Did You Know?
N°1 - 2015

Newsletter of the 23 European member Forums dedicated to improving knowledge of cancer of the prostate

Europa Uomo Board

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Editorial

Malcolm G. Duncan - *Newsletter Coordinator*

Enthusiasm for the Newsletter continues to abound and, for reasons of space, we have had to delay some articles for the June edition. The Excellent Nordic Survey merits special attention and will appear as a special Newsletter Supplement in April.

In his letter to our readers our Chairman, Ken Mastris, has rightly stressed the need for a strategic plan in order to give priority to our most important and ambitious mission which he summed up as “A world in which no man suffers or dies from prostate cancer”. Louis Denis was promptly appointed as Strategic Plan Consultant and in charge of this important initiative.
Tania Estape from Spain enlarged on the

psychological needs of PC patients and ways to combat depression and the important role of Support Groups in overcoming a feeling of social isolation and depression.

Claudio Verusio touched on the same problem and described the recent HuCare project whose intent was to humanize cancer care. The important role exercised by the mass media, in particular the TV, was clearly evidenced.

The PCa Europe 2014 Conference was reported by Brigitte Dourcy-Belle-Rose which spoke of the important role of Active Surveillance in low risk prostate cancer and the need to avoid overtreatment which can be both painful and amount to a needless expense. The important role of Multidisciplinary Centres was stressed in order to favour the quality of life of patients. This was duly supported by statistical evidence. Louis Denis affirmed that for many patients the quality of life was more important than pure survival. Lastly, the EU Health Policy Programme, called Horizon 2020, includes the implementation of important EU legislation, economies of scale, the promotion of best practices and networking results to all member States.

Ireland provided a short summary of the UIA (Union of International Associations) Roundtable Conference held in Dublin in November 2014, and stressed the need to encourage a greater exchange of news on reciprocal initiatives by international association networks in order to achieve increased membership benefits, thanks to international connections and engagements. We have in fact included a short article of Europa Uomo of the Czech Republic of a whole series of praiseworthy initiatives which it organized in the latter part of 2014. Possibly the most interesting activities regarded their attempts to sensitize GPs on the danger of contracting prostate cancer, and thus overcome a common shortcoming in many countries – a general unawareness both of GPs and male patients.

The regular Hippocratic Corner column touched on the common problem of the lack of a State solicited preventive check-up in most European countries, at times aided and abetted by physicians who sometimes even consider such preventive measures as dirty or aggressive, whereas, at times, they could prove most gratifying even from a sexual viewpoint.

At present we have no official screening program for prostate cancer as the physical examination as well as the PSA blood test failed to meet the balance of advantages vs. disadvantages in population screening studies based on a few randomized clinical trials. However since we know that the PSA test alone decreases the specific mortality of prostate cancer it is up to the individual informed patient to request the PSA test and a DRE as a tool to detect prostate cancer in the earliest curable stages of the diseases. The search for a practical screening test for prostate cancer remains an absolute priority.

We hope to have news from the European Clinical Trials Register, introduced in the previous number by Gunter Feick, in time for the June issue.

We have now introduced an article dedicated to news, congratulations and best wishes to colleagues and good friends.

Due to the interest shown for “Did You Know?, we have now added a new subscriptions form where we also invite you to eventually express your opinion on our Newsletter and how it might be further developed.

A letter from the Chairman

Ken Mastris

As stated it has been a steep learning curve for the Board since the General Assembly in London.

The Board held an strategic seminar in Lisbon last November where we discussed the future of Europa Uomo which recently celebrated its 10th anniversary. We had a facilitator present and the Board agreed on the following: Vision, Missions and Objectives for our association.

The core values for Board members were also agreed. See below.

Vision:
A future where no man suffers with or dies from prostate cancer

Missions:
- **To work for all prostate cancer patients in Europe, under one umbrella, for better treatment, care and quality of life.**

- **To support national organisations to deliver services effectively, efficiently and in line with national priorities.**

Objectives:
- Ensure patients and their families get access to the best possible treatment and care
- Ensure the sustainability of Europa Uomo
- Improve the capacity of member organisations to offer their services
- Increase the membership of Europa Uomo
- Improve the early detection of prostate cancer
- Raise awareness of prostate cancer

Core Values for Board Members:
- Contribute to the decision making processes
- Transparency
- Mutual respect
- Dedication
- Team spirit/cooperation
- Integrity

We agreed to appoint Louis Denis as strategic consultant for one year (a free service) to assist us in completing our business plan for 2015/16. Our most sincere thanks goes to Louis.
We are planning to hold a seminar/workshop in Warsaw on the occasion of our GA next June and to organise an EPAD event in September. This can only happen if we get the necessary funding for such events.

The Board recognises that they cannot do everything and will be seeking assistance from membership, which I consider as our Ambassadors. Full details will follow.

The Board has also agreed to be open and improve our communications with our members, sponsors and the outside world. Hence our Newsletter.

Our thanks go to our Editor in Chief, Malcolm Duncan, for his hard work to get the Newsletter off the ground. Please keep him timely informed of any interesting news items and events.

We recognise the hard work of our Secretariat to ensure that we move ahead in an orderly manner. Our thanks therefore goes to Anja and Brigitte for all their efforts on our behalf.

We will have to be prudent with our revenue and the Treasurer is actively engaged in assuring that all is well.

My thanks to the Secretary, Treasurer and all the Board members for their hard work and support.

It must be a team effort which includes our friends in all member associations in order to achieve our ambitious goals. Therefore please feel free to write to me with any comments or suggestions.

I therefore look forward to an open session at the next GA during which you may inform us of your efforts and successes and draw to our attention issues which you believe are of paramount importance if Europa Uomo is to achieve its mission.

I send you all my very best regards and look forward in meeting your representatives at the forthcoming GA in Warsaw.

Depression and Anxiety: two sides of the same coin; Depression (1)

Dr. Tania Estapé, psycho-oncologist, FEFOC/ Europa Uomo Spain

The most common psychological reactions to cancer are anxiety and depression. Both are, in this case, reactions to a threatening situation. Cancer continues to be a threat to the physical, psychic, social well-being and ultimately for the life of patients. Therefore we often speak of adjustment disorders, as they appear as a response to a stressful situation.

