

We are here for our fellow patients



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

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Boardmember EUOMO
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The European Prostate Cancer Coalition

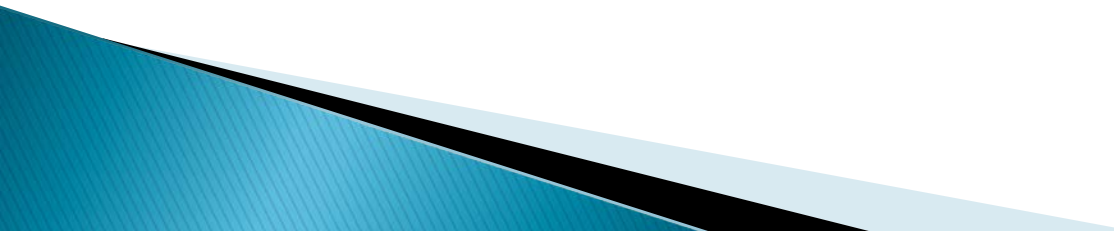
Disclosures

- ▶ I am a prostate cancer survivor since 2003

Content

- ▶ Some facts on Europa Uomo
- ▶ The change to a “managerial driven” approach
- ▶ How we did it

Europa Uomo

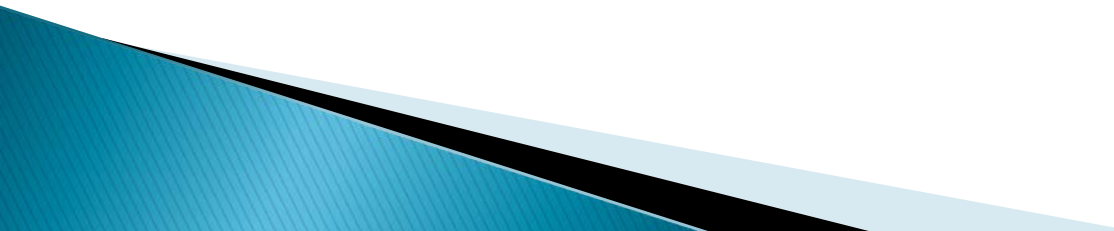
- ▶ Founded in 2003
 - ▶ A coalition of patient groups
 - ▶ All members are patients and representatives of patient groups
 - ▶ Nobody is paid apart from 1 admin staff
 - ▶ Members in 24 countries
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Our members

- Austria
- Belgium
- Bulgaria
- Cyprus
- Czech Republic
- Denmark
- Estonia
- Finland
- France
- Germany
- Hungary
- Ireland
- Italy
- Lithuania
- Norway
- Poland
- Portugal
- Romania
- Slovak Republic
- Spain
- Sweden
- Switzerland
- The Netherlands
- United Kingdom



How we did it?

- ▶ SWOT analysis 2014
 - ▶ Vision and mission 2014
 - ▶ Goals 2014
 - ▶ Projects 2016
 - ▶ Reporting 2015/2016
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Vision

**A future where no man
suffers or dies from
prostate cancer**

Mission

- ✓ **Achieve better treatment, care and quality of life for all prostate cancer patients across Europe**
- ✓ **Provide an effective EU-wide voice representing the needs and priorities of National organisations**

Goals

1. Request early detection of prostate cancer
2. Help establish Prostate Cancer Centers and raise quality at world top level in all European States
3. Have in place and review therapy guidelines and patient information in all European States based upon best evidence
4. Encourage support groups in new European States
5. Develop EUomo organizations, staff and funding
6. Support a coordinated European research program with patient advocate representation

Project based approach

- ✓ **Need to analyse and monitor spending**
- ✓ **Create a link towards our goals**
- ✓ **Better decision making**
- ✓ **Transparency towards all stakeholders**

Project 1: Awareness campaign: a tough nut to crack

Project Description		Publish adverts in different media
Project timing	Start date	11/2016
	Finish	12/2018
Project financing	Total amount	15 000 €
Project deliverables		Measure response to site pages related to campaign

Achieved so far:

- ✓ Publication in December 2016 in Brussels Airlines magazine
- ✓ Publication in *Cancerworld* in March 2017



A HARD NUT TO CRACK – PROSTATE CANCER

A man's prostate is about the size and form of a walnut

Over his lifetime, one man in seven will be confronted with prostate cancer.

Early stages of prostate cancer are symptomless. If symptoms such as pain are attributable to it then the cancer is metastasized.

The majority of prostate cancers detected early are low risk cancers evolving slowly and rarely becoming life threatening, nor needing treatment.

The others, medium and high-risk prostate cancers do need immediate attention as they will progress into metastasis and cause pain and can end in an early death. Early treatment is essential to save your life.

