

# **EUROPA UOMO**

The Voice of Men with Prostate Cancer in Europe

## **Annual Report of the Board 2024/25**

## 1. Chairman's Note

Dear Reader,

We had a productive exchange of ideas with our members at our successful General Assembly in Milan, Italy, and since then have been involved in a wide range of events.

We met our current and new sponsors at the 2024 ESMO Congress in Barcelona. Our 2024 Summer School for members, held in Brussels, proved a great success. We provided speakers and held a Board meeting at the 2024 EMUC congress in Lisbon.

We again contributed speakers and papers and met with our sponsors at the 2025 Congress of the European Association of Urology (EAU) in Madrid. New to the Congress this year was the EAU Patient Office's "Patient Plaza", providing all patient groups with a stand where they could explain their aims and give information about their projects. Europa Uomo provided various speakers for Plaza activities and took part in a very interesting discussion about our AI chatbot.



We have successfully integrated the new members invited to join by the last General Assembly and we look forward to welcoming more new members soon.

I would like to thank the Board and the former Chairman for their contributions and cooperation, as well as for successfully representing Europa Uomo on many occasions. Our continuing aim is to create awareness about prostate cancer, support PRAISE-U and support and promote the early detection of prostate cancer.

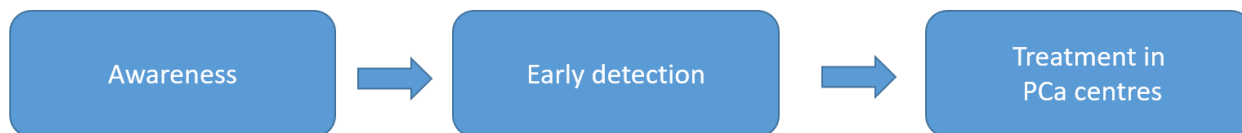
This is my third and final report as Europa Uomo Chairman. Having served the full term as Chairman and seven years as a Board member, it has been a pleasure to work and cooperate with many dedicated people who have sought to improve the position of men with prostate cancer in Europe. In particular, I would like to pay 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 works in the Antwerp office and devotes so much time to Europa Uomo. I would also like to thank all my colleagues on the Europa Uomo Board, who have always been prepared to take on specific topics if necessary. Thanks too to our sponsors and everyone else 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 it should be based on three pillars.



- Awareness of prostate cancer is key: we must change perceptions and challenge “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?

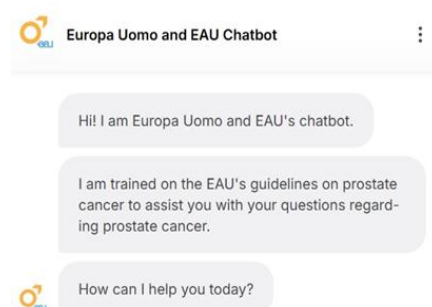
Following the announcement of the EU Beating Cancer Plan in 2022, a European Parliament committee advised in favour of early detection programmes for prostate cancer. Since then, many countries and regions have been busy trying to implement the new recommendation and raise awareness. Europa Uomo has been ready to support its members with advice and materials to do so.

The PRAISE-U project has been a focus of recent activity. This EU-funded project works to encourage early detection and diagnosis of prostate cancer across Europe through customised and risk-based screening programmes. The main contractor is the European Association of Urology (EAU). Europa Uomo is an associate partner and one of the work package teams. Many other experts and groups are members of a research consortium, responsible for coordinating joint action, building on screening efforts and contributing big data on prostate cancer from pilot sites in Spain, Poland, Ireland, and Lithuania.

The [Europa Uomo website](#) provides details of how the work packages are executed. At this year’s EAU Congress we got a glimpse of first results regarding recruitment and heard detailed information from pilots in Silesia/Poland and Galicia/Spain. We are convinced that the goals for PRAISE-U can be successfully reached in 2026.

