfolio, John has constantly reiterated that websites need to be fed. They have a voracious appetite. They need continuous review and periodic renewal or rebuild and

always an active management of site so that visitors can clearly see an organisation that looks alive by its vibrancy, is relevant and worthwhile due to both its fresh appearance and content of interest.

Simon secured us the services of an experienced website designer who was used to working with voluntary organisations and our website was relaunched at last year's virtual GA with a fresh user-friendly look. We have a new webmaster to look after the site and keep it functioning so that new visitors do not encounter the obvious signs of neglect. Simon is updating the website weekly with news articles. Anja constantly scans the journals received in the office in Antwerp, bringing articles of possible interest to John's attention as he is assembling items for the fortnightly newsletter *Update*. If members have articles of local or regional interest, they can be posted on the newsletter and the website. And the translate facility on the website allows all this material to be translated into 108 languages. In the past year, more than fifty news items have been posted on the website, on average one a week.

*Update* includes these items, and other news and events. At the time of publication of the Annual Report more than 150 issues of *Update* have been published since February 2018 and it is now circulated not only to our own member organisations, but also to individual prostate patients, practitioners and other organisations and the medical/pharmaceutical companies both near and far. It is hoped that more member organisations will follow the example of those who supply us with a copy of their local newsletter.

Members are reminded they can also use the translate function on the website to use articles from *Update* and convert them into their own language. Also the EAU Patient Office Information section updates and other newsletters can be accessed in several languages.

As already mentioned, the effect of Covid-19 has been considerable, but we have managed to keep our communications output active and hopefully relevant. Our social media platforms, particularly Twitter, are important ways of spreading our messages to wider audiences. Our Twitter following continues to grow and, associated with it, our website page views are escalating too (see below).

Another aspect of Europa Uomo's busy year was the rollout of a more detailed analysis of the EUPROMS study at the Virtual General Assembly in 2020 and a major drive, led by Chairman André Deschamps, to disseminate the main findings of the study. This entailed the development of easy-to-follow slide presentations about the survey and its conclusions. This process involved Simon, and André and colleagues from the Erasmus Medical Centre. Press releases, briefing materials for various conferences and publications were prepared.

As a result of the success of EUPROMS 1, our Treasurer, Ioannis Vanezos, had virtual meetings with our existing and new sponsors and has been rewarded with commitments for both "core support" and support for specific projects the Board has authorised over recent years.

We have been able to gather the considerable financial, academic and technical support to meet the demand for a follow-up study. With our great analysis team at the Erasmus Medical Centre, Rotterdam, under the aegis of Prof. Monique Roobol, we have been privileged to work with Lionne Venderos, and Sebastiaan Remmers, who have so diligently mined the EUPROMS 1 survey for information and for producing scientific papers for submission to peer-reviewed journals. The team has also provided us with detailed scientific advice about extracting information from the survey. The team has now formulated a proposal for a follow-up study which has been approved by the Board and been christened EUPROMS 2 – this is being prepared for distribution later this year.

To summarise the main Europa Uomo communications outputs:

