

**EUROPA UOMO** 

The Voice of Men with Prostate Cancer in Europe

**Annual Report  
of the Board  
for 2021/22**

## 1. Chairman's Note

Dear Reader,

Although COVID 19 is still among us, the Board decided to organise the General Assembly “live” in Amsterdam. We are all vaccinated and boosted and the current COVID variant shows to be “less dangerous”.

It is time that we see each other again and share ideas face to face. We must realise that the years to come are important for prostate cancer patients.

We know that, thanks to policy efforts from all sides, the EU will include “early detection for prostate cancer” in its Beating Cancer Plan for the next five years. This is a major achievement and I am very happy that health care professionals and patients joined efforts to prove the scientific case and the benefits for all parties involved. But the real work starts now. Awareness of prostate cancer is still low and the taboo is large. So if we want a situation where well informed men are willing and convinced to test there is a lot of work ahead of us.



Every member state must implement the guideline and we must convince men to take the test. Europa Uomo is ready to support its members with materials, advice and experience to make this implementation a success.

The results of our EUPROMS study have without doubt contributed to policy makers' understanding of the burden of prostate cancer and the need to take action. Our follow-up EUPROMS 2.0 survey was a success, with 3600 patient responses. The analysis will deliver more details and help us organise awareness campaigns.

With this General Assembly, as per our statutes, my chairmanship ends. It was an honour to be the Chair of this organisation for the last four years. I would like to thank the Board and members for the support that I have. I am sure that the next Chair (to be appointed during the General Assembly) will make sure that Europa Uomo will continue to prosper and work to the benefit of all prostate cancer patients.

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 prostate cancer
- suffered a delay in the diagnosis or could not receive necessary treatments due to COVID-19 or war.

I would also like to thank our sponsors and 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**

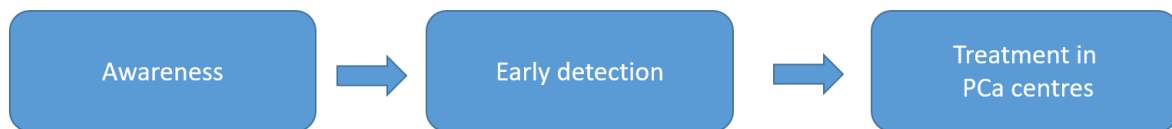
Chairman

Europa Uomo

## 2. Europa Uomo strategy and projects

### 2.1. Unchanged strategy

We still believe that the best care for prostate cancer (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 three elements are equally important and one does not work without the others.

### 2.2. Where are we today?

The EU Beating Cancer Plan will be announced in the second half of 2022. The BECA committee has advised in favour of early detection for prostate cancer. This is a major achievement.

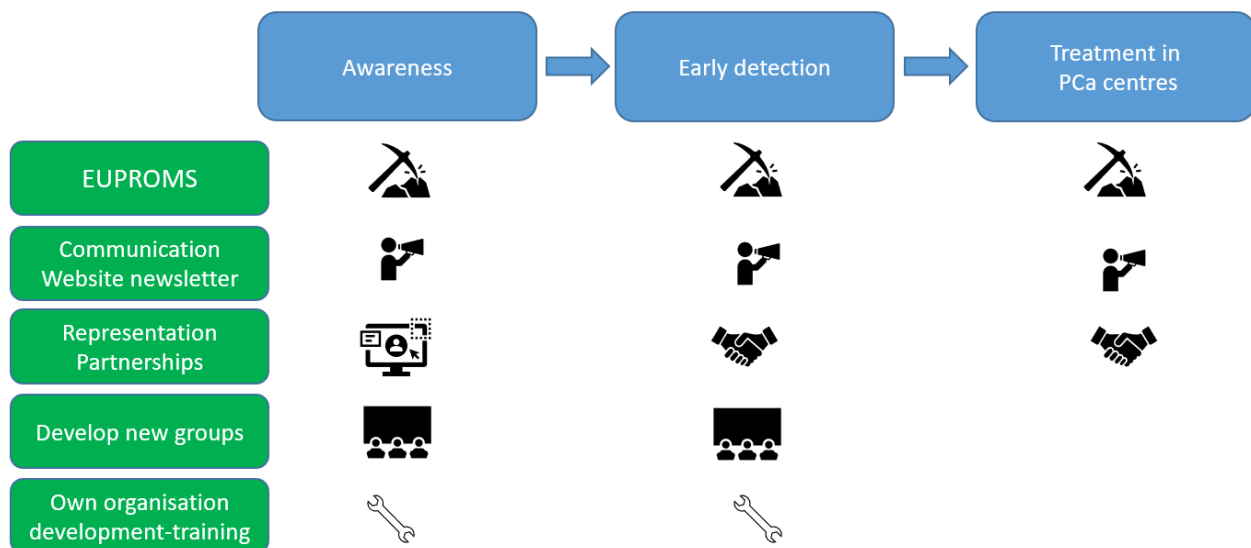
But after the formal announcement the real work will start. Countries, and in some cases regions, will need to implement the new guideline. This will mean raising awareness and breaking taboos. Europa Uomo is ready to support its members with advice and materials to do so.