### 2.3. The Europa Uomo Chatbot

In 2024 we successfully introduced an online AI assistant or “chatbot” on our website to answer questions from men with, or interested in, prostate cancer. The chatbot bases its answers on EAU



guidelines and other authoritative sources of information. It provides rapid responses in 95 languages, even to detailed questions.

Europa Uomo has promoted the chatbot directly, and with the help of our members. It was publicised using a film and leaflets at the 2025 EAU Congress and prompted many enquiries.

## 2.4. EUPROMS

We completed a one-year follow-up of our Europa Uomo Patient Reported Outcome Study (EUPROMS) into quality of life of prostate cancer patients. The results were published in [European Urology Open Science](#). The follow-up found that the impact of continuing treatment for prostate cancer on sexual function is “immediate and detrimental” and continues for a long time.

## 2.5. EU-ProPer



In October 2023, Europa Uomo launched a new survey measuring the burden on the partners of prostate cancer patients – EU-ProPer (Europa Uomo Prostate Partners’ Experience Research). Research on this subject at such scale was unprecedented.

We received 1,135 valid responses.

The first results were disclosed at the EAU Congress in Paris in April 2024, as part of a “game changing” session. The study found a mismatch between the information partners expect and the information given. Only 20% of partners said they had received information about sexuality from a health professional before treatment. Half of the respondents reported that their partner suffered from incontinence after treatment – yet 18% said their healthcare provider had not mentioned the risk of incontinence before.

Further analysis was presented at the EAU Congress in March 2025 congress in Madrid.

The analysis has been completed and a lay language summary of findings is available in [the resources section](#) our website.

## 2.6. EU-PRESS



Patients need to make important decisions during their prostate cancer journey. Shared decision making (SDM) with their healthcare providers is of the essence. Europa Uomo decided to launch a survey to find out about the reality of this process from a patient perspective. We also wanted to know whether shared decision making was related to quality of life and decision regret.

The survey was open from 1<sup>st</sup> November 2024 to 31st December 2024. To minimise memory bias, the survey was open only to patients who had made a treatment decision in 2023 and 2024. We received 613 valid responses.

The first results were presented at the EAU Congress in Madrid in March 2025. They showed that patients who gave a higher SDM score have a better quality of life and have less decision regret. Furthermore 40% of the respondents reported mild or severe decision regret.

Further analysis of the data will take place in the coming months.

## **2.7. Europa Uomo Summer School**

2024 marked the first Europa Uomo Summer School, with 25 participants from across Europe coming to Brussels for an intensive expert and advocacy training week.

The programme had two main parts. The first focused on the diagnostic and therapeutic aspects of prostate cancer and was covered by a faculty from the EAU treatment guidelines committee and added experts.

The second part focused on patient advocacy. A faculty of professional organisations explained clinical trials, regulatory processes, patient reported outcomes and the use of artificial intelligence in chatbots.

All the participants were satisfied with the scientific programme as well as with the quality of the faculty and venue. They received a certificate of presence and became members of the Europa Uomo Academy alumni group.

For 2025, Europa Uomo Board decided to develop this training initiative. There will be two schools – one in summer, one in winter – under the overarching title “Europa Uomo Academy”.



The Summer School will cover the training of expert patients and will take place in September in Brussels. Up to 25 patients from all over Europe can participate as before. The Winter School will concentrate on training in advocacy skills and will also be held in Brussels.

## **2.8. Communications**

The quality and quantity of Europa Uomo’s communications and publicity have continued

to develop.

From April 2024 to end of March 2025, the Europa Uomo website received 36,000 page views, compared with 28,000 page views in the same period the previous year and 20,000 the year before that. This near doubling over two years can be partly attributed to the organisation's growing profile and reputation, but also to the quality of its output and more consistent online presence.

The website's translation function remains available, enabling member organisations to translate material into their language. The addition of the new Europa Uomo chatbot to the website has drawn in new visitors and interest. Publicity for the Europa Uomo chatbot has included a short-explanatory film displayed at the EAU Congress in Madrid.

