

# NEWS AND VIEWS

## FROM PATIENTS AND PATIENT GROUPS

### EUROPA UOMO: THE EUROPEAN PROSTATE CANCER COALITION

Europa Uomo is a European coalition of patients' support groups for prostate diseases in general and prostate cancer in particular. It was launched in Rome in 2002 and was legally established in Milan in 2004. Europa Uomo is an NGO and non-profit organisation under European law. At present it has representatives from 12 European countries: Austria, Belgium, Finland, France, Germany, Ireland, Italy, The Netherlands, Portugal, Spain, Sweden and the United Kingdom.

It is sad that one of the major achievements of public health in European society, the extended survival and well-being of its population, has also brought new challenges. An aging population is a hardship for those who suffer ill health and increases the burden on pensions and health care costs. Of the people who have cancer 75% are over 65 years of age [1].

Among the major cancers in women is breast cancer and in men prostate cancer. Both diseases are common in our affluent society and both diseases affect at least 10% of the population [1]. Breast and prostate cancer are similar in some respects such as their relation to the hormonal status of the patients but are very different in their natural, treated or untreated, history. Enormous progress in understanding both diseases has been made in the last decade but despite the accomplishments in diagnosis and treatment the perception remains that death is around the corner and quality of life lost to severe psychological, emotional and social trauma.

Table 1

Representatives of the founders of Europa Uomo in Antwerp (May 2003)

Tom Hudson	Copes UICC, Ireland
Eric Briers	Wij Ook (Us Too), Belgium
Louis Denis	
Jack Pais	
Roberto Morrazoni	Europa Uomo, Italy
Fabio Sereni	
Ekkehard Buechler	Selbsthilfe Prostatakrebs, Austria
Eoghan Cahill	MAC (Men Against Cancer), Ireland
Lars Eliason	ROP (Riksorganisationen för Prostatacancer), Sweden
Dan Gaffney	PCaSO (Prostate Cancer Network), UK
Jim Stansfeld	
Renate von Kölln-Busch	BDS (Bundesverband Prostatakrebs Selbsthilfe), Germany
Christian Ligensa	
Kay Mielke	
Jean Moreau	Anamacap, France
Roland Muntz	
Hannu Tavio	FDF (Finland Prostatacancer Förening), Finland
Pekka Tuomisto	
Wil de Jongh	EPCEL-Ne, Netherlands
John Page	US TOO, USA
Kathy Redmond	European Cancer Patient Coalition (ECPC)
Paul Dixey	PRONet

Women have accomplished a remarkable collaboration to fight breast cancer and rally the support of society to follow a long-term policy of control and prevention. Only a decade ago a small group of determined survivors met, today Europa Donna, the European Coalition against Breast Cancer, constitutes an impressive moral and energetic power. Even more remarkable is that this success was achieved in collaboration with the medical profession.

It was the concern of one of the pioneers of Europa Donna, Professor

Umberto Veronesi the director of the European School of Oncology (ESO), about the incidence of prostate cancer with associated mortality that inspired the Italian League against Cancer to launch Europa Uomo. At the launch in Rome in October 2002 Prime Minister Berlusconi delivered a clear message that justice is due to the 17,000 Italian men who are diagnosed with prostate cancer every year and whose needs have been neglected far too long.

Europa Uomo aimed to follow the example of Europa Donna and started a coalition of the many existing local support groups for men with prostate diseases while allowing each group to



This section reports recent communications regarding pharmaceutical products of relevance to men's health. Mention in this section does not imply endorsement of the product by ISMH or Elsevier.

maintain its own identity, aims and aspirations. Only 2 months after the launch at a symposium on Women's Cancer in Europe, supported by the ESO and the International Union against Cancer (UICC), Europa Uomo representatives had the opportunity to learn from the delegates of Europa Donna, Reach to Recovery and the European Cancer Leagues and consider the simple questions posed by Liisa Elovainio from Helsinki: Where are we? Do we need to do better? How can we do better?

A brainstorming meeting took place in May 2003 at the offices of the Belgian prostate cancer patients group, WIJ OOK (US TOO), in Antwerp. This

meeting was attended by delegates from 10 different European countries and representatives from the American US TOO group, PRONet (a global prostate cancer network) and the new European Cancer Patient Coalition (ECPC). The representatives are listed in Table 1. At a second meeting in October a steering group of ad hoc officers were confirmed and pledged to primarily focus on patient advocacy, the development of a Prostate Passport, a logbook on prostate diseases, and a Website on Europa Uomo in collaboration with Cancerworld (<http://www.cancerworld.org>). This meeting produced the Europa Uomo manifesto on prostate cancer (see Box 1).

The wish for collaboration from other groups became clear from invitations for Europa Uomo to attend a Masterclass of the ECPC in June in Milan. At this meeting new members from Spain and member candidates from Portugal and Poland were welcomed and a seven-member steering Group was installed to run Europa Uomo for the period 2004–2006. In addition a decision was taken to promote awareness and appropriate early detection in Europe during the period 2004–2005. A further invitation has been received to attend a patient seminar at the annual meeting of the European Society of Medical Oncology (ESMO) in Vienna in October 2005.

The hope of Europa Uomo is to achieve a successful programme of awareness, preventions and treatment to decrease mortality and improve the quality of life of men suffering from prostate cancer. The member groups look for collaboration and shared support and welcome all prostate support groups to join them.

#### Box 1 Manifesto of Europa Uomo

1. To find ways and means to promote quality of life for prostate cancer patients and their families;
2. To promote the dissemination and exchange of evidence-based as well as factual and up to date information on prostate cancer;
3. To promote prostate awareness and appropriate diagnosis and prognosis;
4. To emphasise the need for appropriate early detection;
5. To campaign for provision of and access to optimum treatment;
6. To ensure quality, supportive care throughout and after treatment;
7. To promote multi-professional quality care and appropriate medical infrastructure;
8. To acknowledge good clinical practice and promote its development;
9. To ensure that all men fully understand any proposed treatment options, including entry into clinical trials and their right to a second opinion;
10. To promote the advancement of prostate cancer research.

We as European patients have taken up Our responsibility for control of the disease by establishing the European Prostate Cancer Coalition, "Europa Uomo".

#### Reference

- [1] Boyle P, Autier P, Bartelink H. European Code Against Cancer and scientific justification: third version. *Annals of Oncology* 2003;14: 973–1005.

**Louis J. Denis and Jack Pais**  
Europa Uomo Secretariat  
Oncology Centre Antwerp  
Belgium  
email: louis.denis@skynet.be