

EUROPA UOMO♂

The Voice of Men with Prostate Cancer in Europe

Annual Report of the Board 2023/24



1. Chairman's Note

Dear Reader,

Since our very successful General Assembly in Larnaca Cyprus, when there was a productive exchange of ideas with our members, we have had the opportunity to attend:

- the 2023 ESMO Congress in Madrid, where we successfully met current sponsors and also gained new ones;
- the 2023 EMUC Congress in 2023 in Marseilles, where we held a Board meeting and intensive discussions with the European Association of Urology (EAU);
- the EAU Congress in Paris this April where we presented the exciting first results from our EU-ProPER partners' survey, and made statements on early detection and shared decision-making, leading us to a further survey planned for 2024/2025.



I would like to thank the Board and the Past Chairman for their contribution and cooperation, and for having represented Europa Uomo so successfully at various occasions.

Awareness of prostate cancer is still low and the taboos surrounding it are significant. 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 possible means to create awareness and make sure that the necessary steps are taken to follow the screening algorithms published by the EAU. 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 quality of life study in a variety of speeches, discussions and visual presentations, especially at the EAU Congress in Paris. There was a very positive response from the auditorium wherever we showed data and provided opinion.

Our main goals for 2024 are spreading awareness following the EU's new recommendations on prostate cancer. The early detection campaign is underway and under [the PRAISE-U initiative](#) is visible for all stakeholders within the health environment. Having successfully undertaken our EU-ProPER study assessing the burden of prostate cancer for spouses, partners and family members, and having announced first results at the EAU Congress 2024, we will continue to disseminate and publish data.

This is my second annual report as Chairman. Having served as Vice Chairman previously, with responsibility on quality of life issues, 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 thank you to our Executive Secretary, Anja Vancauwenbergh, who devotes so much time to Europa Uomo, and is successfully working in its new office. I would also like to thank all my colleagues on the Europa Uomo Board who have always been prepared to take over specific topics if necessary.

I would also 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. Strategy

Our strategy remains unchanged. 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) advised in favour of early detection for prostate cancer. This is a major achievement for all of us but a challenge as well.

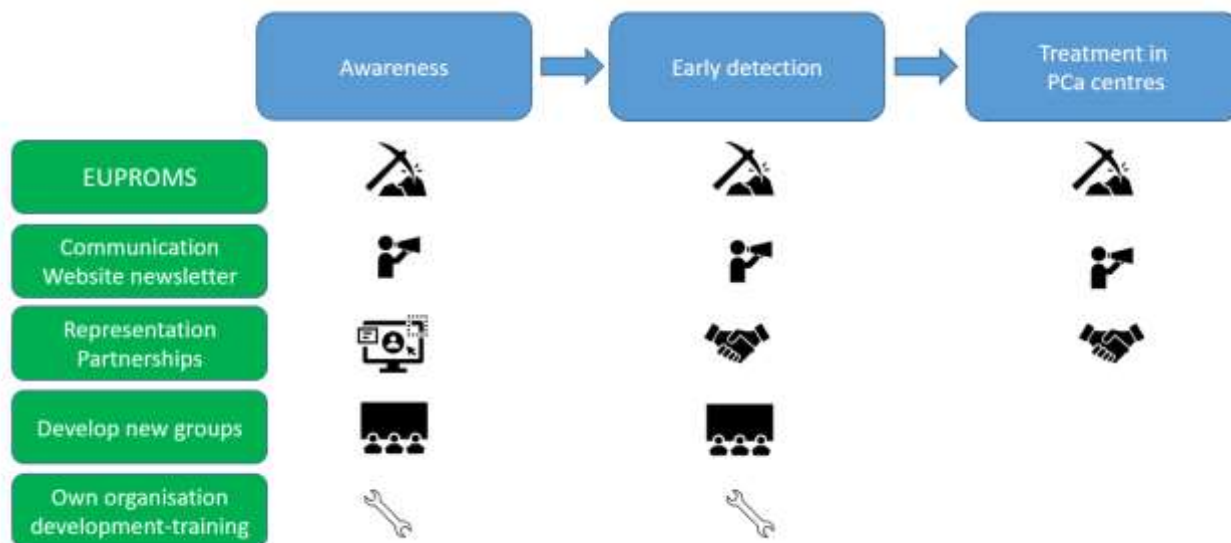
After the formal announcement, the real work starts. Countries, and in some cases regions, will need to implement the new recommendation. This will mean raising awareness and breaking taboos. Europa Uomo is ready to support its members with advice and materials to do so.