Other core Europa Uomo projects such as the EUPRESS study, the Summer School/Academy and PRAISE-U project have also been supported by publicity through the website, social media and online or printed leaflets.

## 2.9. Webinars

Europa Uomo webinars have continued this year with two aims:

- Providing support, particularly on psychological aspects of prostate cancer
- Providing an update on recent research and treatment decision-making tools.

With this in view, we organised the following webinars during 2024-25.

27<sup>th</sup> November, 2024: Prostate Cancer and Couples' Communication. This webinar focused on the burden that a prostate cancer diagnosis can place on a couple's relationship.

12<sup>th</sup> March, 2025: ProCancer-I project. This webinar examined how artificial intelligence tools can be used in diagnosis, staging, characterising cancer, and its value in identifying cancers that will not need to be actively treated.

## 2.10. EAU Guidelines Committee on Prostate Cancer

Since 2013, Europa Uomo has had a patient representative (Erik Briers) on this important committee. This demonstrates the commitment of patients to participate at this level but also the commitment of EAU to include patient voices in discussions.

In 2025, a second patient representative will take part in face-to-face meetings. This will ensure that the patient voice is heard and that there is sustainability. The name of the second representative will be announced at the Europa Uomo General Assembly 2025.

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

P. Cornford (Chair), D. Tilki (Vice-chair), R.C.N. van den Bergh, D. Eberli, G. De Meerleer, M. De Santis, S. Gillesen, A.M. Henry, G.J.L.H. van Leenders, J. Oldenburg, D.E. Oprea-Lager, M. Roberts, O. Rouvière, I.G. Schoots, J. Stranne, T. Wiegel  
Patient Advocate: E. Briers  
Guidelines Associates: P. Chiu, A. Farolfi, G. Gandaglia, N. Grivas, E. Linares Espinós, A. Sachdeva  
Guidelines Office: E.J. Smith, C. Bezuidenhout