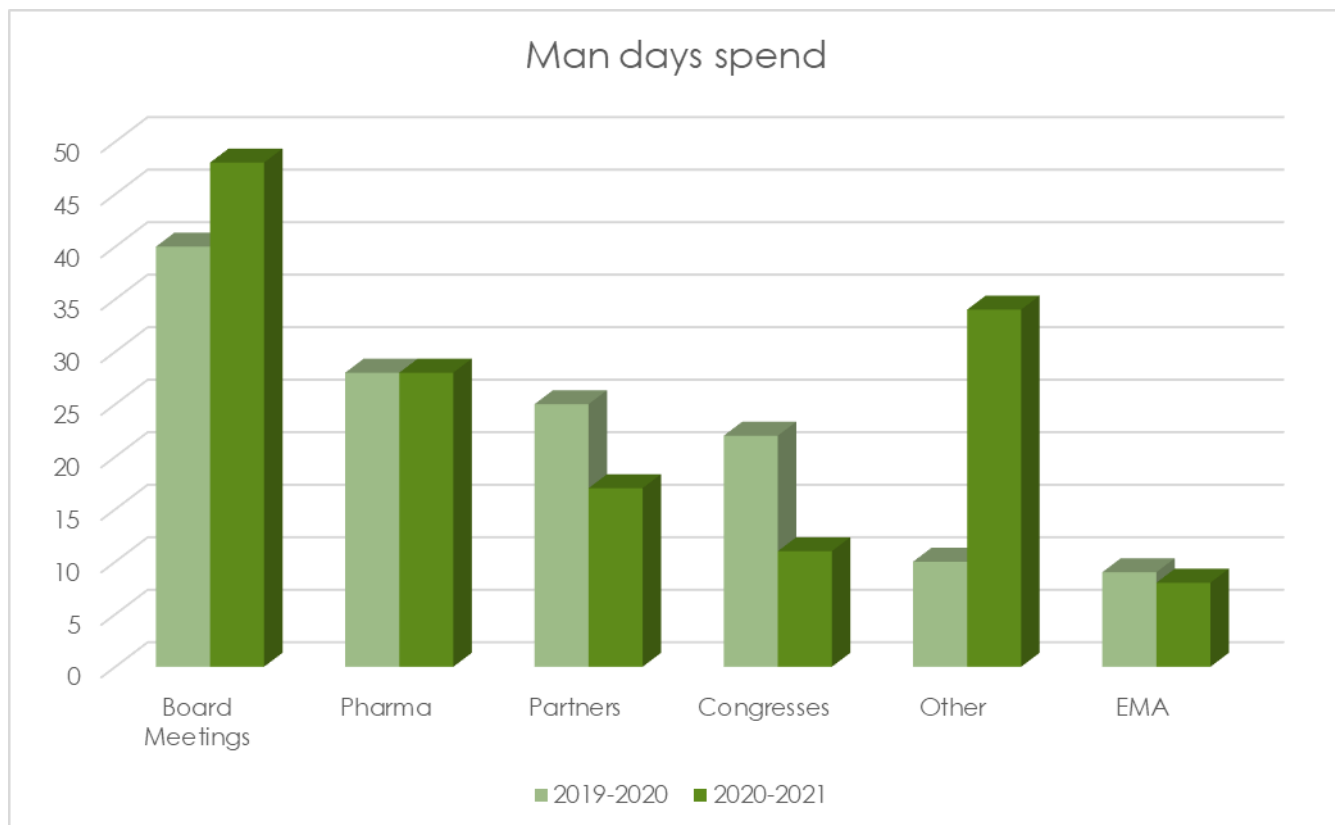
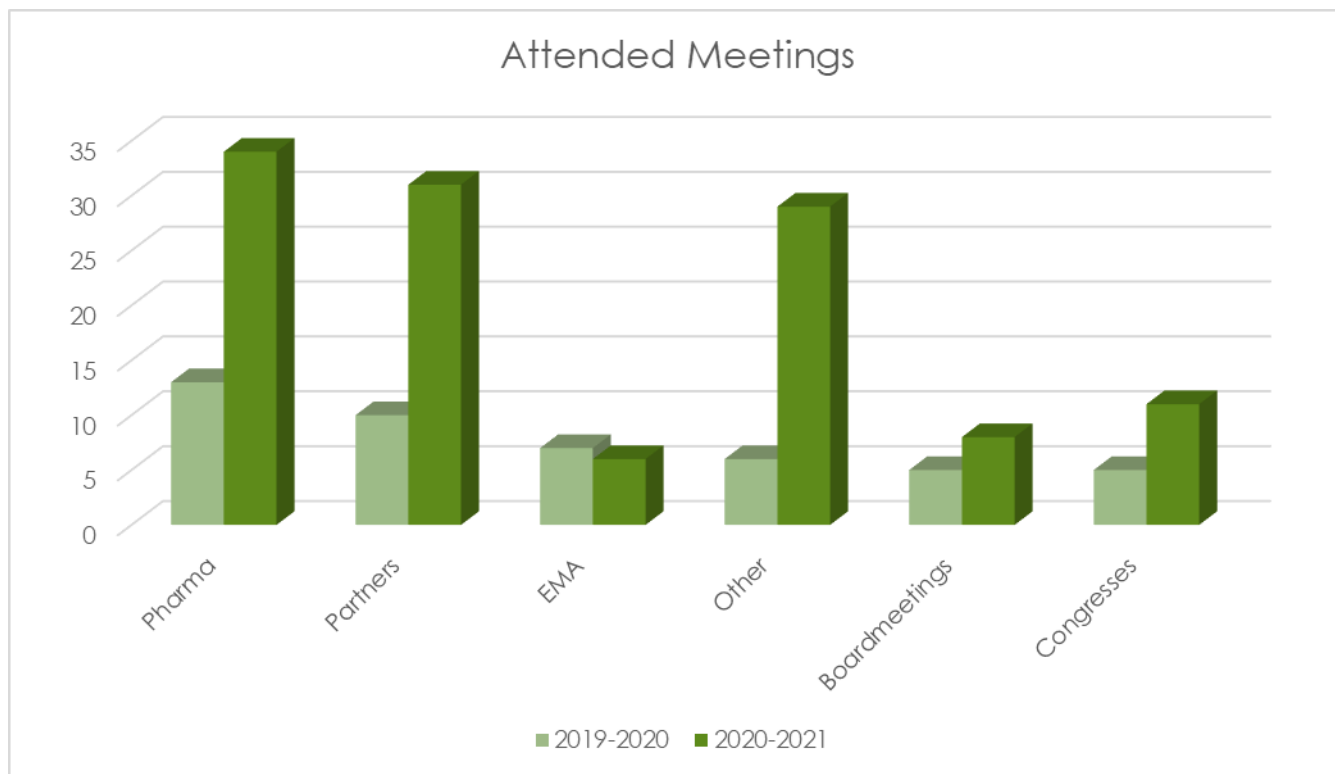
1. Rebuilt website, launched 19th May 2020. In its first year, the new website has seen page views increase by nearly 40% and the average visitor stays 20% longer on the website than they did a year ago. Compared with two years ago, page views are up 70% and session duration is up 54%. See attached graphics.
2. Twitter followers have increased from 231 to 349 followers (+ 118).
3. A EUPROMS 1 PowerPoint patient presentation and EUPROMS 1 web page, have provided accessible information about, and findings from, the study.
4. Translated versions of the EUPROMS 1 PowerPoints, have been made accessible via the website and sent to member organisations.
5. Articles about EUPROMS 1 and Europa Uomo have been prepared for the Government Gazette and the EAU's Patient Information Office newsletter.
6. Europa Uomo's dormant YouTube page has been reactivated, posting videos about the Lets' Talk Prostate Cancer roundtable event, and Europa Uomo Active Surveillance webinars.
7. Various events and activities have been publicised.
8. Continuous news stories and social media postings have been made throughout the year, recently focusing in particular on prostate cancer early detection, and campaigning in the build-up to the EU Cancer Plan.
9. At the time of writing this report Simon Crompton and his design team are developing an on-line booklet summarising the EUPROMS 1 study which will be made widely available. A print version will follow – member organisations may request the number of copies required and the language in which they wish to receive the print version.
10. Our communications team is also working with the academics and survey specialists to finalise the EUROPROMS 2 survey which will issue in the coming months.