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. Europa Uomo is helping within designated regions by appointing a representative to assist within the region. It is also providing support within all other countries involved, including Netherlands, Germany, Belgium and France. The [PRAISE-U website](#) provides details of 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 projects

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 survey, so are new to the data set
- 2,000 patients were willing to answer specific questions and left their email for future contact

An article summarising the results was published in European Urology Focus in May 2023.

One year after the EUPROMS 2.0 survey, we launched the one-year follow-up study as planned.

The EUPROMS 2.0 one-year follow-up survey was available in 19 languages and included validated measures to evaluate generic health (EQ-5D-5L), cancer-specific QoL (EORTC-QLQ-C30) and prostate-specific health (EPIC-26). Furthermore, two items of the International Index of Erectile Function 15 (IIEF-15) were added.

Of the 1942 men invited to complete the one-year follow-up questionnaire, 1006 completed the survey. A total of 641 men underwent no new treatment, 365 did. The results have been analysed and an article is in preparation. It will be submitted for publication in Spring/Summer 2024.

2.5. The EU-ProPer study



When we analysed the EUPROMS 1 and 2 data it was clear that the quality of life of prostate cancer patients was heavily compromised, especially due to incontinence and implications on their sexual life. We also found out that 83% are living with a partner.

So the Europa Uomo Board decided to launch a new survey measuring the burden on the partners of prostate cancer patients. A large survey of this group is unprecedented. Unfortunately there are also no validated questionnaires with which to measure their burden so we developed our own questionnaire.

Our Dutch member PKS has for many years had a group of prostate cancer partners. led by Irma Boogh, and we could heavily rely on their experiences for the design of the test questionnaire.

This questionnaire was tested in five different languages and countries. A final version (with 80 questions and the validated questionnaire SF12 V2) was translated in 17 languages and launched in October 2023.

We received 1135 valid responses.

Many thanks are due to the team that made this happen:

- From Europa Uomo – Irma Boogh, Tania Estapé and André Deschamps
- From the Erasmus medical centre in Rotterdam – Lionne Venderbos, Sebastiaan Remmers, Monique Roobol and Nuno Azevedo.

Some of the results have been presented at a “game changing session” at the EAU Congress in Paris, and a brief summary was also distributed. The results will be further analysed and a journal paper prepared.

2.6. Europa Uomo Summer School

Prostate cancer treatments are in constant evolution and with the EAU guidelines being revised each year it is important to keep our membership informed. Members also need to be kept aware of developments such as the EU Beating Cancer Plan and the European Council’s updated advice on prostate cancer screening. To this end, the Board decided to organise a Europa Uomo Summer School.

Members throughout Europe are being invited to participate in an intensive training week. As well as providing updates on recent developments, we will provide advocacy training based on our work on behalf of prostate cancer patients in Europe over many years.

We will invite top faculty from the EAU Guidelines Committee and other leading speakers on advocacy.

Participants will be invited free of charge, but need to invest their full time in Brussels on the training. They have to be active in their own national patient organisation have a good knowledge of English.

The Europa Uomo Summer School will take place in Brussels on 1st to 6th September.

2.7. Communications

Over the past year, Europa Uomo's newsletter, website and online presence have continued to develop. The website has provided new resources and extensive coverage of the EUPROMS and EUPROPER studies and other Europa Uomo activity.

From April 2023 to end of March 2024, the Europa Uomo website received 28,000 page views, compared with 21,000 page views in the same period the previous year. This continued growth can be partly attributed to growing awareness of the organisation, achieved through a raised profile at international events and regular social media and website coverage of surveys and campaigns. The number of Twitter/X impressions in the year reached a record 24,900.