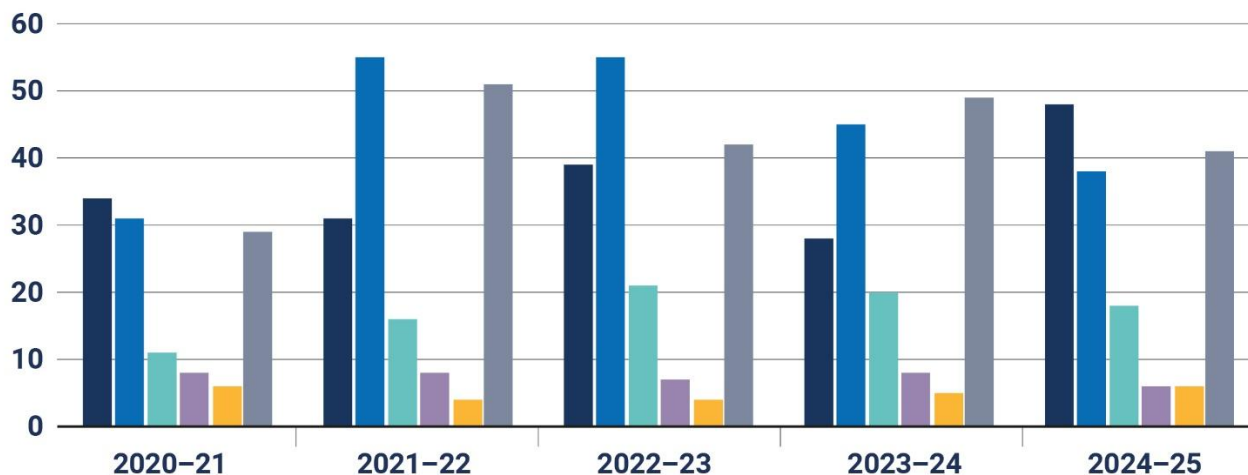
© European Association of Urology 2025

## 2.11. Partnerships and meeting attendance

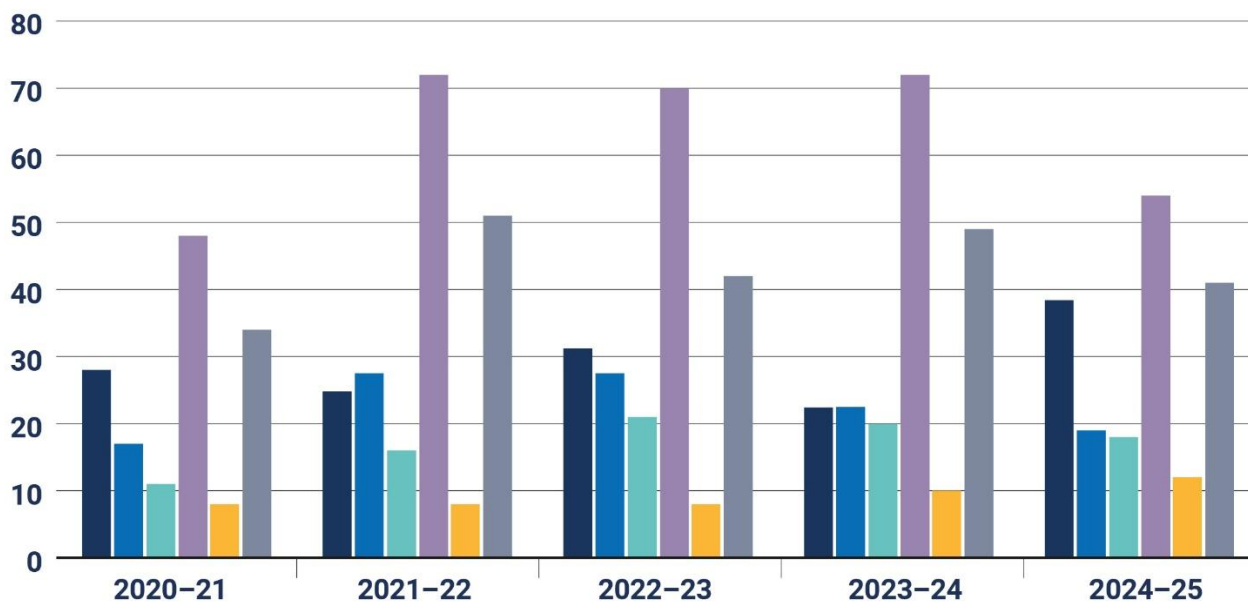
### Partnerships and meeting attendance

Pharma Partners Congresses Board EMA Other

#### MEETINGS ATTENDED



#### MAN-DAYS SPENT



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

#### Attended congresses May 2024-April 2025

Europa Uomo General Assembly and Masterclass, 24-25 May, 2024 – Milan, Italy

Multinational Association of Supportive Care in Cancer Congress, 27-28 June, 2024 – Lille, France

Workgroup of European Cancer Patient Advocacy Networks (WECAN) Academy, 20-22 July, 2024 – Barcelona, Spain

2024 Nordic Prostate Cancer Meeting, 29-31 August, 2024 – Helsinki, Finland

Europa Uomo Summer School, 2-6 September, 2024 – Brussels, Belgium

80y Celebration Congress of the Swiss Association of Urology, 11-13 September, 2024 – Lugano, Switzerland



European Society for Medical Oncology (ESMO) Annual Congress, 14-18 September, 2024 – Barcelona, Spain

European Society of Urological Radiology (ESUR) Meeting, 20-22 September, 2024 – Lisbon, Portugal

EAU Sections of Genitourinary Reconstructive Surgeons and Andrological Urology with the Society of Genitourinary Reconstructive Surgeons Congress, 11 October, 2024 – Antwerp, Belgium

European Association of Nuclear Medicine Congress, 19-23 October, 2024 – Hamburg, Germany