Depression is a mood disorder that has to do with being sad, in low spirits, not wanting to do anything, with negative ideas, sometimes to death related thoughts. That is why in cancer patients we often find evidence of depression. However sometimes there is an overlap of some symptoms: There are a number of specific aspects of cancer diagnosis and treatment that can be confused with those of depression. Among them we can note at physical level (also called somatic level) fatigue, tiredness, weakness, various unspecific pains ... and from the point of most psychological aspects, negative ideas, the difficulty to enjoy life and to make future plans, related thoughts with death or even willingness to die, as he feels uselessness or a burden to others ... If we look at all these

symptoms we can see how they are consistent with the experience of cancer but they also occur in people diagnosed with non cancer related depression. For example, a person may feel fatigued due to anticancer treatments, or because a state of apathy due to depression. That is why we must be careful when we decide that a cancer patient has depression. We should better use the cognitive items (of thought) and be cautious with the somatic ones.

Many studies demonstrate that cancer patients have higher levels of anxiety than depression. Measurement may be made around the diagnosis and/or treatment times and therefore there are moments of tension, fear, and even hostility and irritability that rate even higher in anxiety. However in a medium or long term an increase in the level of depression may be noted. Fatigue due to some therapies, weakness and feeling fed up with the role of being a patient can lead to this.

Another common thing in the studies that have been carried out in people with cancer is that women score higher levels of depression and anxiety than men. This is true also in the general population. Objective measurements show a higher degree in these affective disorders in women. However this data should be interpreted with caution because many men deny any appearance of weakness, sadness or low self-esteem. In oncology questionnaires assessing depression is very obvious and make it easy for people to respond by denying any emotions. In some cultures they are not well seen due to the prevailing male habits of denying any signs of frailty.

We find that prostate cancer is the only one where the general trend is reversed, and patients score higher in the measurement of depression than in anxiety. Prostate cancer and its treatment seem designed to undermine masculinity. This is due to several factors:

- Difficulty or inability to achieve or maintain an erection: sexuality is certainly an important issue in male self-esteem. The fact that it is affected makes a man feel bad and guilty in relation to his partner. Generally speaking the assessment of depression includes aspects of sexual desire. Obviously this item will be weighed by the real situation of most cancer patients and indirectly will add to the depression score.

- Urinary Incontinence: the difficulty of controlling urine temporarily or permanently is a consequence that severely damages the men's self-image and produces shame and avoidance of leisure activities, especially if they entail social relationships. The cut offs and less frequent or lack of relationships with others may also involve depression, and also make the assessed level even higher. It is a common item in the questionnaires or interview tools of depression to ask about social activities and relationships.

- Matching the time of retirement: prostate cancer is often diagnosed in people who are near retirement age. This fact in itself is already emotional in some men who had built up their identity based on their employment or professional performance. Usually the disappearance of that role in their lives entails dramatic changes sometimes even the feeling of worthlessness or a personal handicap. If you add to this the appearance of prostate cancer with the consequences that entails, as cited above, it is logical to think of a mild to moderate depression. This difficulty to adapt to live after retirement is in fact more often found in men.

- Related to the previous point, we often talk about the "empty nest" of women who are naturally greatly dedicated to children. When their offspring mature and, even without having left home, become more autonomous, this makes the mother feel a great void and a difficulty to redefine her role and identity. This is found sometimes in men who also feel less necessary when their children become in-dependent or no longer ask them for advice. Certainly the effect on self-esteem is great, and added to all this, it is easier for men to internalize the fact that they no longer work or are no longer of any use.

- When hormonal treatment is necessary men can experience a feminalization and this means a big drop in their self-image and, therefore, of their self-esteem.

- Social isolation: a feeling of loneliness and isolation is usually reported by cancer patients. They explain that the cancer experience separates them from people outside their usual environment and some feel that others could not handle one hundred percent their feelings or fears. In men

with prostate cancer there is often a feeling of inferiority and shame due to some functional difficulties, such as having to urinate more frequently and even wear diapers. This tends to exacerbate their isolation and may also increase depression.

As we can detect, self-esteem is a value that often arises when discussing depression and prostate cancer. Self-esteem is greatly impaired by depression. The person considers himself as a failure, a weight to society, someone who is useless or not needed. There is a great risk of this occurring in men with prostate cancer. Many of these factors make the men isolate themselves and become irritable and cranky, so that sometimes people around them have serious difficulties in their relations with them. In some cases relatives tend to limit contacts out of fear of angering them or because they do not know how to help or encourage communication with the patient relative, they stop trying to communicate, but this could be interpreted by the patient as a confirmation of his feeling of loneliness or so create an emotional vacuum.

Depression is a spiral which sometimes one does not take into due account. Therefore it is important to pay attention to signs that may occur in people affected by prostate cancer. The most frequent evidence of depression in these cases is normal responses to life situations, so it may be advisable to detect signals to help the patient. Support groups are a good tool to share experiences without embarrassment and achieve a very positive feeling of solidarity. Many cancer patients explain how good you can feel about the fact of not feeling alone and thus able to talk with others who are in the same situation as them, and some say they feel an invisible thread that unites them despite their previous extraneity. Some people however do not benefit from the group experience as their levels of depression are too high to get along with group sessions. In these cases the intervention of a trained professional is advisable. It is important that we do psycho-educational sessions to prevent men from suffering depression as a result of the diagnosis of prostate cancer, so that they do not feel they are going through something very rare or are weak or fragile. We must help them to know how to ask for help when needed. It is of great importance to accept that some kind of sadness or negative feelings when prostate cancer occurs is a normal feeling or reaction.

It is said that in depression the individual is at the same time both the prisoner and the jailer. It is important to let someone open the door of that prison when the patient is unable to do it himself.