Awareness will be the first step in the process. This will require a coordinated effort from the government, the patient community and health care professionals.

I am glad to announce that initiatives are on the way to achieve this. I mention, among others, the “Let’s Talk Prostate Cancer” campaign and joint projects with the EAU.

### 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

We launched EUPROMS 2.0 in autumn 2021. The survey was again a success thanks to the efforts of all members and the Board. Here are some key figures:

- 3600 patients answered (20% more than the original EUPROMS)
- 200 answers from Canada
- 120 answers from the US
- 2500 patients had not responded to the original EUPROMS and are new in the data set
- 2000 patients were willing to answer specific questions and left their email for future contact

The quality of the data is excellent and a first analysis shows that it will be possible to answer a lot of the remaining questions that were raised after the first EUPROMS study.

Analysis will require time. We expect first results in July 2022 and full results by the end of 2022.

We developed a booklet presenting the results of EUPROMS 1 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/>

## 2.5. Communication report

Over the past year, and notwithstanding the continuing impact of Covid-19, the Board continued to maintain and develop Europa Uomo's on-line presence

focusing on the development of the website. In association with our communication adviser, Simon Crompton, the site has been further modified and the *Update* newsletter now integrates with its content.

The year under review was dominated by the development and roll-out of the follow-up quality of life survey for the EUPROMS 2.0 study. Due to wide publicity, this survey was even more successful in attracting respondents than its predecessor, with almost 3500 questionnaires completed. This survey closed in early 2022 and it is hoped that the first results of the study will be available by July for a presentation at the 2022 Congress of the European Association of Urology.

The analysis of the results is being undertaken by a team under the supervision of Monique Roobol at the Erasmus Medical Centre, Rotterdam and she has been aided by Lionne Venderbos and Sebastiaan Remmers.

The website's translation function is available to member organisations to translate material into a range of European languages and members are urged to use the service to enable their national memberships to access the range of material posted on the website.

This is my final report as a Board member. Having served as Secretary for four years and Vice-Chairman for two years and finally as a Board member for the past year, it has been my pleasure to do so with many dedicated people who have sought to improve the position of men with prostate cancer in Europe. In particular, I would like to pay a special thanks to our communications consultant, Simon Crompton, who has done so much to develop our communications function. Also, a heartfelt thanks to Anja Vancauwenbergh who has tirelessly assisted me over the past seven years and provided huge support in terms of the newsletter as well as the website. I would also like to thank all my colleagues on the Board and to pay a tribute to the unstinting leadership and support of our Chairman, André Deschamps.

## **2.6. Active surveillance**

Europa Uomo supports and promotes the use of active surveillance treatment for men with low-risk prostate cancer. Properly implemented, it is an effective and safe means of avoiding over-treatment and ensuring optimal quality of life for as long as possible. Active surveillance is a treatment in itself, and should be considered as valid as any other treatment in stages I and II of prostate cancer. Active surveillance should not be confused with the watchful waiting programmes which are used in the later stages of cancer.

Recent years have seen considerable growth of knowledge on how to apply active surveillance safely. Recent research indicates that this treatment can be useful for up to 30% of patients – those with low or intermediate risk.

## **Europa Uomo active surveillance webinars**

To explore patient experience and issues around the effective use of active surveillance, Europa Uomo organised three online webinars in April to June 2021. Experts examined the successes and challenges of active surveillance (AS) as a treatment strategy, and patients from Italy, Cyprus and Iceland gave their perspectives on what it was like to be on AS.

A fourth event, on 29<sup>th</sup> March 2022 was a video virtual round table, aiming to summarise all the most important points of the previous webinars.

The webinars were designed as educational events, to inform men who are deciding whether to go on active surveillance and to provide support to those who are already on an AS programmes.

### **Next steps**

Board members Cosimo Pieri and Tania Estapé, who are responsible for the AS project, are taking action on awareness of AS among psychologists. Tania Estapé is working to undergo a survey of the 700 members of the International Psycho-Oncology Society to assess their knowledge and experience with prostate cancer patients.

The first three webinars can be viewed in the active surveillance section of our website:

<https://www.europa-uomo.org/who-we-are/raising-awareness/active-surveillance/>.

And the fourth webinar at:

<https://www.europa-uomo.org/news/new-active-surveillance-webinar-discusses-psychological-impacts/>.

