



The board met during the occasion of the 30<sup>th</sup> annual meeting of the European Association of Urology, March 20-24, 2015, Madrid – Spain.

From left to right: G. Feick (ex-officio), Tor Tausvik (Vice-Chairman), Ken Mastris (Chairman), Max Lippuner (Secretary), Malcolm Duncan (Newsletter Editor), Christian Arnold (Treasurer), Ekke Büchler (Vice Chairman) and Anja Vancauwenbergh (Secretary to the Board).

## Contents

- p.1 *Editorial*
- p.2 *A letter from the Chairman*
- p.3 *Depression and Anxiety: two sides of the same coin; Anxiety (2)*
- p.5 *Common Shortcomings in Prostate Cancer Care*
- p.7 *After Twenty Years is there a Future?  
Clinical Trials Registration & Reporting  
The Austrian Charter demands to the Austrian Health Care relative to Prostate Cancer*
- p.8 *Every Moment Matters, an advanced prostate cancer disease awareness programme, and Every Voice Matters survey results*
- p.10 *Cancer Care and Support Services in Ireland  
Prostate Cancer and your Sex Life*
- p.11 *East Surrey Hospital apology over care of cancer patients  
PCa sufferer: "It's either buy the drugs, or die"*
- p.14 *The Hippocratic corner: "On Prostates and Hormones"*

## Editorial

*By Malcolm Galloway Duncan*

In an earlier edition we compared the services and treatments available respectively to the male and female population in Europe, and immediately discerned an enormous discrepancy. Such shortcomings are re-echoed in this edition in the article dedicated to common European defects in the treatment of men suffering from prostate cancer. Such shortcomings are well illustrated in the accompanying table coloured in green as a sign of hope that they will shortly be much reduced. However this discrepancy is mainly the fault of the male population and not of their lifelong partners. Women become very knowledgeable about their bodies at a fairly early age and also appear more willing to cope with evidence of health problems

than their male partners.

In his customary letter to readers, our chairman, Ken Mastris, updates us on recent and forthcoming initiatives of the Board and, in particular, the Strategic Plan due for early adoption.

Prof. Louis Denis's articles are mainly concentrated on trying to improve men's knowledge of their bodies and common diseases in the cancer area. This time he speaks of castration, a solution which goes back as far as prehistoric times and was first practised on animals. As usual there is a light recourse to humour and the article ends with three recommendations before opting in favour of this solution.

Dr. Tania Estapé, who previously wrote on the problem of depression, has dedicated a new article to anxiety which is one of the most common psychological reactions in patients with cancer. As opposed to depression, it tends to be higher in younger patients and may be reflected in insomnia, intense nervousness and repetitive thoughts.

Men are often reluctant to see a physician or urologist and, unfortunately, therefore reduce the chances of an early detection and possible cure. At present an invitation to detect the presence of prostate cancer before it manifests its presence is only available in four European countries. That is in spite of the steady growth of prostate cancer in Europe. May I quote Italy as an example? While 42,600 new cases were estimated in 2012, the estimated number reached 43,390 in the current year.

It is hoped that the situation will greatly improve when the law on the Clinical Trials Registration and Reporting, approved in 2014, comes into force in 2016, as, from then on, all new drugs and trials will have to be immediately reported to a European database of public domain.

During EAU's annual congress, this year held in Madrid in the month of March, a press conference was organised at which our chairman, Ken Mastris, took part, entitled "Every Moment Matters", in which the results of a survey dedicated to advance stage patients were communicated. The survey was sponsored by Astellas and organised on their behalf by RedDoor Unlimited which produced and disseminated via Internet a questionnaire named "Every Voice Matters" which was answered by 688 men from various European States.

While most respondent patients felt that communications with their doctors were praiseworthy, 38% of the respondents complained that treatment decisions were still taken by their doctors and that they had no say in the choice of the treatment. One of the panel speakers, Dr Heather Payne, on the contrary emphasized that individualized care was of paramount importance.

A rather disturbing article arrived from Ireland and faces the financial rebus which has already been experienced by almost a third of our national member associations.