The Humanization of Cancer Care

Malcolm Galloway Duncan

Interview with Dr Claudio Verusio, chairman of the Scientific Committee of Europa Uomo Italy.

head Oncology Physician at the Saronno Hospital in Lombardy, lecturer on oncology at the University of Insubia, psychotherapist member CIPA (Italian Centre of Analytical Psychology and IAPP (International Association of Analytical Psychology).

The main objective of the HuCare project was to improve the efficiency of cancer care encounters of patients with physicians and hospital staff by means of a carefully prepared questionnaire divided into 2 parts and composed of 49 specific questions. This was the work of an Australian medical group. This gives the patients time, after their initial encounter, to reflect before answering each and every question which were carefully worded so as to overcome patients' natural embarrassment and fear of posing ridiculous questions. The hospital staff appropriately qualified to cater for the needs of such patients were carefully trained by attendance at total immersion courses on the appropriate techniques for communication.

Source of information for patients on DBT*

	1st inquiry	*2nd inquiry*
Television/Radio	62%	70%
Mass media	26%	17%
Doctors	5%	5%
Others	7%	8%

*Di Bella Therapy *p<0.01*

Q. What were the principal goals of such a project?

A. Favour a more informal, personalised and relaxed relationship between the patients and the examining doctors and specialized nurses. That patients no longer risk being treated as numbers. Frequently medical staff under-estimate the informative needs of patients at times overlooking psychosocial needs. This shortcoming is often aggravated by the unwillingness of some patients to pose certain questions for a variety of motives. In fact the patients were assigned a personal nurse right from their first encounter and they had a key role in assuring the success of the patients' care and participation.

***Q.** Did the patients appreciate this initiative?*

A. Enormously, as the patients were also able to be accompanied by their wives and members of their families and any possible conflicts or misunderstandings which can occur on such occasions were totally overcome. They also greatly appreciated the assignment of a personal nurse which again helped them to overcome any embarrassment during the course of treatment. We are equally satisfied by the results of this project.

***Q.** What were the indispensable requisites by way of staff and technical means to be able to participate in this project?*

A. Apart from the requisites already mentioned, a PIS (Point of Information and Support) which included a well equipped library and computer which could be consulted by the patients with the help of the assigned specialized nurse and, lastly, pleasant and comfortable rooms in which the meetings took place.

A typical friendly reception room

***Q.** I believe that 11 of the Centres which were initially approached expressed scepticism on the likelihood of the success of a project which had been devised in an Anglo-Saxon social-cultural context, also as no formal QPL (Questions Patient List) at present exists in Italy?*

A. That is true but it was mainly a cultural problem in some of the hospitals which were visited by our team.

***Q.** However only 28 of the 42 Centres who agreed to co-operate in this interesting project actually did and 27 successfully terminated the project in which 299 patients co-operated. Why was that?*

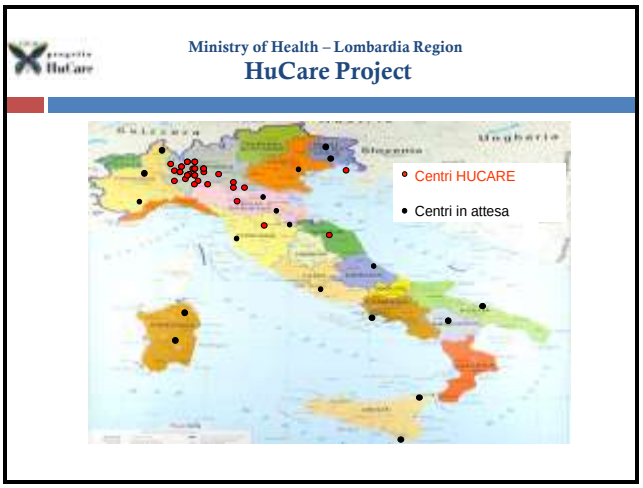
A. It was mainly a case of a lack of the necessary resources and specially trained medical staff. The actual cost for each participating centre ranged from Euro 10,000 to 20,000.

***Q.** How was the HuCare project financed?*

A. It was mainly financed by the Italian Ministry of Health which donated us with Euro 500,000. The region of Lombardy also co-operated but mainly by its psychological support and the issue of a certificate of quality.

***Q.** How was the project organised?*

A. The project involved medical staff of all specialities, including 467 specially trained nurses and 196 oncologists, and the work was carefully co-ordinated by a 14 member Task Force.



***Q.** What important lesson was learnt by this project?*

A. That the simple will to do a project of this nature is not sufficient to assure its success.

***Q.** Lastly, what has been the outcome of this important project and what are the main objectives of this praiseworthy initiative?*

A. An ad hoc school in which to train such specialized personnel is in the process of being set up in which HuCare can count on the help and advice of AIOM (the Association of Italian Oncological Medicine). Our future aims are principally: improve the psychological well-being of patients, develop a nation-wide service of this nature and establish national organizational guidelines.

May I wish you the very best of luck and success.

Best Wishes & Congratulations

Hannu Tavio

Hannu Tavio, former executive director of the Finnish Prostate Cancer Association (Finnish Propo), has been awarded the Cancer Society of Finland's silver medal for cancer control for his trailblazing work on awareness raising among Finnish men of coping with prostate cancer.

Hannu Tavio & Päivi Kärkkäinen
(General Manager Finnish Opera)

Some 4,700 cases of prostate cancer are diagnosed each year in Finland, and the disease accounts for the highest number of cancers in men. Over the last 10 years or so the way people – men in particular – view the disease has altered dramatically, replacing fear and silence with practical, informed and generally more positive attitudes.

Much of this change is due to the contribution Hannu Tavio has made to work on cancer control and how we approach and cope with the disease. Tavio was himself diagnosed with prostate cancer in the late 1990s, an experience that fired his determination to make prostate cancer better understood and discussed more openly.

Through his activism, editorship of Propo magazine, and countless other writings, Tavio has helped change the way prostate cancer is viewed, and given hope and encouragement to great numbers of men in Finland. He has helped break down the taboo of openly discussing the struggle of living with prostate cancer, once a much harder thing for men to do openly.
Tavio's ground-breaking books, "*Prostate cancer – uninvited companion*" (2005) , and "*Life carries*" (2010), the latter written with oncologist Timo Joensuu, have reached, and continues to reach, wide audiences. Much of their appeal lies in Tavio's ability to relate his own experiences of prostate cancer in ways that others with the disease can easily identify with, and to make complicated information easily accessible. His work in Finnish Propo has put the organization on the map of cancer control work both in Finland and abroad through the work of the European Prostate Cancer Coalition.