The website's translation function remains available, enabling member organisations to translate material into their language.

In the coming year, the website will be further developed to include new campaigning resources of member organisations. There are also plans to embed a new prostate cancer chatbot, providing automated answers to queries based on EAU guidelines.

2.8. Active surveillance

Europa Uomo believes there is still a need to make men and patients aware of the possible benefits of active surveillance (AS) for men with low-risk prostate cancer. Europa Uomo active surveillance webinars have continued this year with two aims:

- Give support to men, particularly focusing on psychological issues aspects).
- Provide an update on recent research on the implementation of AS and treatment decision-making tools

With this in view, we organised the following webinars.

27th September, 2023: Anxiety and Depression in Prostate Cancer Patients, focusing on the sociocultural aspects of cancer, anxiety, depression, fear of death and suffering.

25th January, 2024: Pushing the Limits of Prostate Cancer Diagnosis and Characterisation through AI-based Tools, presenting early results from a new European Commission-funded research project was validating new AI models for detecting lesions and predicting aggressiveness.

20th March, 2024: A urine test to identify patients with clinically significant prostate cancer, examining new research on potential tools for the early diagnosis of prostate cancer.

Videos of the webinars can be viewed on [Europa Uomo's YouTube channel](#).

2.9. EAU Guidelines Committee on Prostate Cancer

Erik Briens represents Europa Uomo on the EAU Guidelines Committee on Prostate Cancer. [The guidelines](#) are formulated in Europe, but are influential globally.

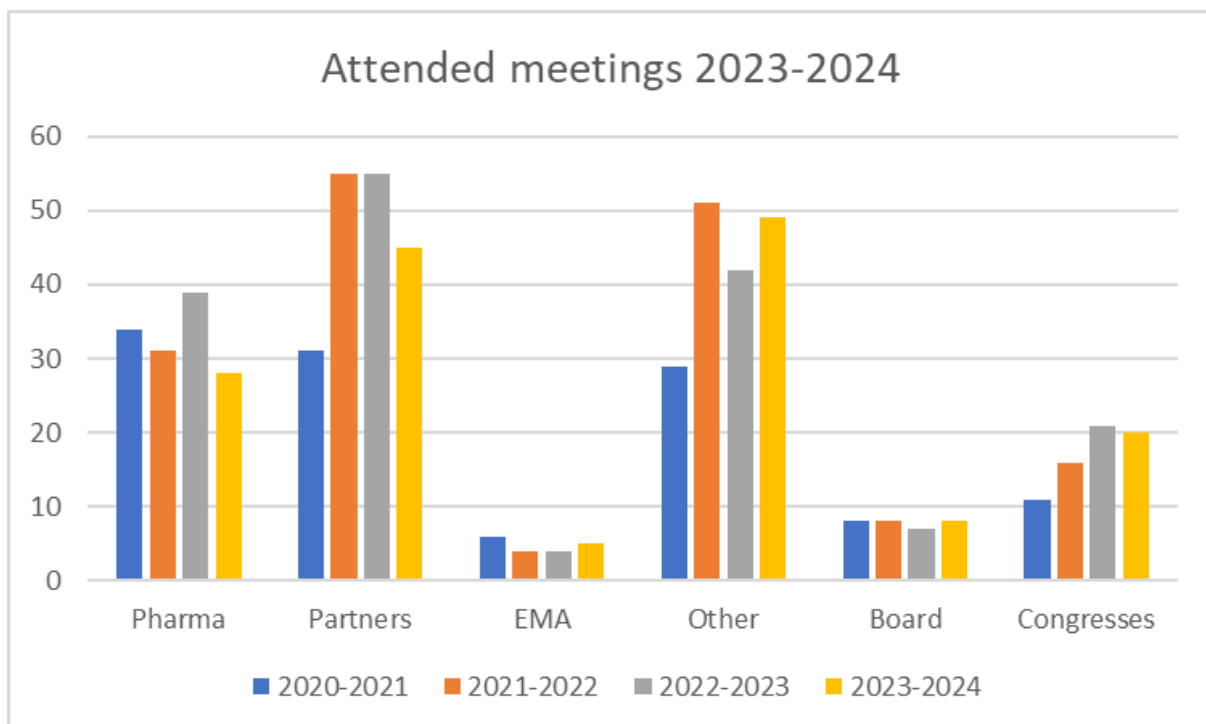
They are reviewed every year to reflect changes in science. Patient representatives work with other members to provide a patient perspective and provide an honest opinion in discussions.