MAC's (Men Against Cancer) dilemma stemmed from a change in the peer-to-peer support previously assured by the Irish Cancer Society. MAC immediately set up a Steering Committee to examine the problem and deduce its possible solution. One of the problems, similar in other member States, is the concentration of membership in only a small area of the country, in the case of Ireland – Dublin. Fortunately the Cancer Care & Support Services organization in Ireland has promptly proposed and adopted a programme which now assures excellent treatment in 8 specialised centres well distributed throughout the country, and at the service of its 4.5 million population.

One regrettable aspect which still exists in Europe is the limited interest in prostate cancer by European mass media. Europa Uomo hopes to overcome this persistent problem by the forthcoming approval of a Strategic Plan, co-ordinated by Prof. Louis Denis, which is the main item in the forthcoming Warsaw assembly agenda.

However two recent articles published respectively by BBC News and the Telegraph give reason for hope. The first refers to the sacking of a urologist accused of giving inappropriate cures to 27 patients, and the other article speaks of the unwillingness of the British health authority NHS to finance a patient who needs to take a new expensive drug called Enzalutamide. That is notwithstanding the patient's doctor's comment "Buy the drug or die!"

## **A letter from the Chairman**

*By Ken Mastris*

As we approach our General Assembly in Warsaw I thought that those who may not be able to attend

will wish to have an update on the activities of the Board during the last twelve months..

We are halfway there with the agreement with Prof. Louis Denis as our Strategic Consultant and without his precious and knowledgeable help the organisation would not have moved forward. My sincere thanks to Louis for assisting me in dealing with the impact of our strategic seminar. We have to adapt ourselves to the new circumstances if we wish to survive in these difficult times as patient advocates.

I would like to thank both Ekke Büchler and Gunter Feick for the hard job of organising the seminar and General Assembly in Warsaw. I know it will be a success. A very special thanks goes to our invaluable secretary Anja, who oversees all our efforts and assures their punctual completion.

I would also like to thank all our sponsors who contributed in funding this important event.

It was an honour and a pleasure to reach an agreement with EAU and sign a winning working plan. Patients working together with the professionals are sure to do the best for patients. Details will be in our next newsletter. Thanks must also go to Malcolm our editor who is always ahead in the game.

We are working hard to get other important European groups to assist us in our mission and can now say we have also agreed a partnership with ESO: yet another lasting successful story for cooperation.

The hard work of the other elected officers, Christian and Max, must be recognised as we are all volunteers.

As I writing this our vice Chairman Tor Tausvik has communicated his decision not to stand for re-election at the GA for personal reasons. I would like to thank him for all his efforts over the last 3 years. We will miss his invaluable contribution and counsel at our meetings.

After the GA we will welcome two new members and in order to achieve our vision and mission the Board will need to put them all to work as a team. The Board can't do everything, hence the launch of volunteers as Liaison Officers at the GA, which is vital for our continued survival and success.

With Louis and the Board we are also organising

another EPAD event in September 2015: further details will follow in due course.

In conclusion, I must express my most sincere appreciation and thanks to all members of the Board for their continued support in helping me as Chairman to assure the continual development of our important European federation.

I look forward to another successful GA thanks to your indispensable co-operation and help.



**Professor P.A. Abrahamsson receives a famous bottle of Cognac from Ken Mastris as a token of our gratitude for all the EAU support over the years.**

## **Depression and Anxiety: two sides of the same coin; Anxiety (2)**

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

Anxiety is one of the most common psychological reactions in patients with cancer. In oncological settings, it is commonly greater than depression. It is an unpleasant reaction to things or events that we fear or that are a threat. It can also be a way of anticipating a terrible or negative event. Our body prepares itself to run away from it or to develop ways of coping with it. In this sense anxiety is

adaptive, comes from when men lived in caves and helped themselves by hiding when they foresaw a danger. We must distinguish anxiety from fear. Fear can be an instinctive reaction to a "real" danger, while anxiety is mentally more complicated and does not always have a clear stimulus that provokes it. It is an emotion that appears related to anger, fear, hostility or uncertainty. In this sense it is positive as it prepares us to cope with the danger that provoked it. But it is maladaptative when it is too high, when it is not related to any specific stimuli and/or continues. There is an anxiety trait (people with an anxious basis in personality features) and an anxiety state (temporary situation that causes anxiety states). Of course both can potentially cause anxiety-inducing situations in people with stable trait anxiety who even feel more nervous because both are added. Anxiety, conversely to depression, is higher, generally in younger patients. It is estimated that between 20% and 60% of men with prostate cancer have clinically significant anxiety at some point in their illness.