The Cancer Society of Finland's gold, silver and bronze medals for cancer control have been awarded since 1956 in recognition of their recipients' outstanding contribution in the areas of tackling and managing cancer.

Josef Blazek

We wish Prof. Josef Blazek, member of Europa Uomo Slovakia and an active member of Did You Know's editorial staff, every success in his new endeavour. Prof. Blazek has recently been appointed as Vice-Rector for Science and Research at the University of Security Management in Kosice, Slovakia. His main mission is to develop science and international projects for H2020, EDA and NATO: It is a PhD study.

Prof. P.A. Abrahamsson & Prof. C. Chapple

Our very best wishes go to Prof. Per-Anders Abrahamsson who will shortly step down after a very successful mandate as Secretary General of EAU (European Association of Urologists). A post he has held for eight long years and which began in 2007. Prof. Abrahamsson, MD, PhD, is Chairman and Professor in Urology at Skane University Hospital, Malmo (Sweden). Prof. Abrahamsson is also currently Adjunct Professor in Urology at the University of Rochester Medical Center, New York, USA. He has received numerous awards, published over 300 peer-reviewed articles and over 80 book chapters in the field of Urology.

We wish Prof. Christopher Chapple, his successor as Secretary General of EAU, every success. Prof. Chapple is currently a consultant urological surgeon at Sheffield Teaching Hospitals and professor at Sheffield Hallam University. He is past director of the European School of Urology and previously Adjunct Secretary General of EAU. He is also an active member of many international urological associations and societies.

Union of International Associations (UIA) Round Table, Europe – Dublin, November 2014

Frank Brennan & John Dowling, MAC Ireland

The UIA was founded in 1907 and seeks to promote and facilitate the work of international associations. The meetings of the UIA Associations Round Table – Europe have been developed since 2007 to provide associations with "an opportunity to learn through networking and through practice".

Europa Uomo was represented at the Round Table in Dublin last November by the current and past Chairmen of MAC (Men Against Cancer), Frank Brennan and John Dowling.

Because there is no common thread among those represented at such gatherings, other than their membership of an international associations, the organisers have an undoubted difficulty in finding topics and speakers who will engage a broad cross-section of the attendance in any meaningful way. Almost by default the emphasis of the programme is on networking and although the plenary sessions comprised an afternoon and a morning there was more time spent by the delegates in what is sometimes disparagingly called the "junket" functions of receptions and visits to the host city attractions and gala dinners and lunches. These allow the visitors to meet one another and to seek out those who may have common problems in the organisation and management of their organisations.

The first plenary session was held by Cyril Ritchie, Vice-President of UIA who posed three questions: (1) *What do international organisations contribute to society? (2) What stops them from contributing? And (3) What will they contribute in future?* He reviewed a range of developments in international organisations and of his experience of working with various United Nations bodies and the obstacles encountered and their prospects for overcoming them. He suggested that the delegates present engage with each other in discussion, explaining to others at their table the strengths and weakness of their own organisation and what stops them from achieving more and the delegates were to ask themselves where they saw their organisation in 5 or 20 years. Delegates then used Post-It notes on boards provided. The discussions at the various round tables led to a profusion of responses to be posted and the conference organisers tried to extract from this some common themes which were to inform the following mornings round tables.

The first afternoon closed with an address by Reggie Henry of ASAE – The Centre for Association Leadership on "*Building membership value through connections and engagement*". He pointed to research that suggested

- Involved members don't drop out
- Meaningful connections and experiences for your members will keep them coming back
- It costs five to six times more to recruit a new member than it does to keep an existing one

In answer to the question as to what he meant by engagement he suggested that it was investing time and/or money with the association in exchange for value.

He also postulated that new technology was bringing about a staggering amount of fundamental change to our basic understanding of what this new technology means, how it happens, and who and what drives innovation. He said that he had seen more significant technology change in the last 5 years, than in the previous 20 years. It argued that it demands a shift, a significant one, in how we think about technology today. Examples – mobile, social networking, location awareness, cloud computing, etc.

Mr. Henry also cautioned delegates that "Value" meant different things to different people, as he put it "they don't all want the same apples, in fact some don't want any apples". He quoted one writer on the subject of Membership Value that "*the number one reason individuals or companies join an association is because they believe the association will help them solve a problem".* He went on to suggest that the members of an organisation decide what has value and that value is validated by a member's willingness to exchange money or time for something and most

importantly "Value" is different for different members.

Mr. Henry outlined four challenges to engagement in member organisations:

- Members having time to participate
- Getting to know members at a deeper level
- Getting their Attention: Communicating in an appropriate way - **on their terms**
- Keeping members' interest through continuous engagement

He suggested that organisations should figure out ways in which to connect members to all of the organisation's resources in a way which creates value for them. How to do that? He argued that firstly there must be a common language that can be used for classifying the organisations resources, and to describe its members needs and interests. This amounted to a taxonomy which should be kept as simple as possible. This taxonomy should be used to connect members to content. At this point the presentation took on a more didactic tone.

"1. You must have a taxonomy! It is the common language that's used to categorize your resources and by which your members indicate their interests/needs. **The taxonomy must be present in every digital system you have. Period!**

"2. In future most organizations will have multiple websites or other types of content repositories. Most likely they will have multiple content management systems. You've got to find a way to mitigate content silos!"

"3. It's not about searching and finding any more, it's more about knowing and delivering. Increasingly, member access to value is digital and mobile, technology has a huge role to play. **Digitize everything** and think **mobile first!**

The final plenary session the following morning had a number of brief presentations by Christopher Raundonat, Director of the European Society of Association Executives on (re)defining an association to meet changing needs, Gert Willems of the Board of European Students of Technology spoke on the issues relating to running an organisation with a high turnover of board members and membership in general. Prof. Dr. Jonathan O'B Hourihane is the Irish representative of the European Academy of Allergy and Clinical Immunology, and he spoke on the topic of hosting an international meeting.

