

EUROPA UOMO 

The Voice of Men with Prostate Cancer in Europe

**Annual Report
of the Board
for 2022/23**

1. Chairman's Note

Dear Reader,

After our last General Assembly in Leusden, all matters regarding COVID went more or less back to normal, so we were able to arrange face-to-face meetings within Europa Uomo and with our sponsors. The ESMO Congress 2022 in Paris gave us the opportunity to follow this up, with André Deschamps outlining the EUPROMS results, a presentation on metastases by me and various meetings with sponsors. The yearly WECAN meeting complemented our presentations.

At this point I would like to thank the Board and Vice Chairmen for representing me during my short absence due to surgery, taking over at the EMUC Congress in November and during the important period leading up to the long-awaited EU recommendation for the early detection of prostate cancer to be included in the Beating Cancer Plan.



Awareness of prostate cancer is still low and the taboos surrounding it are large. So if we want a situation where men are well-informed and convinced that testing is the right thing to do, then there is a lot of work ahead of us.

We have to use all means to create awareness and make sure that the necessary steps are taken to follow the algorithms published by the European Association of Urology. Europa Uomo is ready to support its members with materials, advice and experience to make this implementation a success.

We have made use of the second part of our EUPROMS study, especially at the EAU congress 2023 in Milan, in a variety of speeches, discussions and visual presentations. There was a very positive response from the auditorium wherever we showed data. We published an English version of vital EUPROMS data for the EAU Congress and this is available on our website. We will use the email addresses given to us in the EUPROMS 2.0 study for a short third questionnaire to be disseminated within the first half of 2023.

Our main goals for 2023 are spreading awareness following the EU early detection recommendations, and undertaking a study assessing the burden for spouses, partners and family members who have a prostate cancer patient at home

My thoughts are with prostate cancer patients who are still suffering delays in treatment or getting a second opinion as a result of COVID.

This is my first report as Chairman. Having served as Vice Chairman before, mainly handling quality of life, it has been my pleasure to work 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 big thanks to our Executive Secretary Anja Vancauwenbergh who is now devoting her time to Europa Uomo, working in its new office. She helped me as I settled into the role as Chairman. I would also like to thank all my colleagues on the Board of Europa Uomo who were always prepared to take over specific topics if necessary.

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

Günther Carl

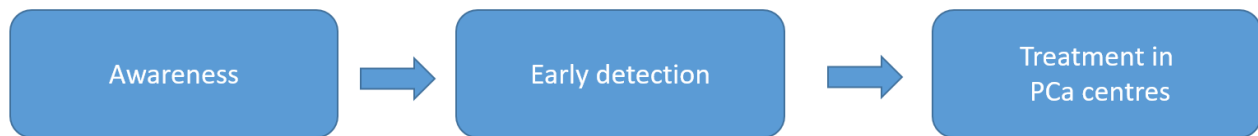
Chairman

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 cancer 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” was announced in 2022. The BECA committee (a special committee on BEating CANcer within the European Parliament) has advised in favour of early detection for prostate cancer. This is a major achievement for all of us but a challenge as well.

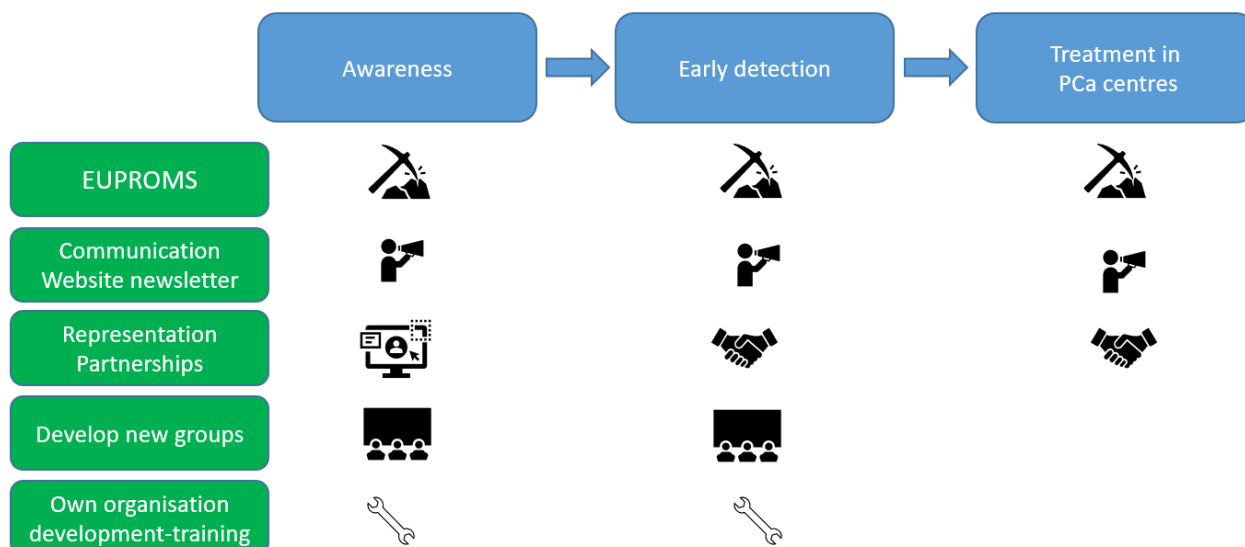
After the formal announcement the real work will start. Countries, and in some cases regions, will need to implement the new recommendation. This will mean raising awareness and breaking taboos. Europa Uomo is ready to support its members with advice and materials to do so.