## **2.7. EAU Guidelines Committee on prostate cancer**

Erik Briers represents Europa Uomo on the EAU Guidelines Committee on prostate cancer. The EAU evidence-based guidelines are formulated in Europe, but are influential globally and are used in countries such as Argentina and China.

The prostate cancer guidelines are reviewed every year to reflect changes in science. Patient representatives work with other members, provide a patient perspective and provide an honest opinion in discussions.

# EAU - EANM - ESTRO - ESUR - ISUP - SIOG Guidelines on Prostate Cancer

N. Mottet (Chair), P. Cornford (Vice-chair), R.C.N. van den Bergh, E. Briers, Expert Patient Advocate (European Prostate Cancer Coalition/Europa UOMO), M. De Santis, S. Gillessen, J. Grummet, A.M. Henry, T.H. van der Kwast, T.B. Lam, M.D. Mason, S. O'Hanlon, D.E. Oprea-Lager, G. Ploussard, H.G. van der Poel, O. Rouvière, I.G. Schoots, D. Tilki, T. Wiegel  
Guidelines Associates: T. Van den Broeck, M. Cumberbatch, A. Farolfi, N. Fossati, G. Gandaglia, N. Grivas, M. Lardas, M. Liew, E. Linares Espinós, L. Moris, P-P.M. Willemse



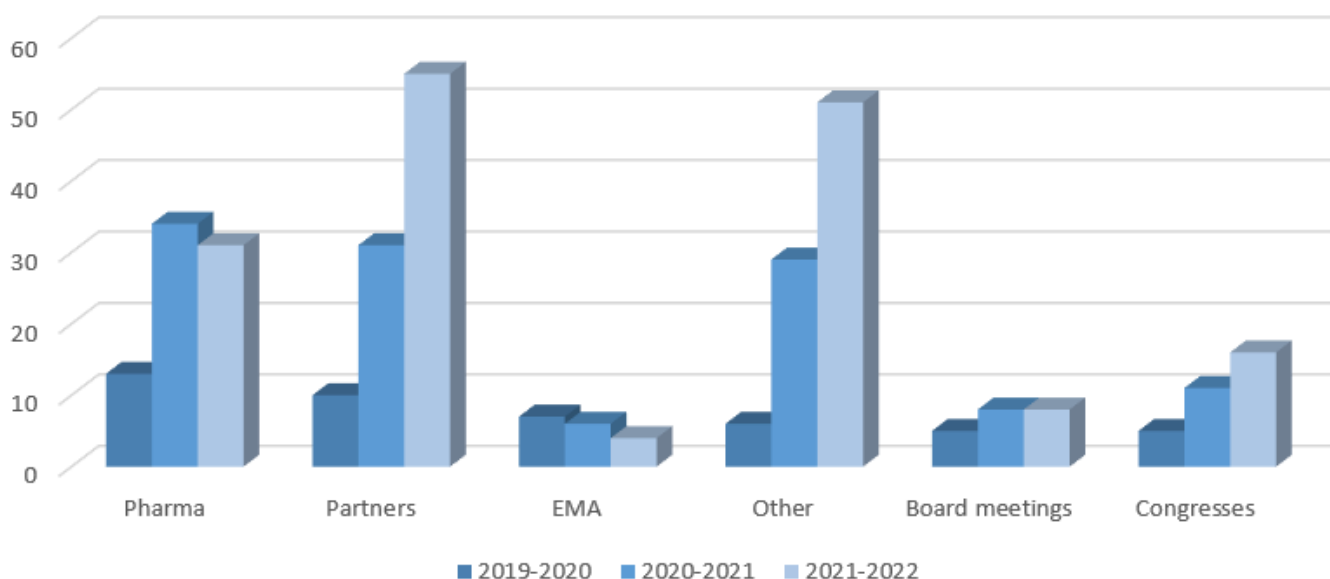
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<http://uroweb.org/guideline/prostate-cancer/>