These presentations were followed by a number of round table discussions on various topic raised by the morning speakers and also issues flagged by discussions the previous day. The two groups covered by Europa Uomo delegates related to governance issues and the use of technology. While the exchange of views and experiences were interesting it was not always readily apparent as to how the discussion could be integrated into individual member organisations.

The closing address was given by Dr. Dragana Avramov, expert for the European Commission, Council of Europe and United Nations. He dealt with the topic of: *Achieving Impact and Finding the Funds.* He said that as science and technology are seen as driving forces of modern society and shape many aspects of public and personal lives, they often do so in a complex and unpredictable way. He outlined the shift in policy making from predominantly ideological premises of societal value of research questions toward a more knowledge-based approach to research questions which address important societal issues and take on board end user needs. He stressed the importance of non-academic and non-formalised knowledge that comes from relevant societal actors. Unfortunately, as often happens at the end of a conference the last speaker, no matter how interesting the topic has to endure a shrinking audience as some delegates leave early to catch their planes or in the case of your correspondent , deal with an urgent family phone call. Dr. Avramov's presentation is available in PowerPoint slides on the UIA website: http://www.uia.org/roundtable/europe-2014 and is worth perusal.

Many of the delegates clearly enjoyed their few days in Ireland and the hospitality provided by the Irish tourist authorities. No doubt some networking bears fruit and useful points can be gleaned from the presentations, but it is difficult for the organizers to meet the needs of such a diffuse gathering and thus ensure that value is delivered.

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Compliments to our colleagues in the Czech Republic for their very active programme in the latter part of 2014

Dalibor Pacik

- ***Counselling on-line office*** *where e*very patient can easily ask questions concerning prostate disease and get answers from professional urologists within 48 hours: http://www.europauomo.cz/
- ***Website EUomo CZ****: where are* displayed a network of medical Centers of Excellence treating prostate cancer
- ***Web Cast****:* three lectures focused on the importance of an early diagnosis of these malignant diseases (prostate, testicle and kidney cancers). See http://www.preventio.cz/webcast/. Created by the Czech Medical Chamber.
- ***Leaflet with a practical update on the use of PSA:*** displayed on EUomo CZ's website and distributed among GPs throughout the Czech Republic.

- ***Brochure benign prostatic hyperplasia for patients:*** also displayed on the EUomo CZ website and distributed to the waiting rooms of GPs.

- ***Press conference recommending an early diagnosis of malignant diseases. Participation in a TV talk show****:* on the occasion of 70th birthday anniversary of a famous Czech artist, a EUomo member, successfully cured of prostate cancer. An initiative organized by EUomo CZ.
- ***Preventio*** - partnership in this project http://www.preventio.cz/.
- The co-organization with MOVEMBER 2014 of a three day Brno "counselling office" in a caravan parked in front of the biggest shopping mall in Brno with urologists on duty there to give advice and service for moustache trimming.

A Plea:

Our Newsletter editor invites other national associations of Europa Uomo to give news of their activities, so that we can share our experiences and learn from one another.
Perhaps the most innovative activity of our Czech colleagues regards their effort to sensitize GPs on the danger of getting prostate cancer and so overcome one of the principal problems – general unawareness.

PCa Europe 2014 Conference

Brigitte Dourcy-Belle-Rose, Secretary US TOO Belgium

The International Centre for Parliamentary Studies organised on October 28-29, 2014 a specific symposium with this compact title. The organization happened in cooperation with the European Association of Urology (EAU) and Europa Uomo (EUomo).

Prof. P.A. Abrahamsson, secretary general of EAU, chaired the first day focused primarily on the professional management of prostate cancer.
As the slides are available on the website: http://www.pca.parlicentre.org/presentations.php (password ProCert) we only present the priority messages of the different speakers.
He presented the Five Golden Rules for transforming PSA screening:

1. Get consent
2. Don't screen men who won't benefit
3. Don't biopsy without a compelling reason

4. Don't treat low risk disease
5. If you have to treat, do so at a high volume center

Prof. M. Emberton presented the aspects of accuracy of our current techniques to identify low risk and high risk prostate cancer. He emphasized the modern concept that Gleason pattern 3 is a benign disease and that Gleason score 3+3=6 does not need treatment. These patients could be under surveillance as in active surveillance or watchful waiting.
Figures talk:
- Out of 14,123 radical prostatectomies Gleason 6, 22 cases had + nodes.
- After 15 years of follow-up on Gleason 6, prostate cancer only 3 of 9,957 patients died of the disease.
Future clinical research is focused on multiparametric magnetic resonance imaging (MRI), innovative ultrasound as histoscan and biological markers.
We leave the static histo-pathology to dynamic expressions of high risk disease.

Dr. S. Chowbury focused on the other side of the spectrum of the evolution of high risk disease into metastatic castration resistant prostate cancer (mCRPC).
We entered the era where we can offer treatment for these patients. The choices include new chemotherapy, new hormones (androgen receptor targeted agents), bone targeted therapies, radioisotopes as Radium-233 and immunotherapy. The future challenges include the sequence of treatments and integration of new technologies with decreasing health budgets.

Prof. C. Bangma presented an update on active surveillance (AS). This is really an active observation for patients diagnosed with low risk prostate cancer. Its principle is to watch the untreated natural history of these cancers without treatment for signs of progression. At that time based primarily on a PSA rise or doubling (many times prematurely) or on an increase of the Gleason score (remember 3+3 or maximally 3+4) in a control biopsy.
The 15 year results confirm the expectations. The longest surveillance are shown by Prof. Klotz (Toronto, Canada) in a prospective cohort study started in 1995. A total of 993 men were assessed and only 15 men died of prostate cancer with an additional 13 men alive with metastatic diseases. The risk of dying from another disease was 10x greater. The PSA failure rate during follow-up was 28% at 5 years and 10.2% at 10 years after diagnosis. These outcomes match the outcomes of patients managed with initial definitive treatment such as surgery and radiotherapy.
Prof. Bangma continued with the update on the largest global action plan on AS for low risk prostate cancer. This Global Action Plan (GAP), supported by the Movember Foundation and launched in 2011, is primarily based on the PRIAS study (Prostate Cancer Research International Active Surveillance) with 3,500 registered patients in 17 countries. At this moment AS is "a treatment approach in evolution" as an alternative to radical treatments with curative intent for men with low risk prostate cancer.
The first phase of the GAP includes the start of a central database coordinated in the Erasmus University Medical Centre in Rotterdam. In the second phase starting this year, guidelines for the selection and follow-up of candidates for AS will be determined.