Raising awareness will be the first step in the process. This will require a coordinated effort from governments, patient communities and health care professionals.

We are pleased to announce that initiatives are on the way to achieve this, in particular the EU-funded PRAISE_U initiative, which aims to design a nationally-tailored and cost-effective early detection algorithm for prostate cancer screening across the EU. We have to assist not only within the decided regions by appointing a Europa Uomo member to take care of the region, but also within all other countries involved including advanced regions like Netherlands, Germany, Belgium and France. The website www.praise-u.eu shows in detail how the work packages will be executed.

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:

- 3,600 patients answered (20% more than the original EUPROMS)
- 200 answered from Canada
- 120 answered from the US
- 2,500 patients had not responded to the original EUPROMS and are new in the data set
- 2,000 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.

The analysis of the results has been 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.

Some dissemination has taken place, with the first data made public in 2022 and a summary given at the EAU congress 2023 in Milan. A EUPROMS booklet in English was made available at the EAU Congress and for download from our website. The translation of the revised language slides into the respective languages is underway and will be available via our website in due course.

2.5. **Communications**

Over the past year the Board continued to maintain and develop Europa Uomo's website and online presence. In association with our communications adviser, Simon Crompton, the site has been further modified and the *Update* newsletter now integrates with its content.

The website's translation function enables member organisations to translate material into their language. Members are urged to use the service to enable their national memberships to access the range of material posted on the website.

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.

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 the period January 2022 to April 2023.

The webinars were designed as educational events to inform men who are deciding whether to go onto active surveillance and to provide support to those who are already on an AS programmes. Interest in webinars on active surveillance was confirmed in the outcome of the EUPROMS surveys.

In order to plan webinars that matched the needs of patients of the 27 local associations, Board members Cosimo Pieri and Tania Estapé (who are responsible for the AS project) contacted all member associations. To build on interest, the 2022 webinars presented new tools related to active surveillance.

There is still a significant room to improve participation. To achieve this, we will have further contacts with local associations in 2023.

Our webinars can be viewed on the active surveillance section of our website: <https://www.europa-uomo.org/who-we-are/raising-awareness/active-surveillance/>.

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.

We are looking for a second Europa Uomo representative to be included on the guidelines committee.