## 2.8. Partnerships and attendance at meetings

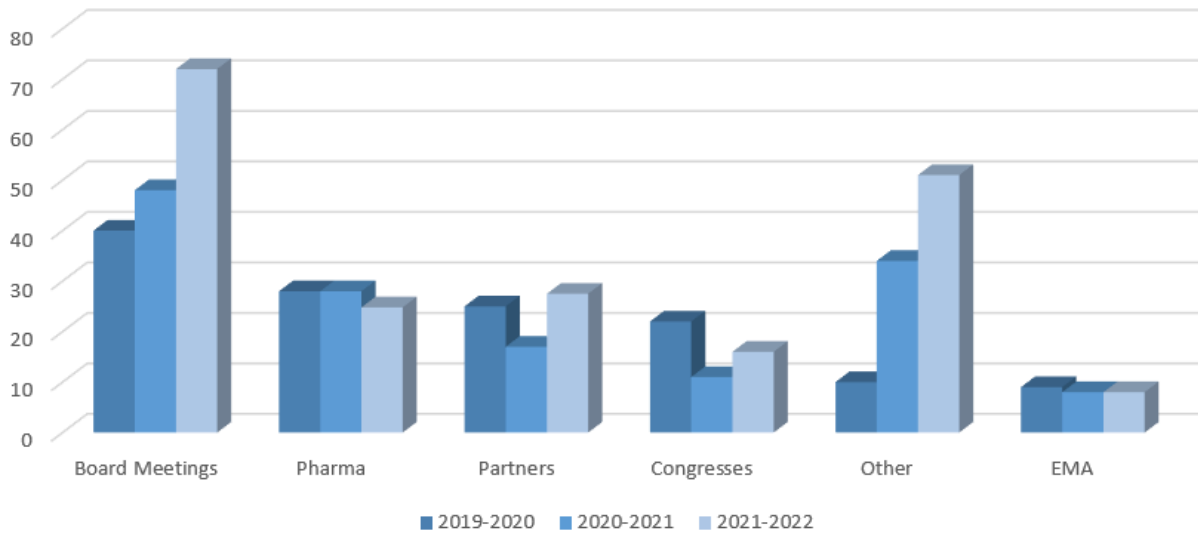
Making partnerships and communicating our views at meetings are both important means by which Europa Uomo can realise its ideas. The infographics below provide a summary of activity in this field.