\*EAU – European Association of Urology, ESMO – European Society of Medical Oncology, ESTRO – European Society for Radiation Oncology and EAON – European Association of Oncology Nurses



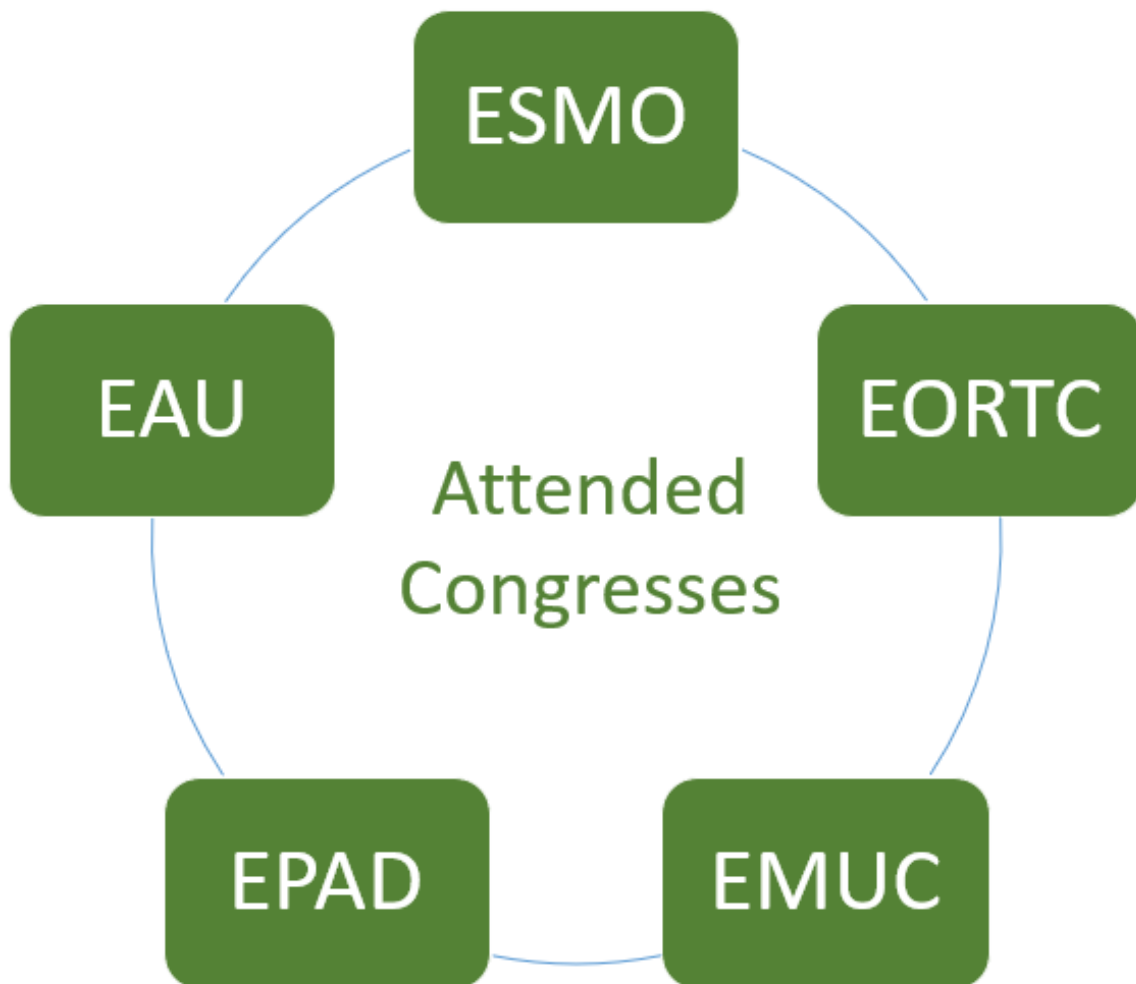
## 2.6. Partnerships and attendance at meetings

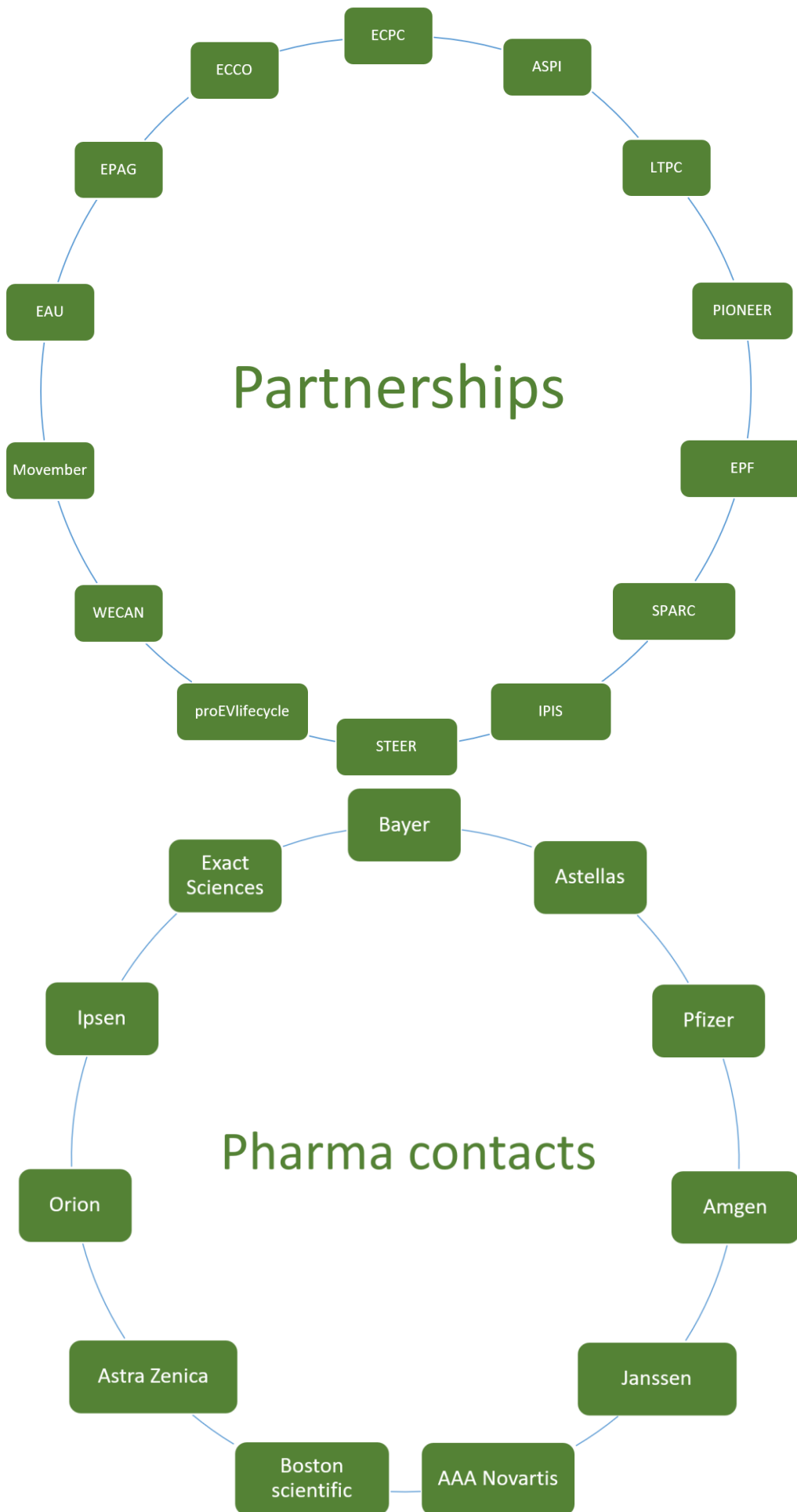
Making partnerships and communicating our views are extremely important if we are to realise our ideas. Rather than providing a list of all our activities, the infographics below provide a summary.