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

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

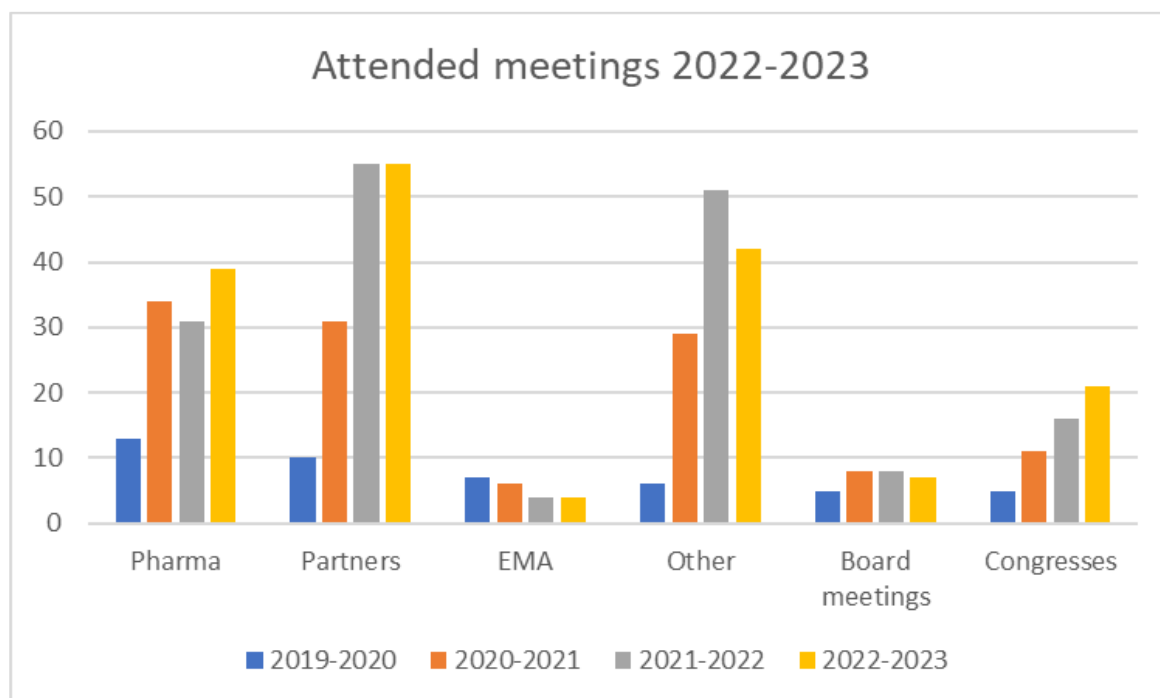
N. Mottet (Chair), P. Cornford (Vice-chair), R.C.N. van den Bergh, E. Briers, Expert Patient Advocate (European Prostate Cancer Coalition/Europa UOMO), M. De Santis, S. Gillesen, J. Grummet, A.M. Henry, T.H. van der Kwast, T.B. Lam, M.D. Mason, S. O'Hanlon, D.E. Oprea-Lager, G. Ploussard, H.G. van der 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. Willems

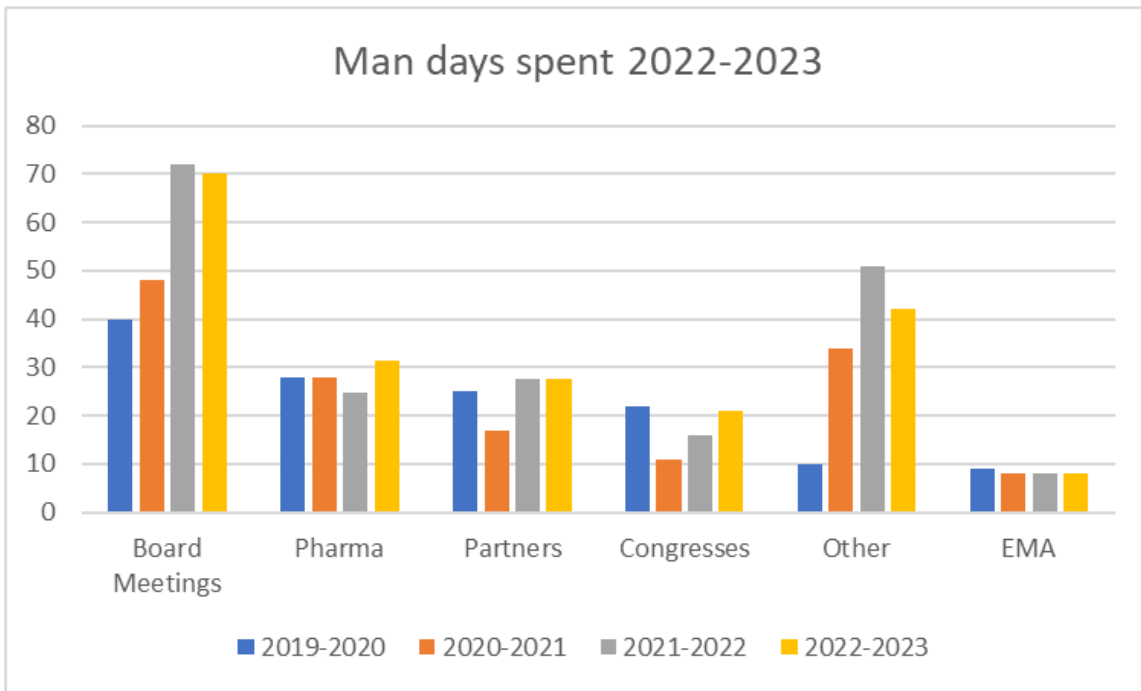


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2.8. Partnerships and attendance at meetings