To detect prostate cancer early, all men as of the age of 45 should ask their doctor to have a PSA blood test. The result is a first indication of their prostate's health and whether further testing is needed.

Want to know more, visit our webpage: www.europa-uomo.org/awareness



Europa Uomo, the European Prostate Cancer Coalition is the umbrella organization for prostate cancer with members in 23 countries.

Project 2:Representation at EU–level meetings in order to spread goals and influence results

Project Description		We send representatives to EMA, ESO, steering committees, EU task force, ECPC, CANCON and others
Project timing	Start date	1/2017
	Finish	12/2017
Project financing	Total amount	0 000 € a year
Project deliverables		List and reports of meetings where we were represented. Reports to board

Achieved so far:

- ✓ See list of attended meetings attached to the annual report appendix 1.

Project 3: Initiatives in new member states/ Polish hub

Project Description		Develop activities specific for New member states training, awareness, new patient groups
Project timing	Start date	10/2016
	Finish	12/2018
Project financing	Total amount	0 000 €
Project deliverables		Training sessions Dedicated personnel Patient sessions

Achieved so far:

- ✓ Information session for 70 Polish PC patients during EPAD in Krakow
- ✓ Discussions with Gladiators in order to establish Polish Hub
- ✓ Training session in Vienna, June 2017 for 40 PC patients from Slovakia and Poland

Project 4: Maintain and design new pages and content for website and use of new media

Project Name		Project 4: Maintain and design new pages and content for website or new media
Project Description		In order to inform all stakeholders make sure that content of website and social media is up-to-date and easy to access
Project timing	Start date	5/2017
	Finish	12/2018
Project financing	Total amount	0 000 €
Project deliverables		Content of site and social media

Achieved so far:

- ✓ New website launched
- ✓ Survey amongst members on needs for communication
- ✓ New weekly newsletter (Update) launched in February 2017
- ✓ Page on website added in order to support awareness campaign
- ✓ Twitter account and Facebook account established

Project 5: Training patient advocates

Project Description		Organize a two-day training session for patient advocates Organisational and travel costs will be involved. Day 1: Training on PCa. Day 2: Patient advocate skills.
Project timing	Start date	3/2018
	Finish	4/2018
Project financing	Total amount	60 000 €
Project deliverables		Training session. Program To Be Arranged

This project will be subject to GA approval and support from sponsors.

Project 6: Auditing PCUs

Project Description		ESO has asked us to be involved in PCU audits. These audits will lead to an “approval” of the unit and a recommendation for patients.
Project timing	Start date	2018
	Finish	2019
Project financing	Total amount	0 000 €
		Patient recommendation for PCU

This project is supported and partly sponsored by ESO.

Project 7: Early diagnosis in newer states

Project Description		Promotion of initiatives which will result in earlier diagnosis of PCa
Project timing	Start date	2017
	Finish	12/2018
Project financing	Total amount	0 000 €
Project deliverables		Documentation in local language and increasing early diagnosis in developing countries

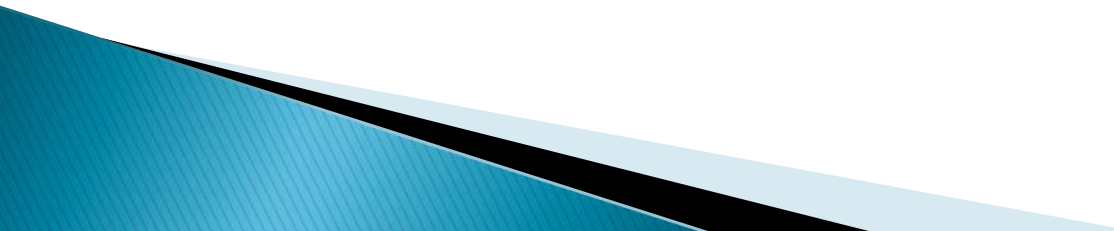
Link between projects and goals

Project	Goal 1 Awareness	Goal 2 PCU s	Goal 3 Guidelines	Goal 4 New groups	Goal 5 Organisation	Goal 6 Research
Awareness campaign: a tough nut to crack						
Representation at EU-level to meetings						
New member states/ Polish hub						
Website and new media, communications						
Training patient advocates						
Audits in PCU						
Early diagnosis in states with less developed healthcare						

Reporting

- ✓ Every boardmeeting
- ✓ Every year general assembly
- ✓ Annual report on our website
www.europa-uomo.org

Our annual report

- ▶ Business plan
 - ▶ Report of activities
 - ▶ Budget and financial figures
 - ▶ Statutes and bylaws
 - ▶ List of sponsors
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Take home messages

- ✓ “Business approach” is possible in non profit organisations
- ✓ “Judgement” of projects is not based on profit but “most benefit”
- ✓ This approach is seen as best practice by our stake holders