Attended meetings 2021-2022



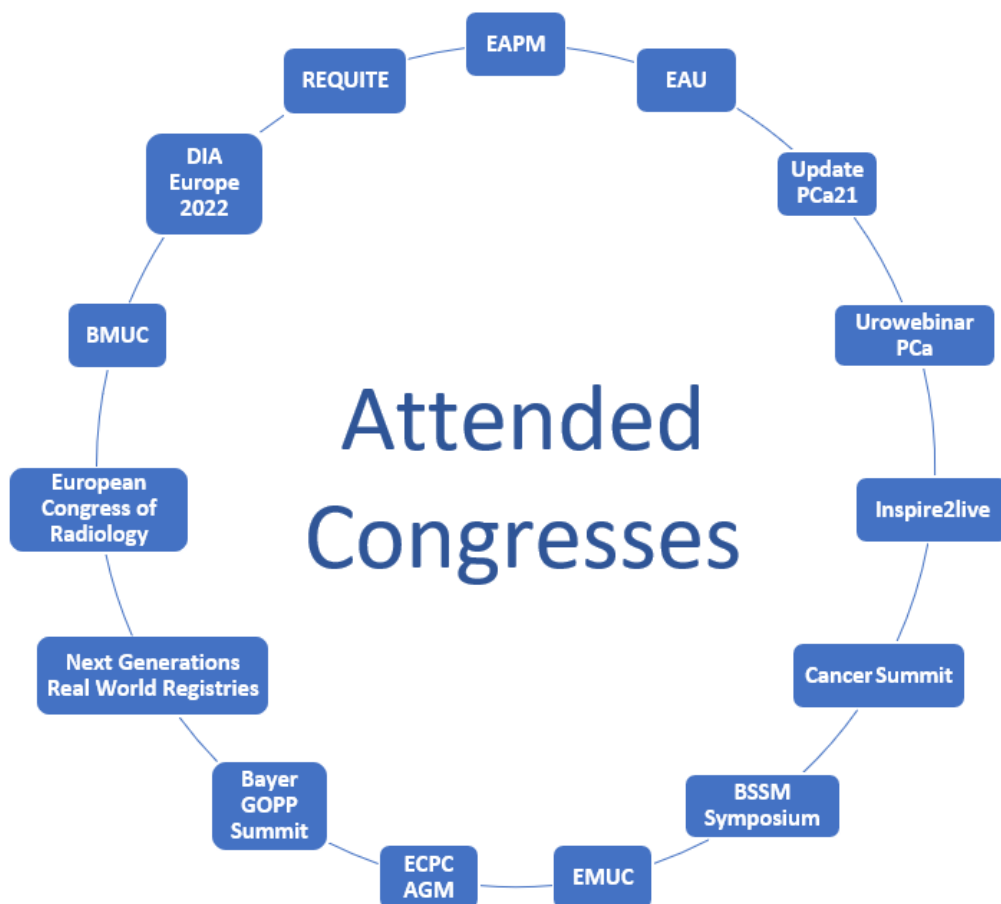


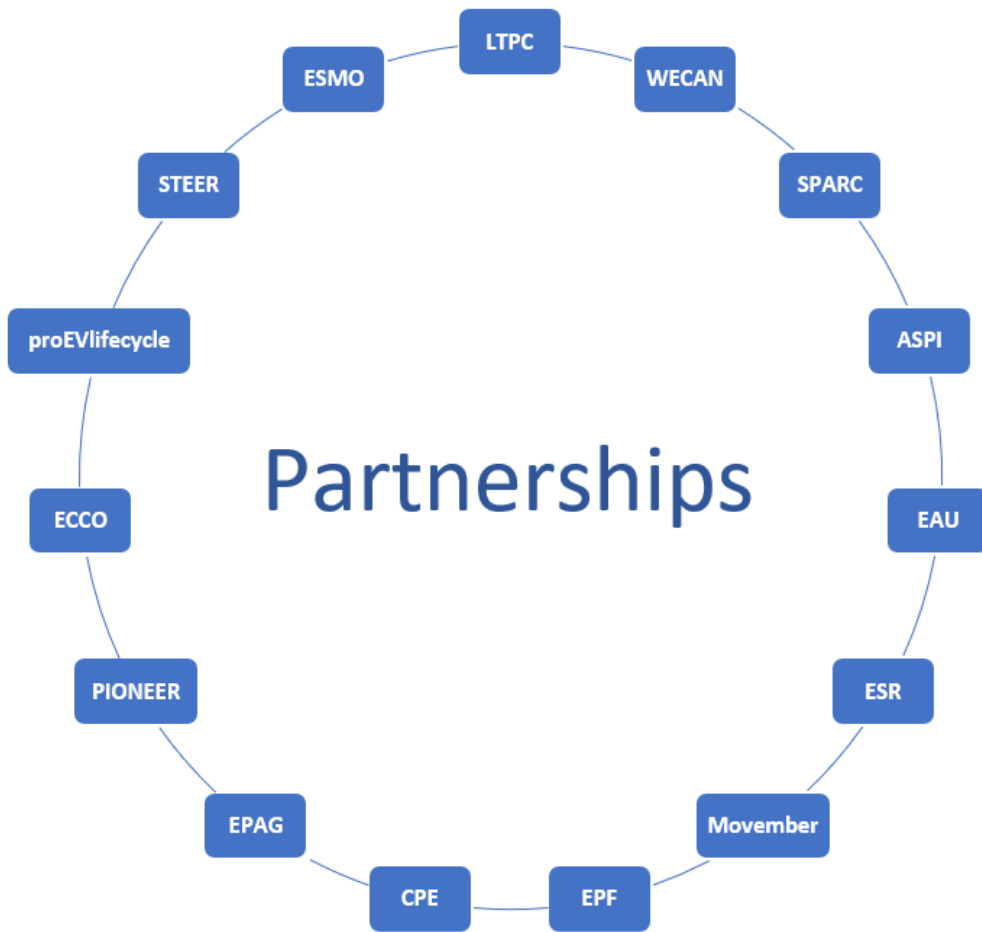
## Man days spent



The total of meetings attended by our board members increased by 38% from 119 in the period 2020-2021 to 165 in the period 2021-2022. The amount of days spent on those activities was 199.3 in 2020-2021 compared with 146 days in 2021-2022 – an increase of 36.5%.

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





## **2.9. 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 these activities soon.

## **2.10. Development and training in our own organisation**

Our General assembly 2022 will be held live and preceded by a full day of training for the attendees. We like to thank our Dutch member organisation for their cooperation in helping us to realise this.

As you can read in other parts of this report, during the past year many training and development activities have been held online. This is one of the positive lessons learned from COVID and we will continue working in this way because it has been shown to be beneficial.

### 3. Board membership

The Board has nine 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 2021, two positions needed to be filled as these two new Board positions have no incumbents having been created by the General Assembly in 2020 and filled for the first time.

The newly elected members were Erik Briers (Belgium) and Tania Estapé (Spain).

The new Board met virtually on 8<sup>th</sup> July 2021 and the officers were elected. The full Board for 2021-22 was:

Chairman:	André Deschamps (Belgium)
Vice-Chairmen:	Guenther Carl (Germany) Erik Briers (Belgium)
Treasurer:	Ioannis Vanezos (Cyprus)
Secretary:	Will Jansen (The Netherlands)
Other members:	John Dowling (Ireland) Tania Estapé (Spain) Cosimo Pieri (Italy) Nils Petter Sjøholt (Norway)

Ex-officio members nominated by partners:

Hein Van Poppel (EAU)  
Alberto Costa (ESO)  
Louis Denis (OCA, † July 28, 2021)

The Board met seven times since the last General Assembly:

- 1) 08.07.21 by Zoom
- 2) 10.09.21 by Zoom
- 3) 26.11.21 in Athens during EMUC21
- 4) 31.01.22 by Zoom
- 5) 21.03.22 by Zoom
- 6) 28.04.22 in Amsterdam
- 7) 09.06.22 in Leusden

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 more or less equals spending

The funding of Europa Uomo comes from small contributions from member organisations through their annual dues, contributions from non-pharma sponsors, contributions from a number of pharmaceutical companies and cost reimbursement when members of Europa Uomo have attended meetings or given presentations.