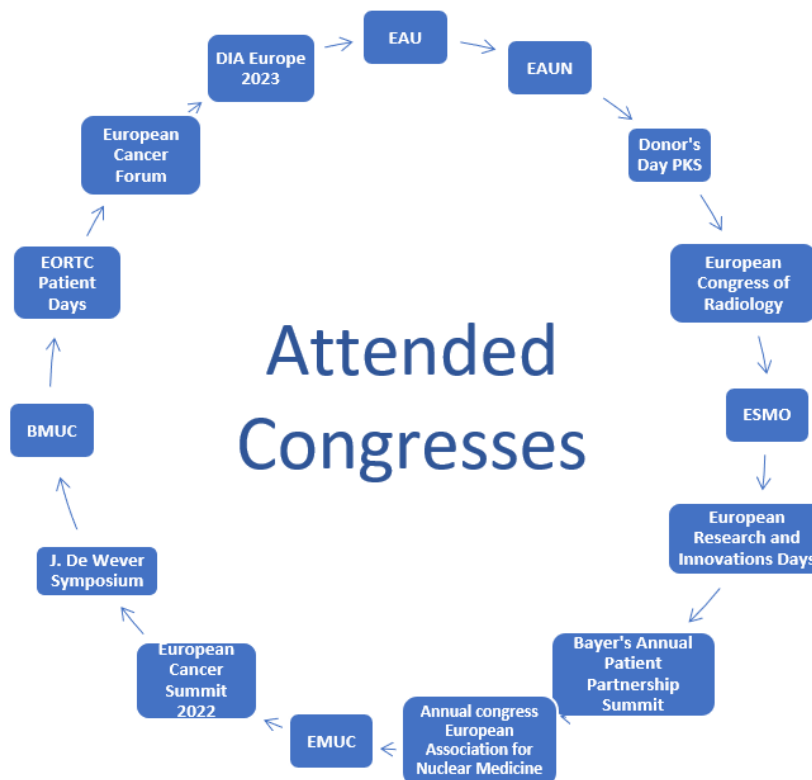
Making partnerships and communicating our views at meetings are both important means by which Europa Uomo can realise* its ideas. The infographics below provide a summary of activity in this field.

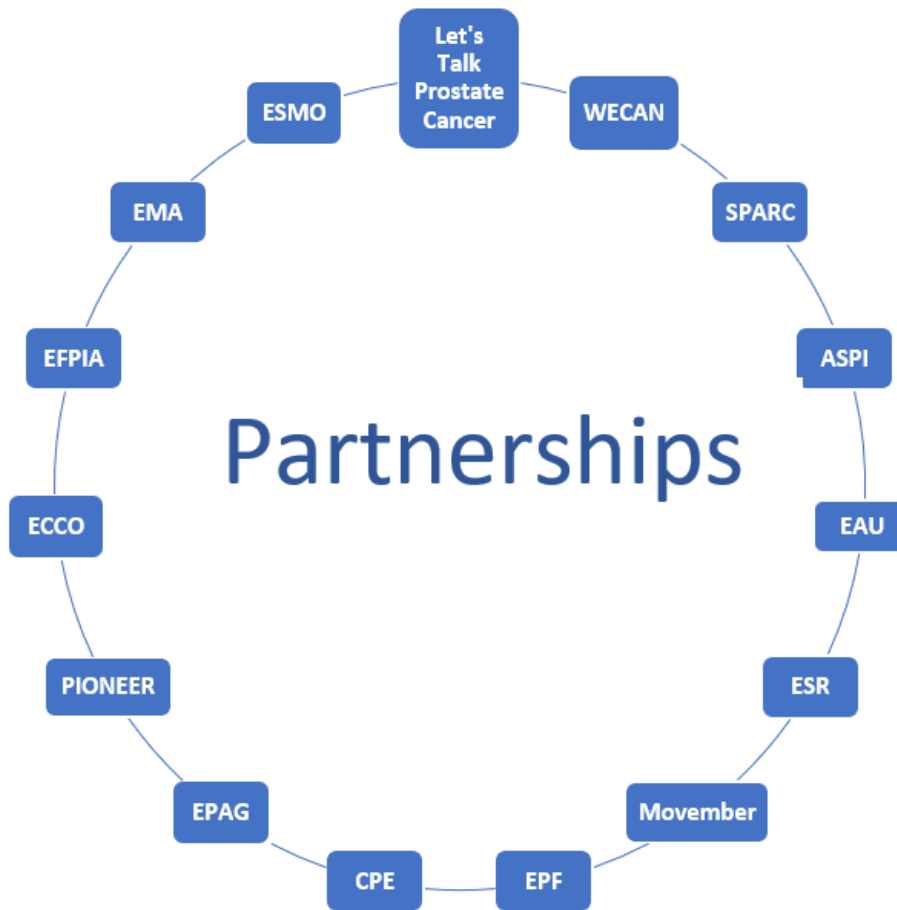




The total number of meetings attended by our board members in 2022 to 2023 was almost the same as the previous year, with 168 congresses and meetings attended (165 in 2021-2022). The number of days spent on those activities remained at the same level, with 199.7 days in 2022-2023 compared with 199.3 days in 2021-2022.