Conference on Prostate Cancer Screening, 4 November, 2024 – Ljubljana, Slovenia

European Multidisciplinary Congress on Urological Cancers (EMUC) Congress, 7-10 November, 2024 – Lisbon, Portugal

European Cancer Summit 2024, 20-22 November, 2024 – Brussels, Belgium

European Patients' Forum 'Data Saves Lives', 26-27 November, 2024 – Brussels, Belgium

PROSCA 2024 – Global Forum on GU Oncology, 28-30 November, 2024 – Vienna, Austria

European Cancer Forum 2024, 4 December, 2024 – Brussels, Belgium

European Congress of Radiology (ECR), 27 February-2 March, 2025 – Vienna, Austria

European Federation of Organisations for Medical Physics (EFOMP) Congress, 17-19 March, 2025 – Brussels, Belgium

European Association of Urology (EAU) Congress, 21-24 March, 2025 – Madrid, Spain

## Pharma contacts

**Amgen** | **Astellas** | **Astra Zeneca** | **Astra Zeneca** | **Bayer**  
**Daiichi Sankyo** | **Eli Lilly** | **IPSEN** | **Janssen** | **MSD** | **Novartis**  
**Pfizer** | **Roche** | **Telix**

## Partnerships

**ASPI** | **Blue Earth Therapeutics** | **Patient Preference Study**  
**DAND PAG** | **WECAN** | **EPF** | **EAU** | **EONS** | **Mac4Me** | **LTPC**  
**PIONEER** | **EORTC** | **EAU EPAG** | **Safe Poly Med** | **SPARC**  
**ESR PAG** | **OPTIMA** | **OnHOME** | **PRAISE-U** | **DE-ESCALATE**  
**ECO PAG**

### 2.12. Development and new groups

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

At the 2025 General Assembly, the Europa Uomo membership will be asked to vote on whether to admit four organisations as full members: the Association of Prostate Cancer Patients of the Federation of Bosnian Herzegovina; the Croatian Society of Prostate Cancer Patients; Europa Uomo Hellas; and the Serbian Centar za muskarce – BRKA. Members will also decide whether to admit the Malta Male Cancer Support Federation as an associate member.



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

### 2.13. Development and training in our own organisation

The Europa Uomo General Assembly 2025 in Helsinki will be followed by two half days of training for the attendees. We would like to thank our Finnish member organisation for their cooperation in helping us to realise this.

### 2.14 The DE-ESCALATE trial

Europa Uomo continues its involvement with the 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 trial is yet to start, with ethics committee delays in some countries. New negotiations are underway to better explain the specific structure of the pragmatic clinical trial.

## 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 2024, three positions needed to be filled because one incumbent (Cosimo Pieri) had completed his first three-year term and was not standing for a second term. Erik Briers and Tania Estapé have completed their first three-year term and stood for a further three-year term.

The newly elected member was Kees Vos (The Netherlands).

The new Board met in person on 24<sup>th</sup> May 2024 and officers were elected. The full Board for 2024-25 was:

Chairman:	Günther 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) Paulius Rakštys (Lithuania) Kees Vos (The Netherlands)
Advisors to the Board:	André Deschamps (Past-Chairman) Simon Crompton (Communications)

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

Executive Secretary: Anja Vancauwenbergh

The Board met six times since the General Assembly, twice by Zoom and four times in person (in Lisbon, Amsterdam, Madrid and Helsinki).

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 for 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 implement our major projects: EU-ProPER, EU-PRESS (still ongoing), the Summer School and the chatbot. We should also record our achievement on defending and implementing our strategy by raising our voice and being present at all major prostate cancer events such as EAU, ESMO and EMU and through the excellent training during General Assembly.

Comparing this year's figures 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 2025.