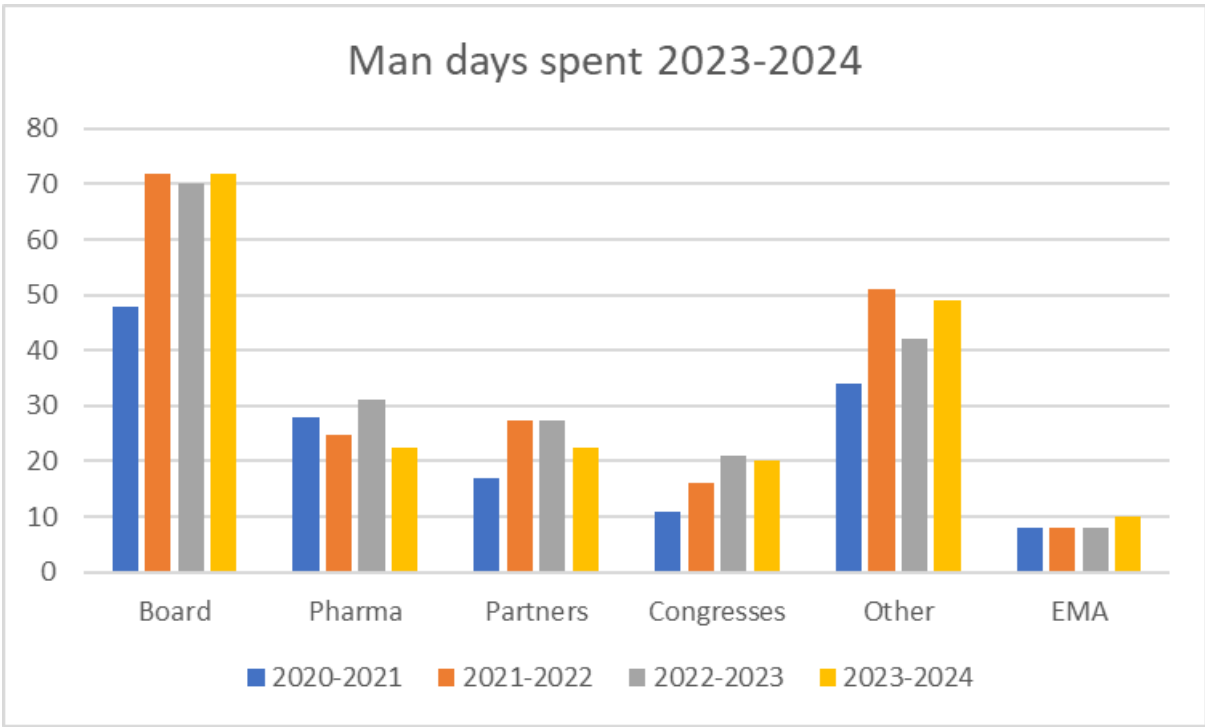
Europa Uomo is looking for a second representative to be included on the guidelines committee.



2.10. Partnerships and meeting attendance

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





	2023-2024	2022-2023
Number of meetings attended by Board members	155	168
Number of days spent at meetings	195.9	199.7





2.11. Development and new groups

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

At the 2024 General Assembly, the Europa Uomo membership will be asked to vote on whether to admit Društvo uroloških bolnikov Slovenije from Slovenia and PROSCA from Switzerland as full members, and Ellok from Greece and the Asociace mužů sobě z.s. from Czechia as associate members.

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

2.12. Development and training in our own organisation

Our General Assembly 2024 in Milan will be followed by two half days of training for the attendees. We would like to thank our Italian member organisation for their cooperation in helping us to realise this.