This perhaps reflects the only “positive” influence of the COVID 19 pandemic: the realisation that 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.





We have also partnerships with the following projects:
 DE-ESCALATE, OPTIMA, 4D-Picture, EURAMED, TOPRA, LUNGevity, OPTION, ...



2.9. **Development and new groups**

We have continued our efforts to encourage membership from new patient groups within Europe.

During our 2023 General Assembly we will ask the membership to vote on whether to admit the Estonian Prostate Cancer Patient Society as an associate member and the Marigold Foundation from Malta as a supporting member.

Europa Uomo is also actively developing contacts with prostate cancer patients' organisations outside Europe with a view to setting up partnerships.

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

Our General Assembly 2023 will be held in-person in Cyprus and will be followed by a half day of training for the attendees. We would like to thank our Cypriot 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. We learned the benefits of meeting this way under COVID, and will continue with it.

2.11. **The DE-ESCALATE trial (EORTC)**

Europa Uomo is engaging more in scientific research. At the end of 2022, Europa Uomo was invited to become an active member of an EU-funded clinical trial called DE-ESCALATE. The principal sponsor is the European Organisation for Research and Treatment of Cancer (EORTC).

DE-ESCALATE is a "pragmatic" trial, meaning that it is not investigating a new medicinal treatment but an existing treatment. The purpose is to improve or investigate new combinations in the real world.

DE-ESCALATE will study treatments for metastatic hormone-sensitive prostate cancer. The standard of care is androgen deprivation therapy (ADT) with the addition of, for example, an androgen receptor pathway inhibitor (ARPI). This combined treatment (ADT+) can cause serious side effects which affect quality of life.

In the trial, patients will be put on ADT+ until their PSA level drops and shows that the treatment is working. At that point the ADT+ treatment will be paused until the PSA increases again. This intervention will be compared to the standard of care where the treatment is not paused.

Endpoints will include overall survival and elements of quality of life.

2.13. **Europa Uomo Summer School**

Europa Uomo will organise a summer school for its membership in September 2024. This one week-long intensive training will focus on the basic science underlying diagnosis and treatment of prostate cancer. It will cover the clinical trials scene and the regulatory system at the EU level and in member states. Participants will need a good knowledge of English and to be active in their local organisation.

2.14. **PRAISE-U**

The PRAISE-U project works to encourage early detection and diagnosis of prostate cancer across Europe through customised and risk-based screening programmes. It is EU-funded and the main contractor is the European Association of Urology. Europa Uomo is an associate partner, and will be part of one of the work package teams. Many other groups are part of a research consortium, which includes experts on prostate cancer and decision-making, and a network of hospitals, medical societies, patient advocates and national authorities. The consortium members have responsibility for coordinating joint action, building upon screening efforts, and contributing big data on prostate cancer from pilot sites in Spain, Poland, Ireland, and Lithuania.

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 General Assembly in 2022, four positions needed to be filled as two incumbents (André Deschamps and John Dowling) had completed their two three-year terms. Ernst-Günther Carl and Ioannis Vanezos have completed their first three-year term and are standing for a further three-year term.

The newly elected members were Steven Lerys (France) and Paulius Rakštys (Lithuania).

The new Board met live on 11th June 2022 and officers were elected. The full Board for 2022-23 was:

Chairman:	Guenther Carl (Germany)
Vice-Chairmen:	Erik Briers (Belgium) Nils Petter Sjøholt (Norway)
Treasurer:	Ioannis Vanezos (Cyprus)
Secretary:	Will Jansen (The Netherlands)
Other members:	Tania Estapé (Spain) Steven Lerys (France) Cosimo Pieri (Italy) Paulius Rakštys (Lithuania)

Advisor to the Board: André Deschamps (Past-Chairman)

Ex-officio members nominated by partners:
Hein Van Poppel (EAU)
Alberto Costa (ESO)

Executive secretary: Anja Vancauwenbergh

The Board met seven times since the last General Assembly:

- 1) 02.07.22 in Amsterdam during EAU
- 2) 19.09.22 by Zoom
- 3) 11.11.22 in Budapest during EMUC22
- 4) 26.01.23 in Antwerp at the new office
- 5) 11.03.23 in Milan during EAU23
- 6) 19.04.23 by Zoom
- 7) 25.05.23 in Larnaca

In addition to the responsibilities set out in the 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 organisations through their annual fees, contributions and sponsorship from pharmaceutical and non-pharma companies and reimbursement for costs where Board members have attended meetings or given presentations.