As with any organisation, especially those run by volunteers, it is not always possible to roll out projects to the intended timeline. This was the case last year with the pandemic crisis, but we managed to achieve and complete our major projects: the EUPROMS 2.0 quality of life study, the active surveillance project and upgrading our communications.

Looking back at the budget presented in our previous annual report, some projects 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 2022 and 2023 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 European Medicines Agency guidelines are imposing stricter rules on sponsors and those receiving funds.

Open bookkeeping is a key to our further success. That is why our budgets and reports distinguish between the sponsorship given for core activities and that for projects.

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

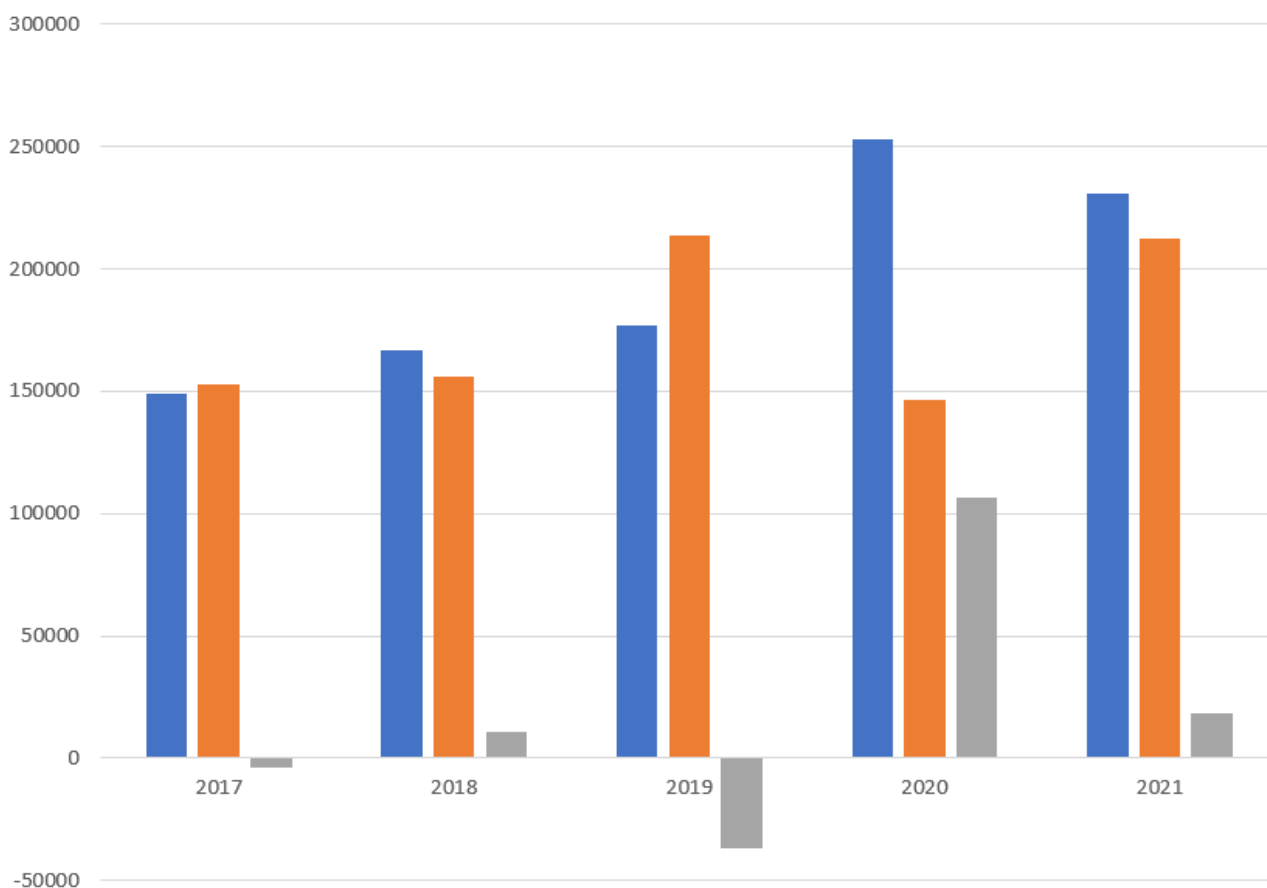
In accordance with Belgian law it is necessary that these financial reports will be approved by the General Assembly.