2.13. The DE-ESCALATE trial

Europa Uomo is engaging more in scientific research. At the end of 2022, we were invited to become an active member of an EU-funded clinical trial called DE-ESCALATE, investigating current treatments for metastatic hormone-sensitive prostate cancer. The principal sponsor is the European Organisation for Research and Treatment of Cancer (EORTC).

The standard of care is androgen deprivation therapy (ADT) with the addition of an androgen receptor pathway inhibitor (ARPI). This "intensified" combined treatment (iADT) can cause serious side effects which affect quality of life.

In DE-ESCALATE, patients will be put on iADT until their PSA level drops and shows that the treatment is working. At that point the iADT treatment will be paused until the PSA increases again. This intervention will be compared to the standard of care, continuous intensified androgen deprivation therapy, where the treatment is not paused.

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 is 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. 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 2023, two positions needed to be filled because one incumbent (Will Jansen) had completed his two three-year terms. Nils Petter Sjøholt had completed his first three-year term and stood for a further three-year term.

The newly elected member was Marko Koivuneva (Finland).

The new Board met live on 26th May 2023 and officers were elected. The full Board for 2023-24 was:

Chairman:	Guenther Carl (Germany)
Vice-Chairmen:	Erik Briers (Belgium) Nils Petter Sjøholt (Norway)
Treasurer:	Ioannis Vanezos (Cyprus)
Secretary:	Steven Lerys (France)
Other members:	Tania Estapé (Spain) Marko Koivuneva (Finland) Cosimo Pieri (Italy) Paulius Rakštys (Lithuania)
Advisors to the Board:	André Deschamps (Past-Chairman) Simon Crompton (Communication strategy)
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) 05.07.23 by Zoom
- 2) 19.09.23 by Zoom
- 3) 04.11.23 in Marseille during EMUC23
- 4) 08.01.24 by Zoom
- 5) 28.02.24 by Zoom
- 6) 05.04.24 in Paris during EAU24
- 7) 23.05.24 in Milan

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 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 fees, contributions and sponsorship from pharmaceutical and non-pharma organisations, 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. We managed to achieve and complete our major projects: EUPROMS 2.0 phase B and C, our active surveillance project and upgrading our communication status. We should also record our achievement on defending and implementing our strategy by raising our voice and be present on all major prostate cancer events such as EAU, ESMO, EMUC, etc... and the excellent training during General Assembly.

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. We have made great efforts on paving the road for 2024.

Our budgets for 2024 and 2025 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. From this year onwards, all our received funds are indicated on our website with their contributions for the year.

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.

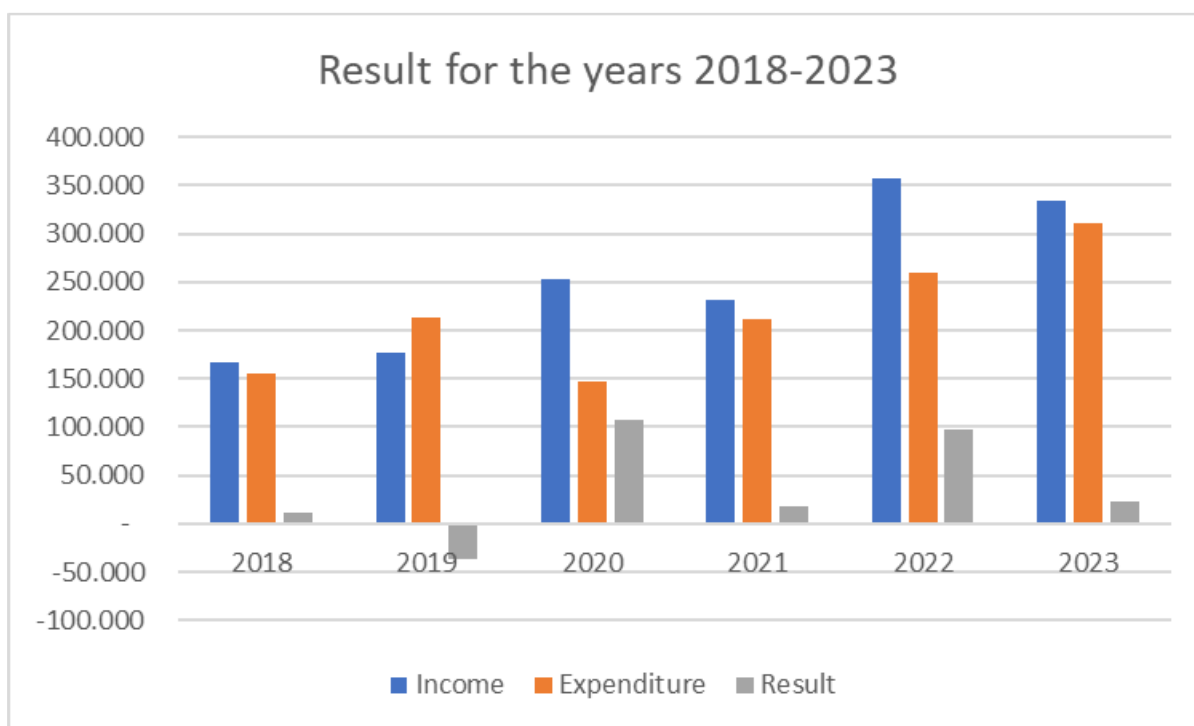
In accordance with Belgian law it is necessary that these financial reports be approved by the General Assembly.