As with any organisation, but especially one run by volunteers, it is not always possible to roll out projects to the intended timeline. This was the case last year, with the COVID crisis still having its effect, but we managed to achieve and complete our major projects: EUPROMS II phase B and C, our active surveillance project and upgrading our communication status. We should also record our achievement on “defending our strategy” and the excellent training during General Assemblies.

Comparing with the budget presented in our previous annual report, it is clear that 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.

Because our approach is cautious, our budgets for 2023 and 2024 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. The statements below are a true and honest account.

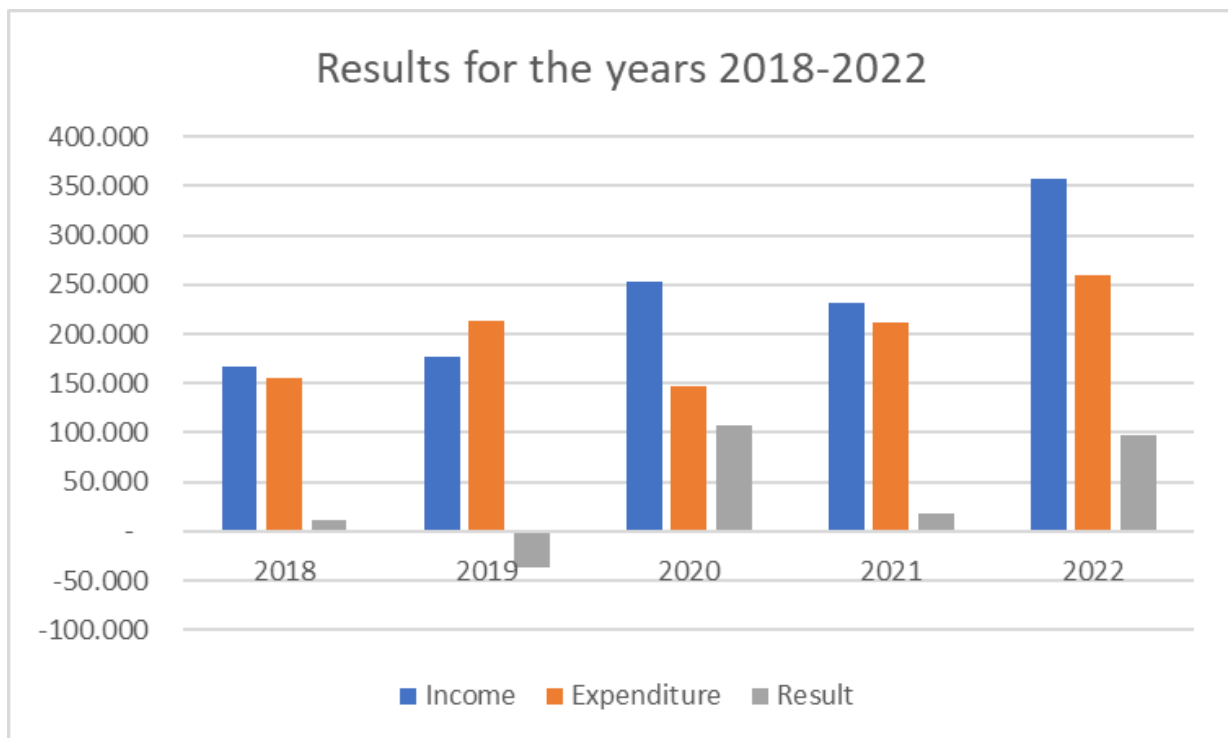
In accordance with Belgian law it is necessary that these financial reports be approved by the General Assembly.