The second day of the program, chaired by Prof. L. Denis, focused on patient-centered problems as multidisciplinary approach (MDT), advances in personalized management, treating senor adults and quality of life.

Prof. D. Jacqmin and Prof. M. Aapro presented the multidisciplinary approach to prostate cancer based on a presentation by the late Prof. John Fitzpatrick of Dublin. They had no problem to convince the audience that multidisciplinary treatment of any cancer improves outcomes though randomized, clinical trials are lacking. One instance where evidence-based medicine bows for the rapid acceptance of the principle of team treatment. MDT adheres to established guidelines in + 70% of cases and exceptions are age, co-morbidities and performance status of patients. MDT is crucial in PCa patients because of the multiple treatment options for the different forms of this heterogeneous cancer. MDT in practice following different steps including patients' preferences improve outcomes including quality of life (QoL) and cost/efficacy of treatment. Communication and cooperation remain the corner stones in health care.
This presentation was a first class introduction to the treatment in senor adults presented by Prof. N.

Mottet and Prof. M. Aapro. They presented the need for specific guidelines for this patient cohort defined by the EAU and SIOG (International Society of Geriatric Oncology). In practice individualized treatment is based on risk (specific) evaluation, co-morbidities (non specific) and patients priorities and decisions. They included watchful waiting (life expectancy < 10 years) and AS (low risk disease) in their treatment scheme. However curative local treatment is effective and feasible as in younger patients.
Prof. Mottet presented an updated overview of all local and advanced PCa stages. All treatments aim to optimize efficiency and lower the side-effects with new hormonal, immune and chemotherapy in a clinical research phase for optimal treatment. As an example in high technology research, Dr. N. Tselis presented a detailed overview of high dose brachytherapy as monotherapy in PCa.

The afternoon closed with a presentation by Prof. L. Denis on holistic personalised management to improve quality of life.
He emphasized the two sides of the coin in dividing management into optimal individual medical treatment (multidisciplinary, evidence-based) and holistic, personalized patient-centered care (multiprofessional, quality of life and cost/efficacy). Continuing on quality of life it is noted that a majority of patients prefer quality of life over pure survival. It is clear that survivorship, life after treatment, is a modern day priority where treatment and care complement each other in overall management and policies. The quote of Sir William Osler (1892) is still valid: "*If it were not for the great variability between individuals, medicine might as well be a science, not an art*".

The day was concluded by Ms. Ladiges, Policy Officer DG Sanco (Programme Management and Diseases) of the European Commission. She presented the European Added Value of the Horizon 2020 health program.
Cancer was already included in EU health policy programs as of 1985. After three successive programs of Europe against Cancer the EPAD (partnership for action against cancer) report was published in 2014.
The Horizon 2020 program includes: implementation of EU legislation, economics of scale, best practice promotion, benchmarking for decision-making, cross border policies, free movement of persons and networking for disseminating results to all member states.
The extended European Code against Cancer was launched in 2014 as a landmark platform in implementing basic information and education on the prevention of cancer mortality and morbidity. Guidelines on screening were accepted for breast, cervical and colorectal cancer. Further progress is expected from CanCon (Guidelines on Quality Improvement in Comprehensive Cancer Control) in cooperation with a Commission Expert Group on Cancer Control. Europa Uomo is represented in both committees. We move forward but it is a long way to Tipperary.

Ken Mastris ended the symposium by thanking the International Centre for Parliamentary Studies (ICPS) for the invitation of the different organizations, speakers and staff for the congenial, high quality organization. He hoped to see a 2015 update on prostate cancer management in view of the rapid changes in control and care of this cancer that we turned into a chronic disease with ever decreasing mortality and increasing quality of life.

Obituary

It is with deepest regret that we have to inform you that **Juraj Tölgyessy**, a founder member of Europa Uomo Slovakia, passed away on 25th December 2014.
We will miss his detachment, the proverbial diligence, vitality, versatility, foresight and experience, and we will remember him with love. He will be remembered for his great masterpiece and his fight for nuclear energy, nuclear chemistry and nuclear radiation as well as for his brilliant universities career. He was awarded the title "Doctor Honoris Causa" by The University of Matej Bel on 20th April 2011. He will forever remain in our hearts. Honour to his memory!

The hippocratic corner

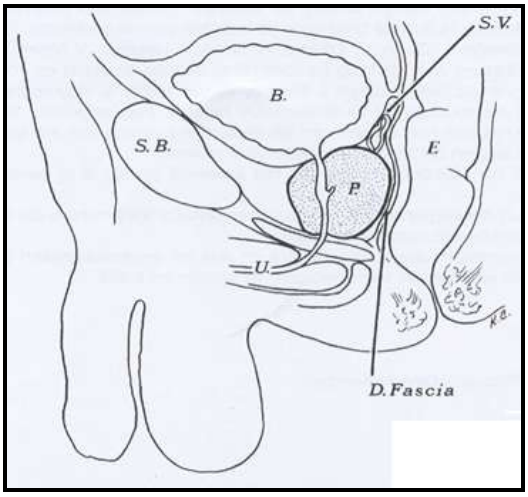
"All about the digital, rectal examination (DRE)"