4.1. Balance Sheet at 31st December, 2023

Accounts audited by Guido Smet

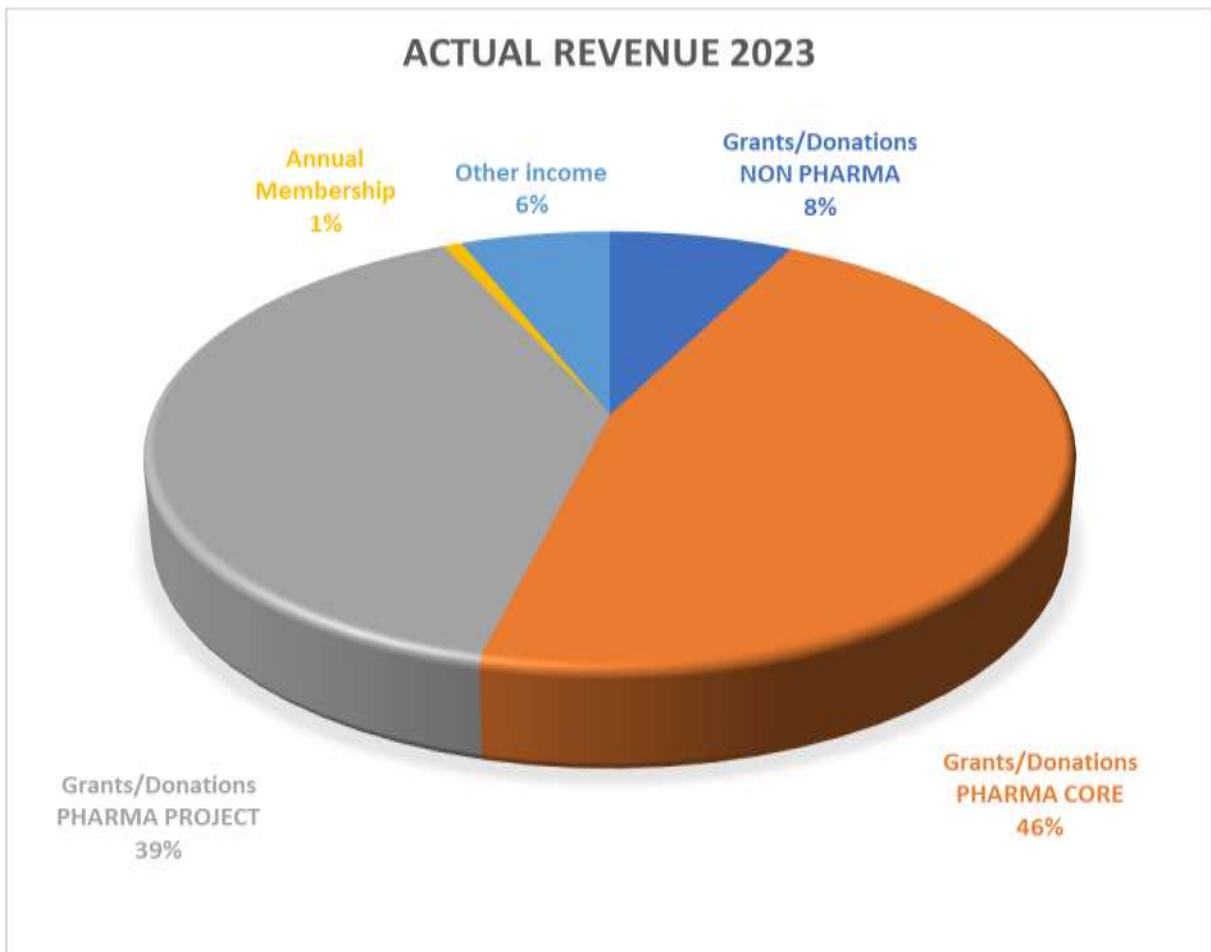
ASSETS		LIABILITIES	
Business Compact account	536.124,95	Balance at 31/12/2016	221.591,55
Saving account	50.435,25	Positive result 2023	23.336,49
Deferred expenses	15.453,94	Results carried forward	191.641,01
Office machines and equipment	1.060,24	Deferred invoices	1.814,79
Receivables within 1 year	30.000,00	Withholding tax + RSZ to be paid	2.522,54
Guarantees	2.044,33	Provision holiday fee	7.511,02
		Revenues to be transferred	186.701,31
	635.118,71		635.118,71