4.1. Balance Sheet at 31st December, 2022

Accounts audited by Guido Smet

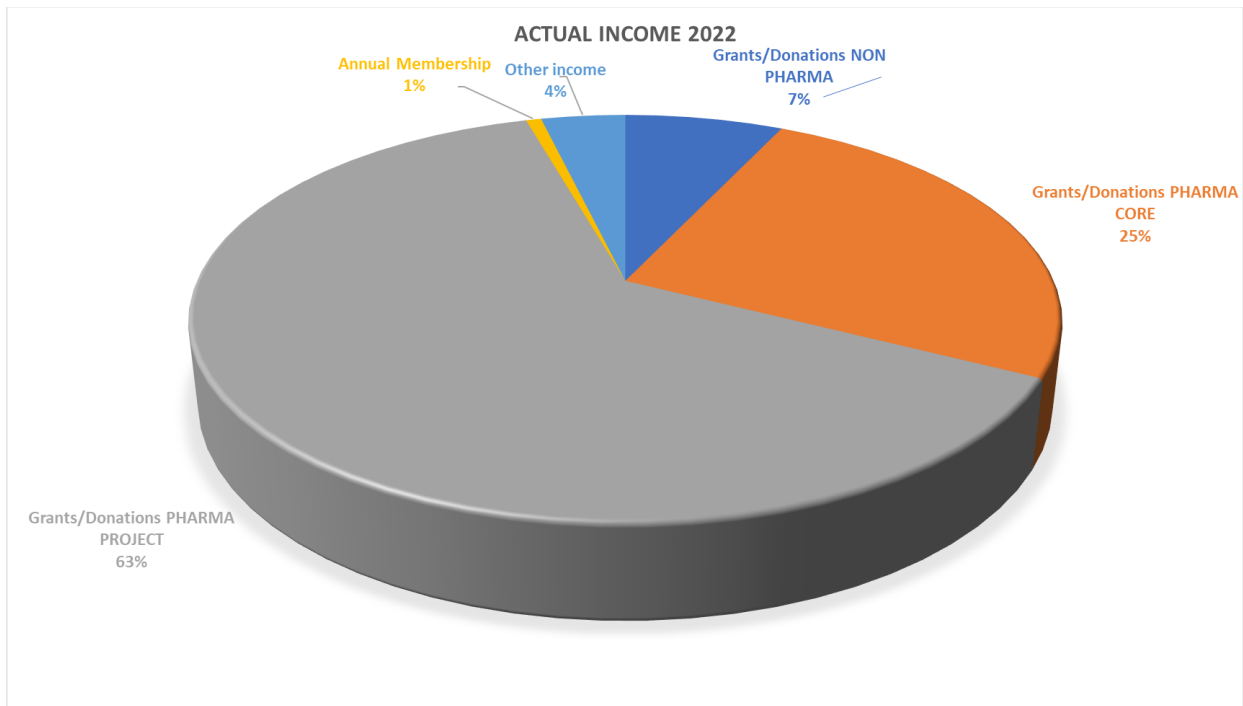
ASSETS		LIABILITIES	
Business Compact account	480.616,20	Balance at 31/12/2016	221.591,55
Saving account	50.314,34	Positive result 2022	96.936,51
Deferred expenses	580,11	Results carried forward	94.704,50
Office machines and equipment	1.413,65	Deferred invoices	101.491,74
Rental guarantee	1.800,00	Deferred income	20.000,00
	534.724,30		534.724,30

4.2. Results for the years 2018-2022



	2018	2019	2020	2021	2022
Income	166.474	176.596	253.101	230.821	356.720
Expenditure	155.759	213.712	146.670	212.390	259.783
Result	10.715	-37.116	106.530	18.431	96.937