#### **Anxiety has three basic components:**

- **Biological:** which is the physical state and it leads to cardiological palpitations, tremors, sweating, muscle tension, shortness of breath, abdominal and urinary discomfort....
- **Cognitive:** what we think, how we evaluate the threat, and negative thoughts like "I will not be able to do this" or "I'm going to die"...
- **Behavioural:** behaviour consequences to anxiety: an attempt to escape or avoid coping with danger. In the case of prostate cancer, it can lead patient to try to avoid situations that create more anxiety or fear by the person (such as from social gatherings and delaying again and again a visit to a doctor or a medical test).

Referring to the various phases of the illness, in patients we found several points where he is more likely to suffer from anxiety:

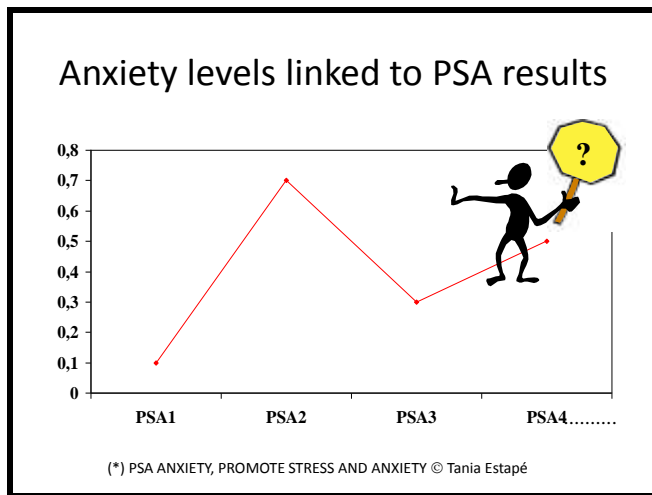
- On the onset of symptoms: sometimes, depending on the age of the patients, some symptoms of prostate cancer may be confused with normal phenomena such as difficulty urinating, urine retainment etc. However, once the

patient feels that they persist or others appear and increase (such as pain), he may begin to notice anxiety. These may be reflected in insomnia, intense nerves, repetitive thoughts and so on. In some cases the high level of anxiety leads to a visit to a doctor, while in other cases the paradoxical reaction due to high anxiety levels is to avoid the situation and the person is unwilling to see a physician for fear that he or she may confirm that there is something wrong thus decreasing the chances of early detection and cure.

- Given the expectations of results: once the patient has been placed in the hands of the physician due to body signals either by routine tests and while waiting to be told the results of a complete diagnosis, and after completing these, waiting for complementary tests results. All such situations provoke high anxiety situations.

- Related to treatment: once men have been diagnosed of prostate cancer and somebody indicates to them the course of treatment to follow they may feel some relief to see that something is being done, but also fear and suffer from anxiety because of the uncertainty that generates this new situation and doubts about how they will face it and how it will be. We have all heard of the anti-cancer treatments as something terrible, and this fear can easily be reflected in our inner being.

- In the follow up: men with prostate cancer have a special type of anxiety unlike other cancers. It is anxiety before the PSA. This is called PSA anxiety or jokingly it is said the PSA is to Promote Stress and Anxiety. The man is very aware of the marker which even sometimes sets a graphical control of results over time. His anxiety in monitoring focuses on this issue and its oscillations. Anxiety in men with prostate cancer is marked by this PSA anxiety. This is a special case that we find in men with prostate cancer. It is said to be a kind of anxiety that is reflected in the high peaks of waiting for results periods or when knowing it is increasing. Men in this situation canalize anxiety by control with graphics and data collection. Men have more difficulties to express their psychological suffering and negative emotions and they sometimes do not cope with them through conventional channels but other related medical forms of the disease. In some cultures men are not prone to cry or give voice to fear or frailty.