The total of attended meetings by board members has more than doubled from 46 to 119. The amount of days spend on those activities was 146 days compared with 134 days in the previous year, an increase of 10%

This shows maybe the only "positive effect" from COVID 19. Virtual meetings are less time consuming than face to face. We believe that in the coming years we will see a mixture of face to face and virtual meetings.





## 2.7. **Development and new groups**

Due to COVID it was not possible to visit possible new members or take local initiatives on new groups. We hope to resume those activities soon.

## 2.8. **Own organisation development and training**

Unfortunately, all plans for all in-person meetings had to be cancelled. We were forced to hold our General Assembly and an extraordinary general Assembly on line.

That does not mean that training and information activities have been stopped. Where possible, we communicate and inform “virtually”. Our website has been upgraded and we started with on line training and information sessions. Following our strategy the first cycle of meetings is devoted to active surveillance.

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 2020, Board member, Pentti Tuohimaa (Finland), completed the first term of his membership of the Board and decided to step down. The newly elected member was Cosimo Pieri (Italy).

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:	Cosimo Pieri (Italy) 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 six times (all virtually by Zoom) since the last General Assembly:

- 1) 30.06.20
- 2) 15.09.20
- 3) 24.11.20
- 4) 26.01.21
- 5) 16.03.21
- 6) 18.05.21

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
- Income equals more or less spending

The funding of Europa Uomo comes from small contributions from member organizations through their annual dues, contributions from sponsors non Pharma, pharmaceutical companies and reimbursement for costs where Board members or LOCs have attended meetings or given presentations.

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, with the pandemic crisis . When comparing the budget presented in our previous annual report, some projects which were launched more slowly than expected and did not reflect the full financial provision made. Hence, we show less spending in the actual –budget comparisons.

As we like to be cautious, our budgets for 2021 and 2022 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.