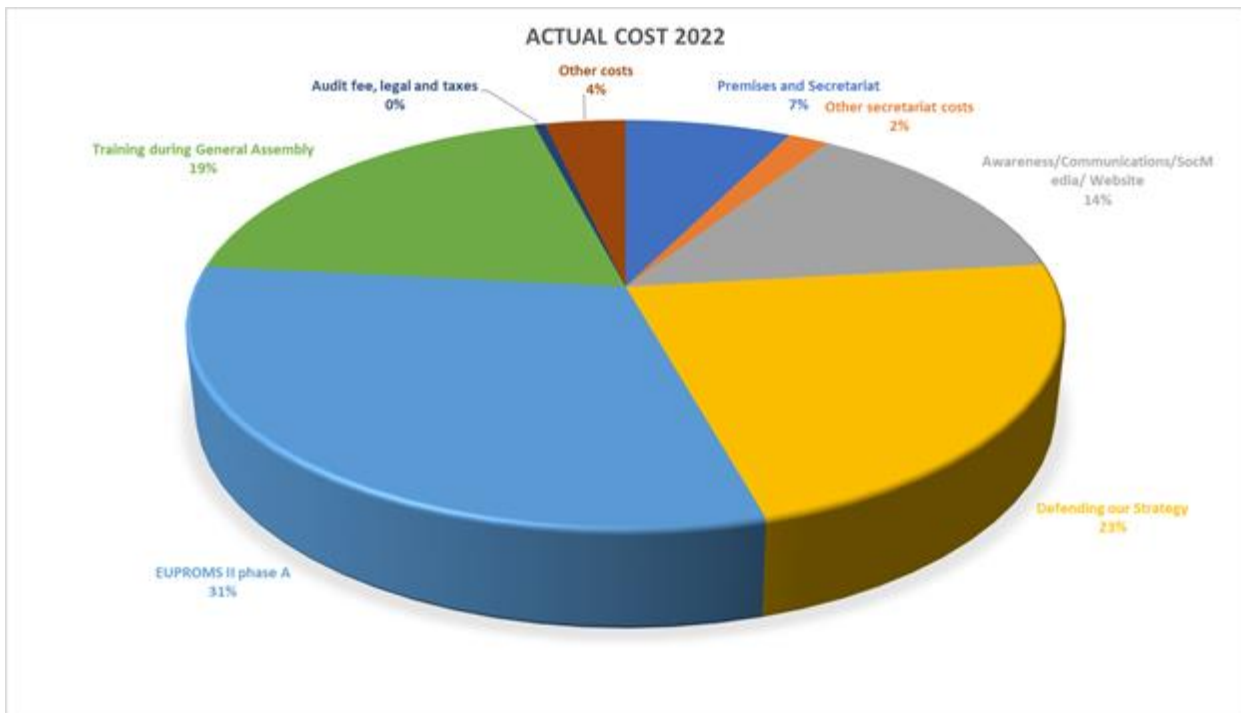
4.3. Revenue 2022 distribution



4.4. Revenues 2022 breakdown

	Actual revenue 2022	Budget 2022
Grants/Donations NON PHARMA	25.000,00	35.000,00
Grants/Donations PHARMA CORE	91.000,00	80.000,00
Grants/Donations PHARMA PROJECT	225.000,00	160.000,00
Annual Membership	2.400,00	2.500,00
Other income	13.319,98	10.000,00
	356.719,98	287.500,00

4.5. Expenses 2022 distribution



4.6. Expenses 2022 breakdown

	Actual cost 2022	Budget 2022
Premises and secretariat	19.000,00	16.000,00
Other secretariat costs	4.660,00	1.000,00
Awareness/communications/social media/website	36.520,00	40.000,00
Defending our strategy	58.500,00	60.000,00
New members		16.500,00
EUPROMS 2.0 phase B+C	80.500,00	130.000,00
Training during General Assembly	50.120,00	80.000,00
Audit fee, legal and taxes	1.230,00	2.500,00
Other costs	9.253,00	12.000,00
Contingency		5.000,00
	259.783,47	363.000,00

4.7. Budget and actual 2022

	Budget	Actual	%
Income	287.500,00	356.719,98	124,08 %
Expenses	363.000,00	259.783,47	71,57 %

4.8. Revised projects 2023

Revised projects 2023	Project cost
Website/social media/communications/awareness	55.000,00
Active surveillance initiative project	26.000,00
EUPROMS 3.0	130.000,00
Training members at GA	60.000,00
New members organisation support	15.500,00
Defending our strategy	60.000,00
	346.500,00

4.9. Revised revenue budget 2023 and 2024

	Revised revenue budget 2023	Revenue budget 2024
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	170.000,00
Annual membership	2.500,00	2.500,00
Other income	15.000,00	15.000,00
	292.500,00	302.500,00

4.10. Revised expenses budget 2023 and 2024


	Revised budget 2023	Budget 2024
Premises and Secretariat	24.000,00	24.000,00
Other Secretariat costs	3.000,00	3.000,00
Awareness/communications/social media/website/booth	55.000,00	60.000,00
Defending our strategy	60.000,00	70.000,00
Active Surveillance	26.000,00	
New members	15.500,00	16.500,00
EUPROMS 2.0 phase B/C and 3.0 caregivers 23/24	130.000,00	160.000,00
Training during General Assembly	60.000,00	80.000,00
Audit fee, legal and taxes	4.000,00	5.000,00
Other costs	6.000,00	10.000,00
Contingency	1.000,00	1.000,00
	384.500,00	429.500,00

Thanks to our sponsors during 2022



This report is published by the Board of Europa Uomo.

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