Louis Denis, Strategic Consultant EUomo

This simple physical examination of the prostate is frequently omitted during the annual preventive check-up of men above 40 years of age. A shame.
The causes of this omission are among others the

negative reactions of the patients who consider this examination painful and humiliating but also the attitude of the physicians who like to avoid these reactions or worse consider this examination as dirty or aggressive.
The latter opinion goes straight against the opinion of sex therapists who see the anus as an enjoyable physical opening in the human body. Some recommend introducing a finger in the anus during copulation to enhance the pleasure of the act. Scientifically they have a point as we know a reflex called the bulbo-cavernosus reflex where penetration of the anus increases the tension in the glans of the penis. The reverse is also true.
The sensation of humiliation is also acceptable when we consider rape in all its forms (the same concept applies in women to unwanted vaginal penetration) which is interpreted as a sign of complete submission. A phenomenon that is well described in prison examinations, power abuse between inmates and massive rape reports in war conditions.
Furthermore the examination can be really painful. This is certainly avoidable as the pain is usually a combination of an inexperienced examiner and a tense patient.
What is the deal? Digital (Latin for finger) examination of the prostate consists of the introduction of a gloved, lubricated finger through the anus muscle in the rectum (the end part of the bowel) to feel the dorsal part of the prostate. In French simply “toucher rectal”, the rectal touch, in Latin “palpatio per anum” PPA palpation via the anus.
The anal muscle is a strong, circular muscle standing in a 90 degree angle to the rectum (to prevent leakage of gas and faecal material). Before the penetration one puts a soft pressure on the muscle for its relaxation and only then you can insert your index finger without pain. By moving the finger upward for 3 to 4 centimetres one can feel the prostate in front and try to reach the upper rim of the prostate. This is easy in a normal prostate (20 to 25 cc) but can be difficult in a big benign growth, the famous benign prostatic hyperplasia (BPH). This physical diagnosis can be confirmed by the disappearance of the middle groove dividing the two symmetric lobes of the hyperplasia. At the same time the finger exerts some pressure on the tissue to feel its rubbery, elastic consistency. The prostate cancer can be compared to a chestnut. Its consistency feels in BPH like to muscle part of the thumb while cancer feels like its hard articulation.
This pressure may provoke a stimulus to urinate which subsides after the examination. Still it is wise to invite the patient to empty his bladder before he goes out of the office.
On the scheme (figure 1) it is clear that the back side of the prostate can be checked easily on surface (volume) and possible abnormalities.

Figure 1: Location of the prostate in the pelvis



P Prostate **B** Bladder
E Rectum **U** Urethra
SB Pubis
D Fascia (Denonvilliers’ fascia; separates the prostate from the rectum)
Z Seminal vesicles (run through the prostate in the urethra)

The seminal vesicles cannot be felt during the DRE. The DRE gives an idea of the volume but we know that small prostates are overestimated while big prostates are underestimated.
In a complete urological examination one relies on the transrectal ultrasound methodology (TRUS) to estimate the volume of the prostate.
One records abnormalities starting with the anus. Piles are regular, stenosis and fissures are painful. In the palpation we can find indurations from sites of infections or cancer, small stones and as mentioned the disappearance of the median groove. A stone hard induration is usually associated with advanced cancer of the prostate.

A few anecdotes:
About 20 years ago. On the front page of a Sydney newspaper a brigade/general expressed his wrath at an unnatural examination in prostate cancer screening.

Our first pilot program (a small city + 100 km from Antwerp) in the mega European study on prostate cancer screening (ERSPC) in 1991 asked the participants on unpleasant events in their examination. They answered that they found the DRE more unpleasant than the TRUS examination where a 2 centimetre diameter instrument was introduced in the rectum. This surprising answer was emphasized by the fact that half of the general practitioners refused to make the DRE which was part of the protocol. A relaxed examination by an experienced physician or nurse will convince any patient that DRE is a natural painless examination if performed in the right conditions.

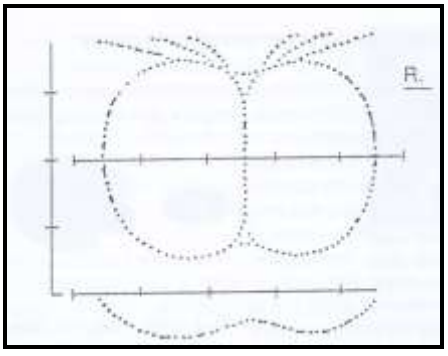
The position of the Patient

In the different positions we have the patient standing up, lying on his back on the examining or cystoscopy table, the knee-elbow position or the left lateral position on the table.

In combination with other examinations, f.i. a cystoscopy, we have the patient on his back with his legs in the stirrups. For a protocological examination the knee-elbow is the preferred position. In both circumstances it is easier to evaluate a difficult DRE and one can execute a bimanual exam by giving counter pressure with the free hand.

In 1976 we surprised our Japanese pioneer colleagues in the TRUS procedure with the patient in the left lateral positions with his knees pulled up and bent in a crouch. With the left hand one can lift the left bottom mass which allows an easy visual inspection of the anus. With this visibility it is easy to put the right index finger correctly in place to massage the circular muscle and smoothly introduce the finger in the rectum. The conclusions of the exam are best reproduced on a scheme (figure 2).

Figure 2: Height and width in cm. The middle groove (bottom line) is the third dimension. Indurations can be marked by stripes.



A winner:

In a normal consultation never remove your trousers and shoes. To put them back on takes more time than the consultation and provides long lines in the waiting room.

Measuring the prostatic volume by DRE

BPH starts normally after the fourth decade of life, your magic 50, and increases with advancing age. ne may state that by the age of 80 all men have an enlarged prostate unless they were castrated in their youth.

The question is if it is important to measure the size of the prostate? BPH becomes an affection only if this condition causes symptoms or undue pressure on the bladder or the upper urinary tract. The latter primarily on huge prostates. A condition that is almost never seen in our modern social health system.

Did you know?

There is no evidence that the size of the prostate is directly related to symptoms and/or undue pressure on the higher urinary tract.

This is straight logic as symptoms are dependent on the pressure exerted on the urethra. The volume correlates with the weight of the prostate with a specific weight of 1.05 gr/cc. On a subjective base one finds deviations in intra-observer variations depending on the experience of the examiner. Some relativity which should be borne in mind. The prostate is not made of plastic and the volume is variable according to temporary swelling caused by infection, alcoholic abuse or constipation. The blood and lymph vessels in the pelvis are shared by prostate and rectum.