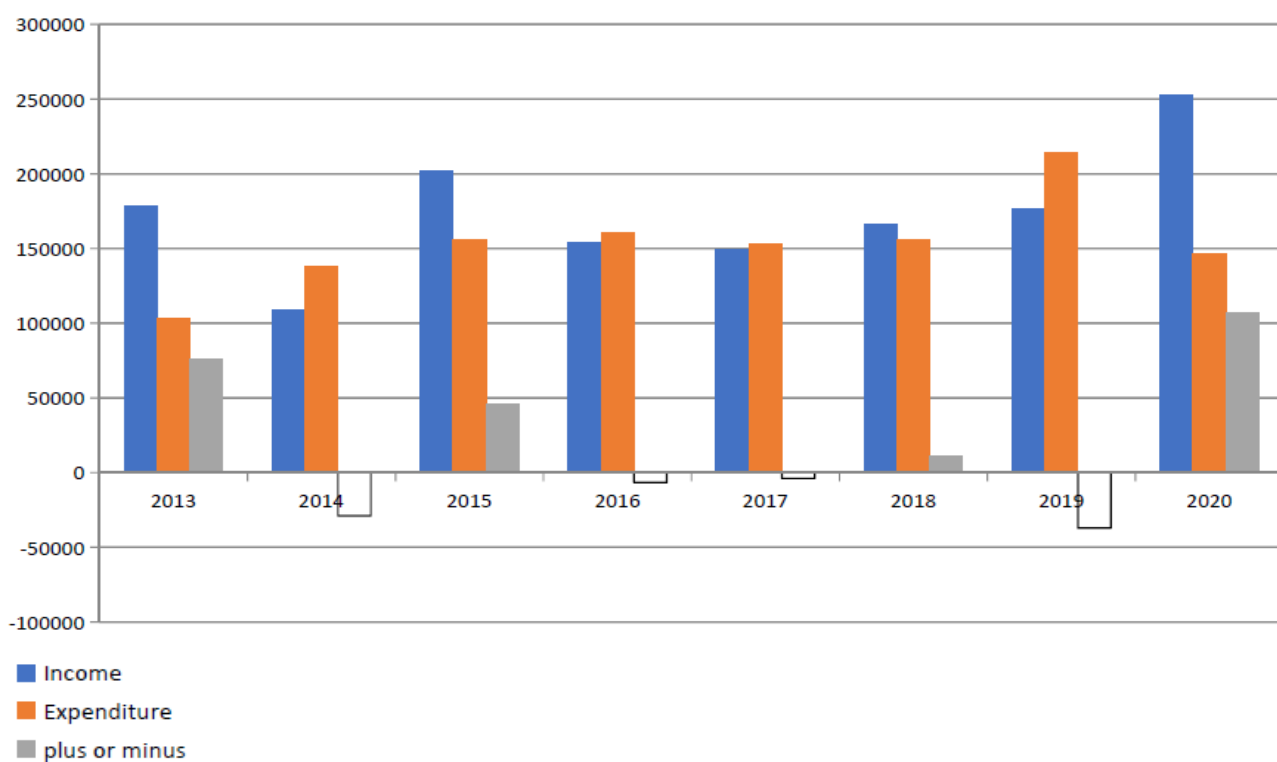
In accordance with Belgian law it is necessary that these financial reports will be approved by the General Assembly.