- We must also highlight a special case of prostate cancer option that is not therapeutic. This is the Wait and See or Active Surveillance option. In some cases patients feel discomfort and vulnerability, by failing to carry out a treatment (although it is hard to agree to the surgical option), knowing that you have thus amputated the tumour which provides some relief or psychological comfort knowing that the cancer "is now out your organism"). Sometimes there are men living with an ongoing anxiety due to the belief that they have a cancer inside their bodies.

Among cancer patients suffering from anxiety, prostate cancer is so special that there are even special psychological tools to measure this. There are different ways of coping with anxiety. But we must keep in mind that low to moderate range anxiety can be normal when there is the possibility or certainty of a cancer diagnosis. When anxiety peaks are very high or persist through time or after the situation that motivated them has been overcome, it may be necessary to go to a specialized professional and learn relaxation or cognitive techniques that can help to reduce anxiety and increase the sense of control that is sometimes lost to a great degree.

Anxiety may also appear after a prolonged depression, since patients may be nervous because of their apathy or lack of activity. Conversely, patients who are continuously anxious may become depressed due to a high level of energy wasted in muscle tension and suffering. That is why we call anxiety as the second psychological consequence of cancer or the other side of the coin. It is therefore most important to ask for help when they are both persistently high.

## Common Shortcomings in Prostate Cancer Care

By Malcolm Galloway Duncan

One of my early contributions to our quarterly newsletter "Did You Know?" was dedicated to the enormous discrepancy in the treatment of prostate cancer in many European States, if compared to the care and attention given to the cancer plights of the genteel sex and from a fairly young age. On the contrary, in many countries men have to sweat it out till they reach the respectable age of 70 when, in many countries, they are finally invited to check the state of their colon retro. I have appropriately named the relevant presentation slide "The European Prostate Cancer Demerits Board."

However this apparent negligence of the males is chiefly their own fault. At an early age women become very knowledgeable about their bodies, beginning with the growth of their breasts and their monthly menstruations and what this entails. At appropriate ages, according to national medical systems, they are formally and periodically invited by letter to submit themselves to tests in order to timely detect any form of cancer growing unnoticed in their bodies. On the other hand an early invitation to detect prostate cancer is at present only available in 4 of the 20 European States which kindly replied to our questionnaire. This is rather disquietening bearing in mind that prostate cancer is second only to cardiovascular defects for the premature death of the male population and, with the increased longevity of the average life, its frequency is expected to steadily grow. To cite Italy as an example, whereas an estimated 42.600 new cases of prostate cancer were reported in the course of 2012, 44,390 cases have been estimated in the current year.

At European level it is now estimated that, on the average, one man out of six gets prostate cancer and the average number of deaths within Europe is estimated at 90,000, that is 3% of the patients who may therefore be estimated, at European level, to number around 3 million.

There is in fact a general unawareness of men of the danger of prostate cancer especially in their forties and fifties and this unawareness is shared almost to the same degree by family doctors or

# The European Demerits Board - 2015

## Common Prostate Cancer Shortcomings in EUomo Member Countries

1. GP unawareness
2. Male unawareness
3. General reluctance to see an urologist
4. No state early detection solicitation
5. Limited or no MultiDisciplinary Centers
6. Limited mass media coverage
7. Limited and predominantly passive membership
8. Difficulty to get voluntary help
9. Common recourse to hospitals which execute few prostatectomies per year. Therefore have less experience and possibly lack the best equipment like robotics.
10. Wrong belief that prostatectomies exclude patients from further cancer risk