Our budgets for 2025 and 2026 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 conflicts 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 31<sup>st</sup> December, 2024

Accounts audited by Guido Smet

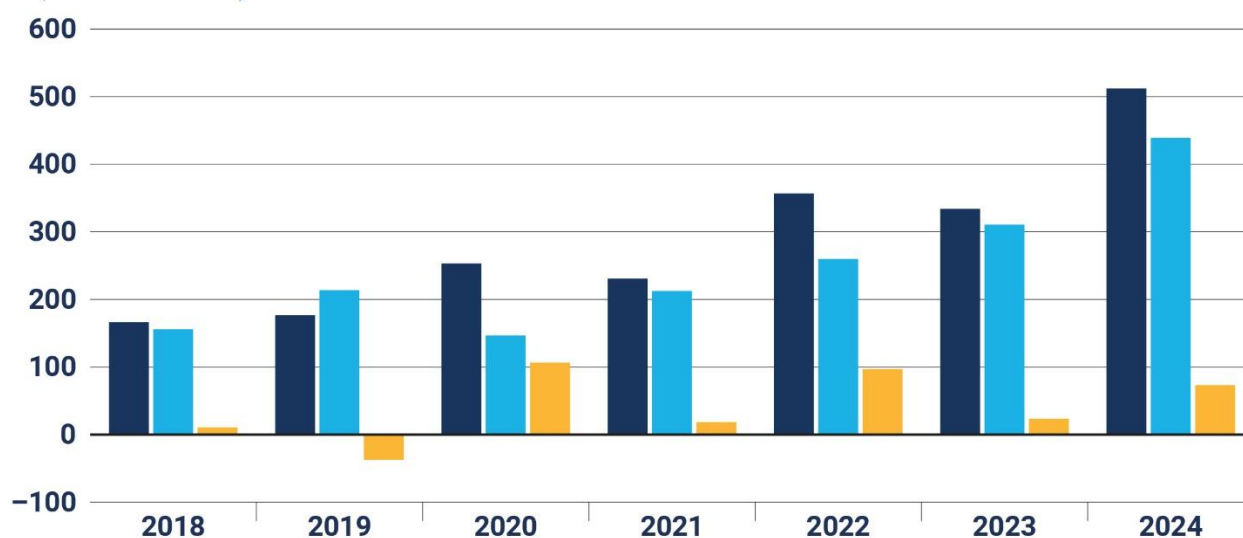
ASSETS		LIABILITIES	
Business Compact account	579.559,32	Balance at 31/12/2016	221.591,55
Saving account	50.646,71	Positive result 2024	73.123,84
Deferred expenses	1.899,17	Results carried forward	214.977,50
Office machines and equipment	706,83	Deferred invoices	6.553,76
Receivables within 1 year	22.223,00	Withholding tax + RSZ to be paid	3.692,41
Guarantees	2.044,33	Provision holiday fee	8.341,88
		Revenues to be transferred	128.798,42
	657.079,36		657.079,36