#### 4.1. Balance Sheet at December 31, 2020

Accounts audited by Guido Smet

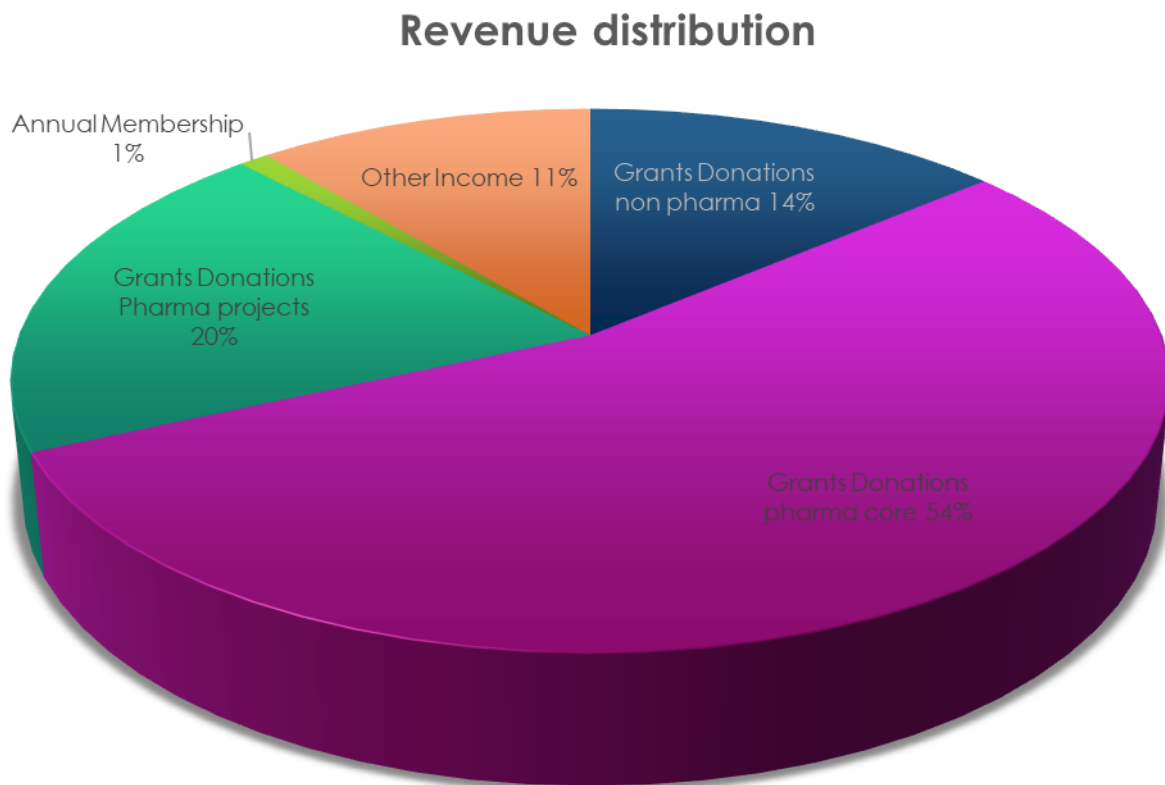
ASSETS		LIABILITIES	
Business Compact account	268.787,63	Balance at 31/12/2016	221.591,55
Saving account	50.314,34	Positive results 2020	106.530,71
Provision receivables	230,00	Negative result 2019	- 30.257,16
Deferred expenses	96,48	Deferred invoices	21.563,35
	<b>319.428,45</b>		<b>319.428,45</b>

#### 4.2. Results for the years 2013-2020



	2013	2014	2015	2016	2017	2018	2019	2020
<b>Income</b>	178875	109116	202150	154282	149183	166474	176596	253101
<b>Expenditure</b>	102768	137989	156231	160867	153041	155759	213712	146670
<b>Result</b>	76107	-28873	45919	-6585	-3858	10715	-37116	106530