Countries	1	2	3	4	5	6	7	8	9	10
AT	x	x	x	x	x	x	x	x	x	x
BE	x	x	x	x	x	x			x	x
CH	x	x	x	x	x	x	x			
CY	x	x	x	x		x				
CZ	x	x	x	x	x	x				
DE				x					x	
DK	x	x	x	x	x					
ES	x	x	x	x	x	x	x			
FI		x		x						
FR	x	x				x		x		
HU	x	x	x	x	x	x	x			
IE									x	
IT	x	x	x	x	x	x	x		x	x
LT	x	x	x			x	x			
NO	x	x	x	x	x					
NL	x	x		x						
PL		x	x			x				
PT	x	x	x	x	x	x	x	x	x	x
SE		x	x	x	x	x				
SK	x	x	x	x		x	x			
UK	x	x	x	x	x					

GPs, and frequently the surfacing of the first symptoms, which would favour an early cure, are ignored and taken to simply be a sign of age. In some countries a visit to an urologist also requires a formal request by the family doctor or GP and may cause a further unwanted delay.

However this far from enviable state of affairs is partly the fault of the Europa Uomo Associations which have been set up in the various European countries beginning as from the '90s; their disappointing limited membership, mostly passive; and limited visibility with a few exceptions like in Germany and Denmark: the latter has in as one of its priorities, achieving a 25% membership of prostate cancer patients. A very praiseworthy and ambitious objective. Last but not least, notwithstanding its dimensions, Prostate Cancer is, at present, almost totally ignored by the national and European mass media. The present Europa Uomo management hopes to rectify this regrettable situation and will shortly approve an

ambitious strategic plan co-ordinated by Prof. Louis Denis, Special Consultant and past General Secretary, as well as one of the 3 founder members of this European Association. Our Newsletter hopes to contribute positively to the success of this important and long awaited initiative.

Apart from Germany, there is a general lack of Multidisciplinary Centres where each patient is no longer confronted by an urologist but by a team of experts of involved medical specialties, which thus enables him to actively participate in the treatment choice. In the near future Prostate Cancer Units are expected to provide the ideal solution and the essential requisites in order to become such a centre are expected to be agreed in the next few months by a special Working Commission chaired by the Italian medical expert Dr Riccardo Valdagni. Hopefully this will put an end to patients resorting to unspecialized hospitals which do few prostatectomies each calendar year and are possibly not equipped with the most modern

technology.

One last belief which needs to be contested is the fact that the extreme prostatectomy operation is no guarantee that a metastatic cancer may still materialize at a later stage.

## After Twenty Years is There a Future?

By John Dowling, MAC, Ireland

MAC (Men Against Cancer) was twenty years old in 2013, but it was at something of a crossroads. A number of issues contributed to this. Firstly, the Irish Cancer Society, with whom MAC had been in partnership since 1995, had modified its policy regarding patient support groups and this had a major impact on MAC.

A second issue arose from the change in the way peer-to-peer support work was delivered. MAC had become very dependent on referrals from the Society's Helpline and, when these declined for various reasons, there was a need to change the focus of peer-to-peer work to the new Rapid Access Prostate Cancer Clinics in the 8 designated cancer hospitals. There was also the realisation that MAC members were very Dublin-centred and outside the capital they were too thinly and unevenly spread across the country to mount an effective volunteer support service to the Rapid Access Clinics.

MAC began to wonder whether there was a future for the organisation. A year ago the Steering Committee decided to hold a top-to-bottom review of the organisation and to discuss whether it had a

future. With help of a detailed SWOT (Strengths-Weaknesses-Opportunities-Threats) Analysis, together with an expert facilitator, the Steering Committee opened the review process to all members that wished to participate. Last October that meeting decided on a range of interim objectives to be reviewed again in 6 months.

In April this year progress was reported – a new MAC logo was adopted, a new MAC leaflet was written, designed and distributed, contacts made with a number of prostate cancer rapid access clinics, work had begun on upgrading the MAC website. While not all objectives were fully met, it was agreed that sufficient progress had been made to justify continuing. A further programme of action over the next six months was agreed and MAC is also to launch a recruitment drive to enable it to meet the group's objectives. An effective recruitment drive will mean the end of the existential crisis.