The volume together with a PSA result allows the determination of the PSA density, a factor in the nomogram of a possible diagnosis of cancer. Volumes higher than 60 to 100 grams of prostate where treatment is indicated are usually removed by open surgery via the abdomen rather than by a transurethral resection (TURP) via the natural ways.

The diagnosis of prostate cancer by DRE

Before the PSA era DRE was the gold standard for the diagnosis of prostate cancer. A nodule felt in the prostate was an indication to have a biopsy to confirm the suspicion of cancer.

The famous Jewitt's nodule as an early diagnosis or just diagnosis of cancer is rare. At the end of his

long and outstanding career in the Johns Hopkins hospital in Baltimore, he had collected 102 cases over his lifetime experience. As a side observation he confirmed that he never cured one of these cases when a high Gleason score was present.
The role of DRE as a screening tool in prostate cancer population screening has been studies and found to be inadequate to serve as a tool to determine the risk of cancer.
For sure:
A hard induration of the prostate, extensive for several square centimetre, is virtually always a late and incurable stage of the local disease. Limited or softer indurations are rare but can be found in chronic prostatitis, prostate stones and tuberculosis.
Only a biopsy can confirm the diagnosis of prostate cancer

The famous Bowery series of Perry Hudson, published in 1994, brought to light that most early cancers of the prostate did not reveal a stony hard induration on the DRE. A total of 300 men, selected from the Men's Shelter operated by the NY City Department of Welfare, agreed to have a complete physical and lab examination on a voluntary basis followed by an open perineal biopsy (1 cm tissue over the width of the prostate) without any symptoms or signs of prostatic disease.
All had a DRE performed during a cystoscopy by pushing the prostate against the shaft of the cystoscopy. The open biopsy was sent for frozen sections. On a cancer diagnosis radical prostatectomy was immediately performed. In case of doubt, a "secondary" radical prostatectomy was performed. The results of the DRE are presented in table 1.

Table 1: Correlation of induration with age and extent of tumor, thirty nine patients

No. cases in groups	Degree of induration		
	0	1-2	3
Group I	4	18	4
Group II		7	4
Group III		1	1
Average age, yr.	51.5 year	58.1 year	67.2 year
Percentage of Ca.	10.3 %	66.6 %	23.1 %

Hudson, 1954

The suspected diagnosis of prostate cancer by a team of expert urologists showed a balance between false negative and false positive pathological diagnosis.
Remember that most of the patients were asymptomatic.
Only 23 percent of cancer patients were found to have an induration suggestive for a cancer diagnosis (*Cancer* 1954; 7: 690-703).
These negative results on the value of DRE in the early detection of prostate cancer were confirmed by the results of the Rotterdam center in the ERSPC study. An initial suspicious DRE had no impact on funding cancer at the first six core biopsy nor on clinical cancer in the later screening rounds. The publication analysed the biopsy results of 2,218 men with a benign diagnosis in the first screening round. No difference was detected in high risk cancers with a normal or abnormal DRE.
The positive predictive value of the initial DRE was 48.6 percent to decrease to 21.2 percent in the later screening rounds.
The cherry on the pie is the experience of the German annual preventive examinations on men over 45 years of age refunded by the social insurance. The aim was simple. An early diagnosis may offer the possibility of earlier treatment in the clinical history of the disease lowering mortality and morbidity as a result. The target population, 9 million men, was already a logistic problem despite the fact that prostate cancer was only detected in one percent of the participating men. About 4.305 cancers were registered in the German Prostate Cancer Registry. A total of 1.5 million men were screened in 1978. An isolated induration was found with DRE in 0.98 percent (14,976 cases) and a total induration in 0.41 percent (6,322 cases). These results showed an increase in incidence of prostate cancer without any evidence that prostate cancer was found in early curable stages. With only a 20 percent participation of the male population it was decided to stop population screening with DRE.

Does DRE plays any role in the early detection of prostate cancer
It is clear that DRE alone may suggest further examinations other than a diagnosis but that population screening based on DRE is not advocated.
The reported studies before and after the PSA era show that this exam is only of value to the individual patient. Together with PSA a slight

increase in early detection especially in the low cut-off values of PSA. You will find a few more cancers as shown in the Bowery series but face a lot more negative biopsies. This was again emphasized in the famous Prostate Cancer Trial (PCPT) where all patients were biopsied. In absolute figures 30 more cancers but 58 needless biopsies on a total of 9,423 controlled patients.

General conclusions

DRE is not recommended in asymptomatic men as a routine test to detect prostate cancer in a population screening.

In individual patients who want to be tested it is important to perform a DRE before the biopsy.

After half a century of prostate cancer screening we are back to square one. The search for a practical clinical test to detect curable prostate cancer remains an absolute priority.

Without gloating we have to remember that the PSA test is more effective than a mammography in breast cancer. But unfortunately one cannot compare apples with pears.

Sponsoring Organisations

We sincerely thank the following institutions and associations for their indispensable support in our aim and mission which is: **"A future where no man suffers with or dies from prostate cancer"**.

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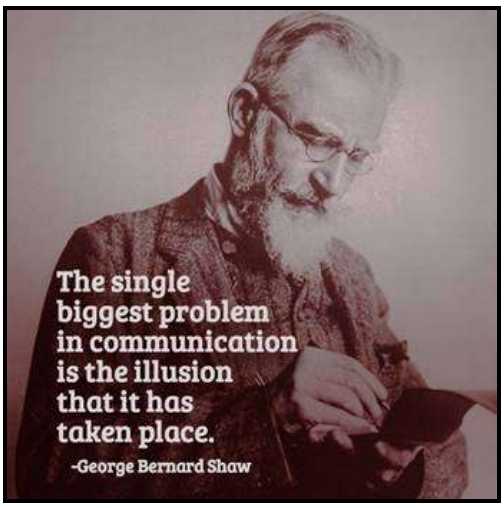

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