#### 4.3. Revenue 2020 distribution

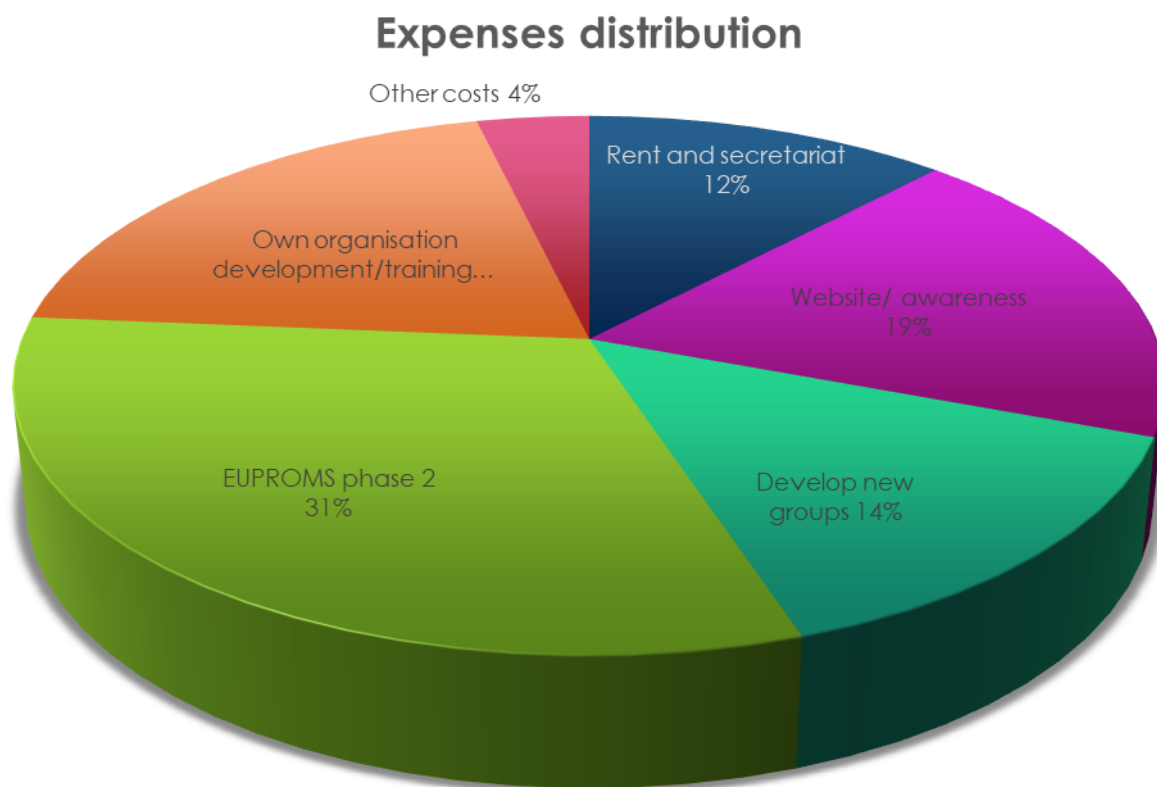


#### 4.4. Revenues 2020 breakdown

	<b>Actual revenue 2020</b>	<b>Budget 2020</b>
Grants/Donations NON PHARMA	35.000,00	40.000,00
Grants/Donations PHARMA CORE	137.725,00	50.000,00
Grants/Donations PHARMA PROJECT	50.000,00	90.000,00
Annual Membership	2.500,00	2.500,00
Other income	27.975,00	13.500,00
	<b>253.201,00</b>	<b>196.000,00</b>



#### 4.5. Expenses 2020 distribution



#### 4.6. Expenses 2020 breakdown

	<b>Actual cost 2020</b>	<b>Budget 2020</b>
Premises and Secretariat	17.600,00	16.000,00
Other secretariat costs		1.000,00
Website/Social Media/Awareness	27.321,00	45.000,00
Other costs	1.408,81	35.000,00
Development new groups	20.715,00	16.500,00
EUPROMS I phase II	45.900,00	25.000,00
Own organisation development/training	29.124,00	45.000,00
Internet	121,00	200,00
Audit fees	1.161,00	2.500,00
Legal publications	134,00	150,00
Insurances	525,00	600,00
Memberships	97,00	300,00
Other meeting costs	1.726,00	11.000,00
Bank charges	519,00	250,00
Taxes on NPO	319,00	500,00
Contingency		1.000,00
	<b>146.670,81</b>	<b>200.000,00</b>

#### 4.7. Budget and actual 2020

	<b>Budget</b>	<b>Actual</b>	<b>%</b>
<b>Income</b>	196.000,00	253.201,00	129,0%
<b>Expenses</b>	200.000,00	146.670,00	73,4%

#### 4.8. Revised projects 2021

Revised projects 2021	<b>Project cost</b>
Website/Social Media/Communications/Awareness	37.500,00
Active Surveillance initiative project	26.000,00
EUPROMS II	150.000,00
Training members/QoL results local presentations	80.000,00
	<b>293.500,00</b>

#### 4.9. Revenue budget 2021 and 2022

	<b>Revenue Budget 2021</b>	<b>Revenue Budget 2022</b>
GRANTS/DONATIONS NON PHARMA	35.000,00	35.000,00
PHARMA CORE FUNDING	60.000,00	60.000,00
PHARMA PROJECT FUNDING	150.000,00	80.000,00
ANNUAL MEMBERSHIP	2.500,00	2.500,00
OTHER INCOME	10.000,00	10.000,00
	<b>257.500,00</b>	<b>187.500,00</b>

#### 4.10. Expenses budget 2021 and 2022

	<b>Budget 2021</b>	<b>Budget 2022</b>
Premises and secretariat	16.000,00	16.000,00
Website/Social Media/PCU audits	37.500,00	40.000,00
Active Surveillance initiative project	26.000,00	
Defending our strategy		40.000,00
EUPROMS II	150.000,00	30.000,00
New members		16.500,00
Own organisation development/training	80.000,00	55.000,00
Legal costs:audit,tax,legal publications	3150,00	3.150,00
Insurances and other admin costs	1350,00	2350,00
Contingency		15.000,00
	<b>314.000,00</b>	<b>218.000,00</b>

## Thanks to our sponsors during 2020



This report is published by the Board of Europa Uomo.

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