4.2. Results for the years 2018-2023



	2018	2019	2020	2021	2022	2023
Income	166.474	176.596	253.101	230.821	356.720	334.032
Expenditure	155.759	213.712	146.670	212.390	259.783	310.695
Result	10.715	-37.116	106.530	18.431	96.937	23.337

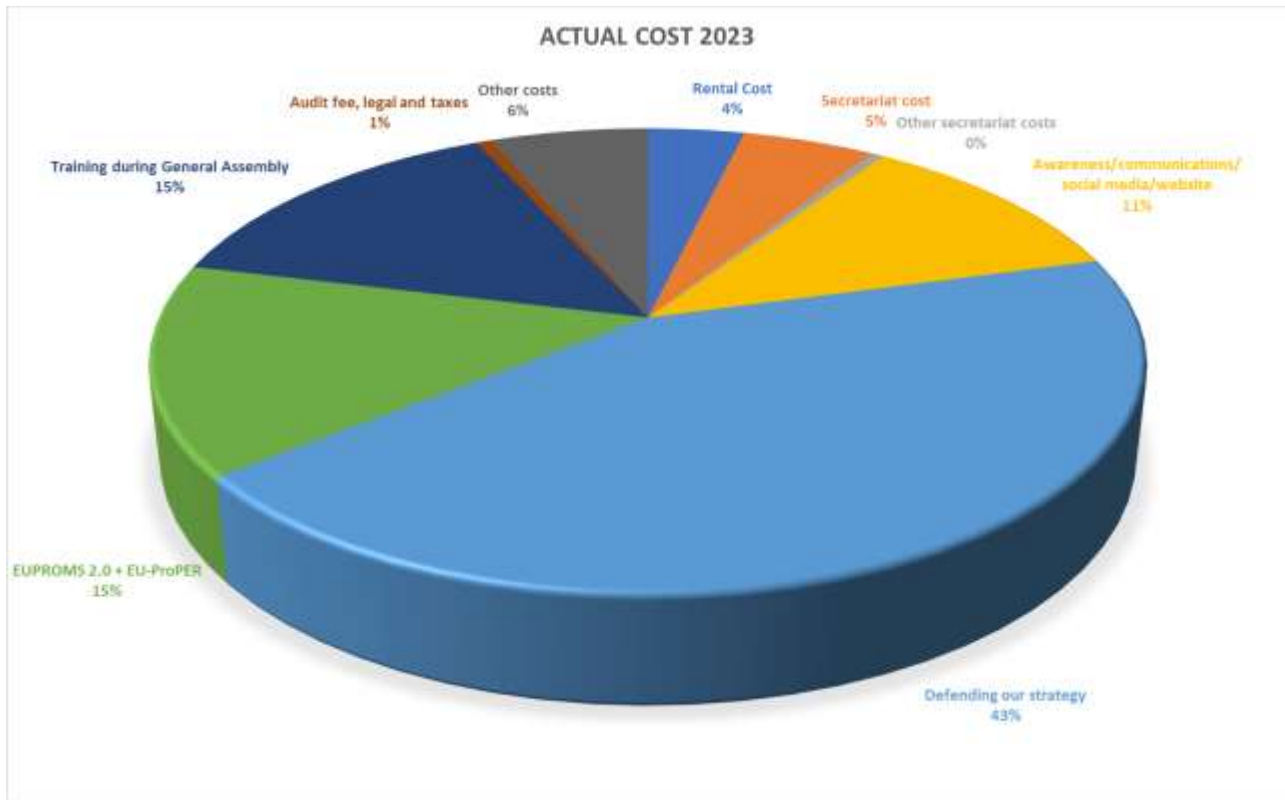
4.3. Revenue 2023 distribution



4.4. Revenues 2023 breakdown

	Actual revenue 2023	Budget 2023
Grants/Donations NON PHARMA	25.000,00	35.000,00
Grants/Donations PHARMA CORE	155.000,00	80.000,00
Grants/Donations PHARMA PROJECT	131.200,00	160.000,00
Annual Membership	2.500,00	2.500,00
Other income	20.332,02	15.000,00
	334.032,02	292.500,00

4.5. Expenses 2023 distribution



4.6. Expenses 2023 breakdown

	Actual cost 2023	Budget 2023
Rental cost	11.661,58	
Secretariat cost	24.000,00	24.000,00
Other secretariat costs	1.500,86	3.000,00
Awareness/communications/social media/website	40.240,02	55.000,00
Defending our strategy	105.068,59	60.000,00
New members		15.500,00
EUPROMS 2.0 + EU-ProPER	48.818,27	130.000,00
Training during General Assembly	48.500,00	60.000,00
Active Surveillance	10.000,00	26.000,00
Audit fee, legal and taxes	1.743,13	4.000,00
Other costs	19.163,08	6.000,00
Contingency		1.000,00
	310.695,53	384.500,00

4.7. Budget and actual 2023

	Budget	Actual	%
Income	292.500,00	334.032,02	114,20%
Expenses	384.500,00	310.695,53	80,81%