#### 4.2. Result for the years 2018-2024

### Result for the years 2018-2024

■ Income ■ Expenditure ■ Result

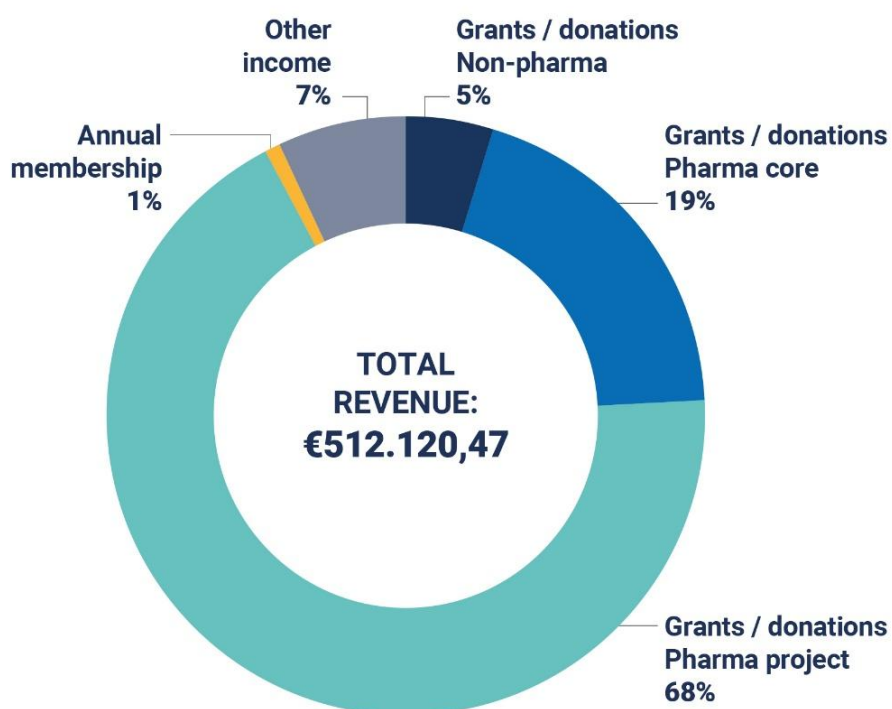
€ (THOUSANDS)



	2018	2019	2020	2021	2022	2023	2024
Income	166.474	176.596	253.101	230.821	356.720	334.032	512.120
Expenditure	155.759	213.712	146.670	212.390	259.783	310.695	438.997
Result	10.715	-37.116	106.530	18.431	96.937	23.337	73.123