#### 4.1. Balance Sheet at December 31, 2021

Accounts audited by Guido Smet

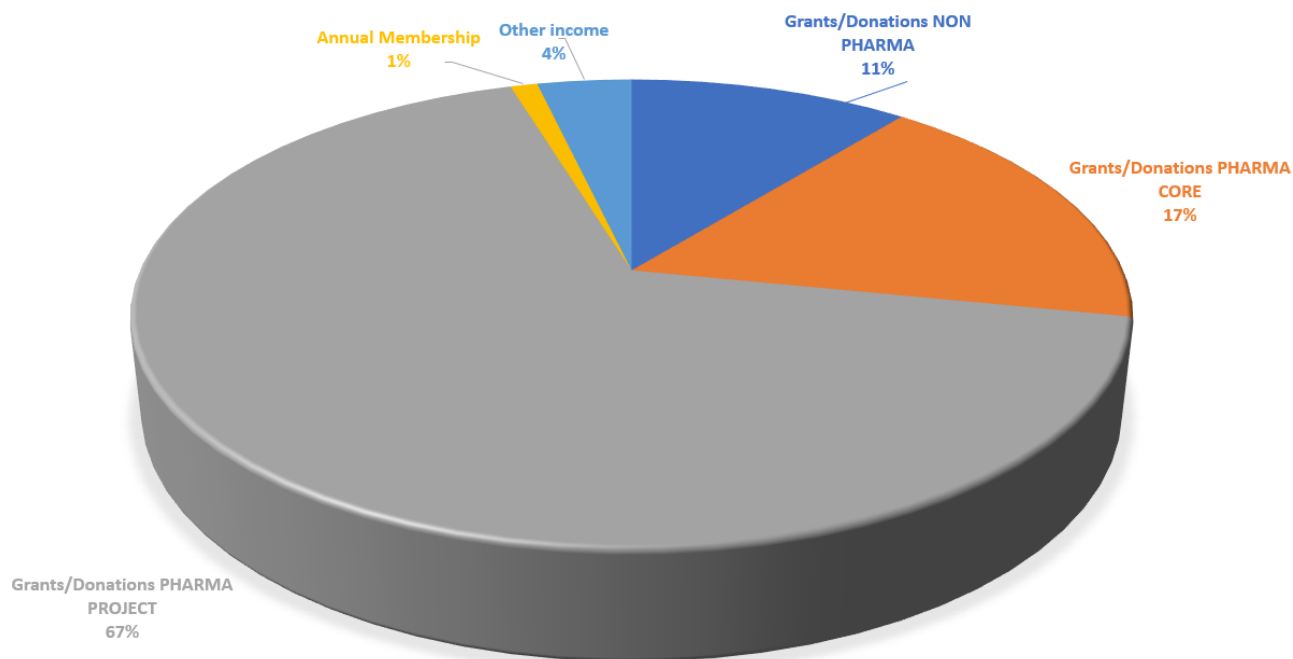
ASSETS		LIABILITIES	
Business Compact account	290.326,74	Balance at 31/12/2016	221.591,55
Saving account	50.314,34	Positive results 2021	18.430,95
Deferred expenses	836,47	Positive result 2020	76.273,55
		Deferred invoices	25.181,50
	<b>341.477,55</b>		<b>341.477,55</b>

#### 4.2. Results for the years 2017-2021



	2017	2018	2019	2020	2021
<b>Income</b>	149183	166474	176596	253101	230821
<b>Expenditure</b>	153041	155759	213712	146670	212390
<b>Result</b>	-3858	10715	-37116	106530	18431