4.8. Revised projects 2024

Revised projects 2024	Project cost
Website/social media/communications/awareness	60.000,00
EU-ProPER and Summer School	160.000,00
Training members at GA	80.000,00
New members organisation support	16.500,00
Defending our strategy	70.000,00
	386.500,00

4.9. Revised revenue budget 2024 and 2025

	Revised revenue budget 2024	Revenue budget 2025
Grants/Donations non-pharma	35.000,00	35.000,00
Pharma core funding	80.000,00	80.000,00
Pharma project funding	170.000,00	190.000,00
Annual membership	2.500,00	2.500,00
Other income	15.000,00	15.000,00
	302.500,00	322.500,00

4.10. Revised expenses budget 2024 and 2025


	Revised budget 2024	Budget 2025
Premises	12.000,00	12.000,00
Secretariat	24.000,00	24.000,00
Other Secretariat costs	1.000,00	1.000,00
Awareness/communications/social media/website/booth	60.000,00	60.000,00
Defending our strategy	60.000,00	60.000,00
New members	16.500,00	16.500,00
EU-ProPER & Summer School	170.000,00	
Shared Decision Making & Chatbot		190.000,00
Training during General Assembly	80.000,00	80.000,00
Audit fee, legal and taxes	4.000,00	4.000,00
Other costs	1.000,00	1.000,00
Contingency	1.000,00	1.000,00
	429.500,00	449.500,00

Thanks to our sponsors and supporters during 2023



This report is published by the Board of Europa Uomo.

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