#### 4.3. Revenue distribution 2024

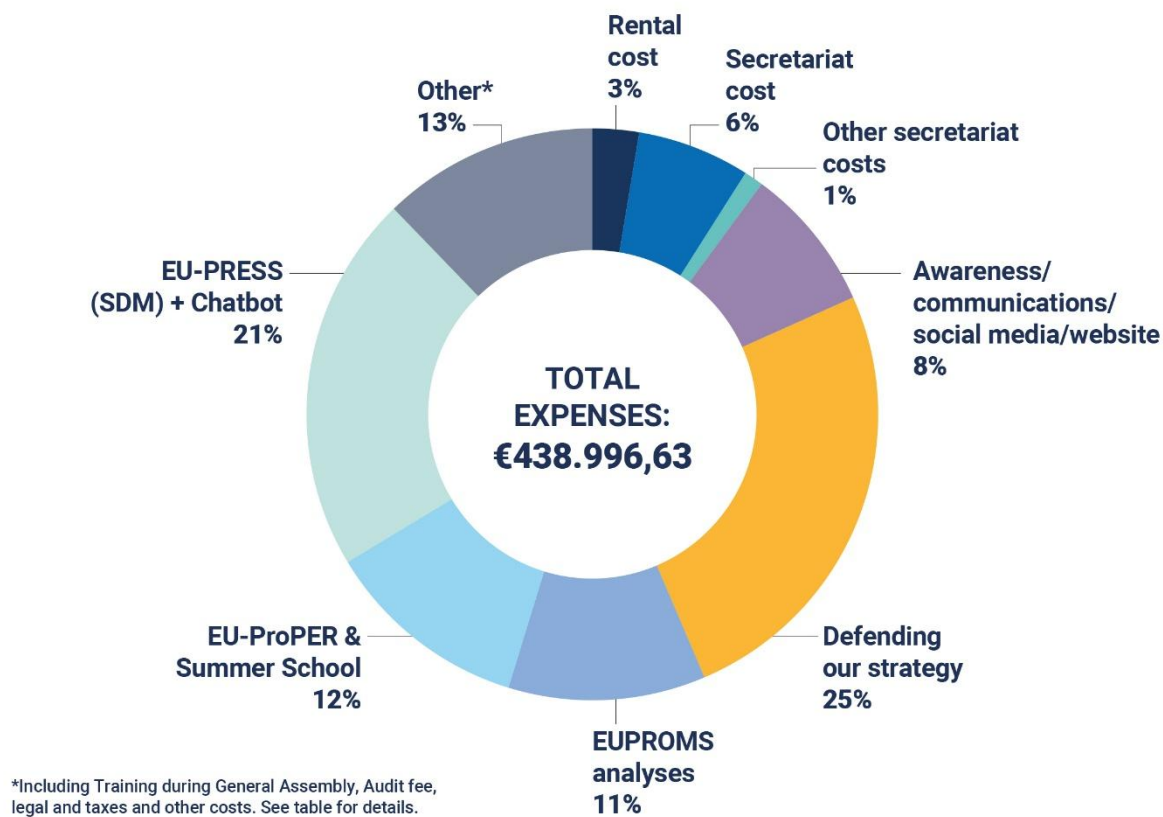
### Revenue distribution 2024



	Actual revenue 2024	Budget 2024
Grants/Donations NON PHARMA	25.000,00	35.000,00
Grants/Donations PHARMA CORE	100.000,00	80.000,00
Grants/Donations PHARMA PROJECT	348.701,31	170.000,00
Annual Membership	3.300,00	2.500,00
Other income	35.119,16	15.000,00
<b>Total</b>	<b>512.120,47</b>	<b>302.500,00</b>

#### 4.4. Expenses 2024 distribution

### Expenses distribution 2024



	Actual cost 2024	Budget 2024
Rental cost	11.541,95	12.000,00
Secretariat cost	28.000,00	24.000,00
Other secretariat costs	4.785,55	1.000,00
Awareness / communications / social media / website	36.000,00	60.000,00
Defending our strategy	111.000,00	60.000,00
New members	-	16.500,00
EUPROMS analyses	49.000,00	-
EU-ProPER & Summer School	51.000,00	170.000,00
EU-PRESS (SDM) + Chatbot	94.000,00	-
Training during General Assembly	48.700,26	80.000,00
Audit fee, legal and taxes	2.664,75	4.000,00
Other costs	2.304,12	1.000,00
Contingency	-	1.000,00
<b>Total</b>	<b>438.996,63</b>	<b>429.500,00</b>

#### 4.5. Budget and actual 2024

	Budget	Actual	%
Income	302.500,00	512.120,47	+ 69,33%
Expenses	429.500,00	438.996,63	+ 2,21%

#### 4.6. Revised projects 2025

<b>Revised projects 2025</b>	<b>Project cost</b>
Website/social media/communications/awareness	60.000,00
EU-PRESS (SDM) phase B & C	80.000,00
Europa Uomo Academy 2025	130.000,00
Training members at GA	80.000,00
New members organisation support	16.500,00
Defending our strategy	70.000,00
Chatbot	30.000,00
	<b>466.500,00</b>

#### 4.7. Revised revenue budget 2025 and 2026

	<b>Revised revenue budget 2025</b>	<b>Revenue budget 2026</b>
Grants/donations non-pharma	35.000,00	35.000,00
Pharma core funding	80.000,00	90.000,00
Pharma project funding	270.000,00	310.000,00
Annual membership	2.500,00	2.500,00
Other income	15.000,00	20.000,00
	<b>402.500,00</b>	<b>457.500,00</b>

#### 4.8. Revised expenses budget 2025 and 2026

	<b>Revised budget 2025</b>	<b>Budget 2026</b>
Premises	12.000,00	12.000,00
Secretariat	28.000,00	28.000,00
Other Secretariat costs	1.000,00	1.000,00
Awareness/communications/social media/website/booth	60.000,00	66.000,00
Defending our strategy	70.000,00	77.000,00
New members	16.500,00	16.500,00
Europa Uomo Academy 2025	130.000,00	140.000,00
Chatbot	30.000,00	40.000,00
EU-PRESS – shared decision making project	80.000,00	new 100.000,00
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
	<b>513.500,00</b>	<b>566.500,00</b>




Thanks to our sponsors and supporters during 2024



This report is published by the Board of Europa Uomo.

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