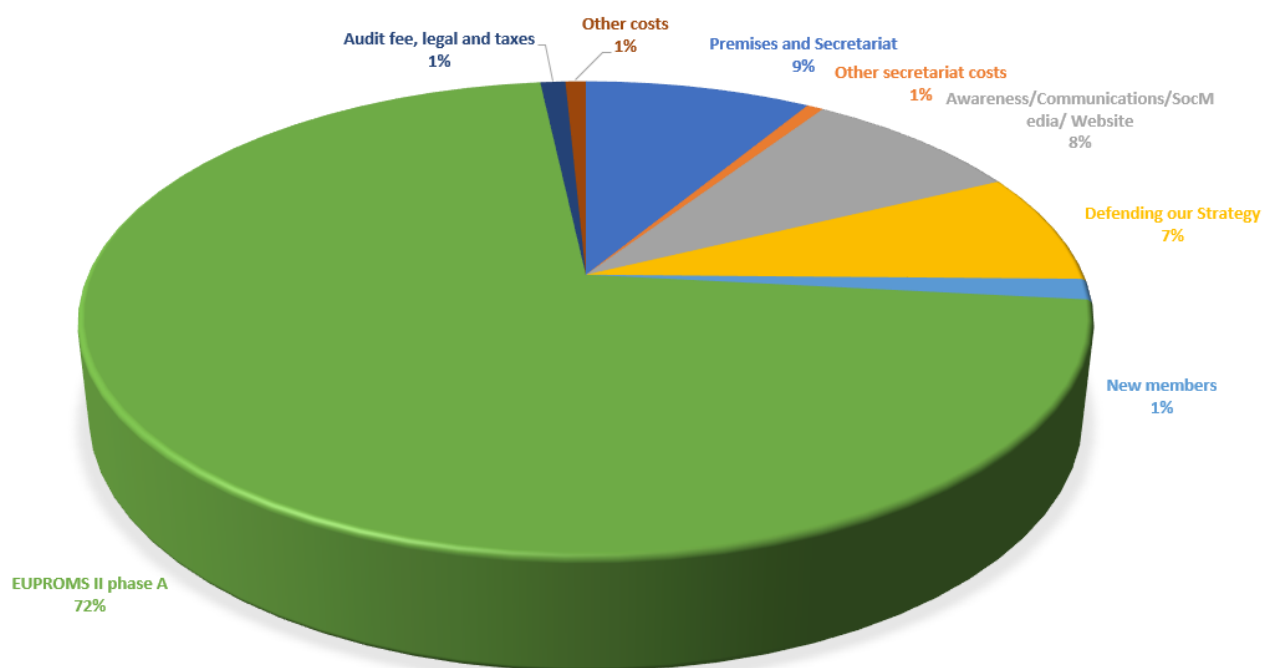
### 4.3. Revenue 2021 distribution



### 4.4. Revenues 2021 breakdown

	Actual revenue 2021	Budget 2021
Grants/Donations NON PHARMA	25.000,00	35.000,00
Grants/Donations PHARMA CORE	40.000,00	80.000,00
Grants/Donations PHARMA PROJECT	155.000,00	160.000,00
Annual Membership	2.400,00	2.500,00
Other income	8.421,00	10.000,00
	<b>230.821,00</b>	<b>287.500,00</b>

#### 4.5. Expenses 2021 distribution



#### 4.6. Expenses 2021 breakdown

	Actual cost 2021	Budget 2021
Premises and secretariat	18.360,92	16.000,00
Other secretariat costs	1.344,36	1.200,00
Awareness/communications/social media/website	18.000,00	40.000,00
Defending our strategy	16.000,00	60.000,00
New members	3.000,00	16.500,00
EUPROMS 2.0 phase A	152.000,00	130.000,00
Training during General Assembly		80.000,00
Audit fee, legal and taxes	2.035,12	3.150,00
Other costs	1.649,65	11.150,00
Contingency		5.000,00
	<b>212.390,05</b>	<b>363.000,00</b>

#### 4.7. Budget and actual 2021

	Budget	Actual	%
<b>Income</b>	287.500,00	230.821,00	80,29%
<b>Expenses</b>	363.000,00	212.390,05	58,51%



#### 4.8. Revised projects 2022

Revised projects 2022	Project cost
Website/social media/communications/awareness	40.000,00
Active surveillance initiative project	26.000,00
EUPROMS 2.0 phase B/C	130.000,00
Training members/EUPROMS results local presentations	80.000,00
New organisation support	16.500,00
Defending our strategy	60.000,00
	<b>352.500,00</b>

#### 4.9. Revised revenue budget 2022 and 2023

	Revised revenue budget 2022	Revenue budget 2023
Grants/Donations non-pharma	35.000,00	35.000,00
Pharma core funding	80.000,00	80.000,00
Pharma project funding	160.000,00	160.000,00
Annual membership	2.500,00	2.500,00
Other income	10.000,00	15.000,00
	<b>287.500,00</b>	<b>292.500,00</b>

#### 4.10. Revised expenses budget 2022 and 2023

	Revised budget 2022	Budget 2023
Premises and Secretariat	16.000,00	16.000,00
Other Secretariat costs	1.200,00	1.300,00
Awareness/communications/social media/website	40.000,00	50.000,00
Defending our strategy	60.000,00	70.000,00
New members	16.500,00	16.500,00
EUPROMS 2.0 phase B and C	130.000,00	130.000,00
Training during General Assembly	80.000,00	80.000,00
Audit fee, legal and taxes	3.150,00	4.100,00
Other costs	11.150,00	11.550,00
Contingency	5.000,00	5.000,00
	<b>363.000,00</b>	<b>384.450,00</b>

## Thanks to our sponsors during 2021



This report is published by the Board of Europa Uomo.

Europa Uomo Secretariat (p/a OCA): Leopoldstraat 34, 2000 Antwerp, Belgium

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