## IMPORTANT NEWS

### Clinical Trials Registration & Reporting

In April 2014 MEPs voted overwhelming in favour of a new law, which will come into effect in 2016, that will require all drug clinical trials in Europe to be registered and their results reported in a public database.

Efforts and support by Europa Uomo, together with other European organisations, have helped make this a win for the All Trials campaign.

This indeed is an important step forward for both patients and physicians. We can be confident that from now on information about clinical trials and their results will be publicly available in the new version of the European Medicines Agency Clinical Trials Database (EudraCT):

<http://eudract.ema.europa.eu/>.

This requires registration with EudraCT <https://accounts.ema.europa.eu/registration> as user before you can log into EudraCT.

However searching for prostate cancer clinical trials seems to be feasible without registration by use of this link: <https://www.clinicaltrialsregister.eu/ctr-search/search?query=prostate+cancer>.



**EUROPA UOMO Secretariat**  
Lange Gasthuisstraat 35-37  
2000 Antwerp – Belgium  
Tel: +32 3 338 91 51  
Fax: +32 3 338 91 52  
E-mail: [europauomo@skynet.be](mailto:europauomo@skynet.be)  
Website: [www.europa-uomo.org](http://www.europa-uomo.org)

## The Austrian Charter Demands to the Austrian Health Care relative to Prostate Cancer

By Ekkehard Buechler, Chair of the Prostate Cancer Support Group Austria

The List of demands and key aspects of the support group for prostate cancer patients (Selbsthilfe Prostatakrebs) regarding necessary measures to be considered by the Austrian health system.

### Introduction

The support group for prostate cancer patients supports an adequate, quality oriented health system which covers all aspects for the protection of the patients.

Let us emphasize a range of topics and objectives necessary to find solutions together with local and national authorities.

We hope that our demands will be evaluated as a constructive contribution on national and international levels in the fight against the stigmatization of prostate cancer which would lead to possible prevention of prostate cancer.

We are looking forward to this opportunity for discussions and to create initiatives for a national plan of action.

The following requests are supported by the Austrian "Krebshilfe" (Austrian Cancer Society). The following points need immediate and complete attention:

1. Improvement of the quality of care
2. Improvement of educational initiatives
3. A comprehensive form of educational information easily understandable by laymen
4. The preparation of a national clinical cancer register
5. The Funding and promotion of science and cancer research.

Our support group for prostate cancer patients is the first and latest established voluntary support group. It is fully competent to work with the Austrian health authorities by offering our knowledge and experience. Our main goal is to represent the interests of prostate cancer patients by being actively involved in changes and future developments in the Austrian Health Care System.

Vienna, April 2015



## ***Every Moment Matters, an advanced prostate cancer disease awareness programme, and Every Voice Matters survey results***

*A short summary of the distributed documents prepared by Malcolm Galloway Duncan with the kind co-operation of Red Door Unlimited.*

During EAU's 30<sup>th</sup> annual Congress which took place in Madrid in March 2015, Astellas, assisted by Red Door Unlimited, organized a press conference to publicize the conclusions of a pan-European survey, the first and largest of its kind which provides an in-depth analysis and personal insight into the lives of 668 men across Europe living with prostate cancer. The panel of speakers included Dr Heather Payne of University College Hospital, London, Prof. Mike Kirby, Visiting Professor to the faculty of Health & Human Sciences, University of Hertfordshire and the Prostate Centre, and Ken Mastris, Chairman of Europa Uomo, the European Prostate Cancer Coalition.

Astellas is committed to enhancing the lives of men impacted by prostate cancer (an average of 89,000 per year in Europe (and amounting in all to one man out of six). Prostate cancer occurs when abnormal cells, supported by male hormones such as testosterone, begin to grow uncomfortably to form tumours. Prostate cancer appears to be the most common non-skin cancer.

### ***Every Moment Matters***

The *Every Moment Matters* programme aims to raise the profile of advanced prostate cancer across Europe, with a focus on a patient's holistic well-being during therapeutic decision-making to optimize patient outcomes.

This is increasingly important as, for the thousands of men each year who are diagnosed with advanced prostate cancer, keeping well throughout the treatment, both physically and physiologically, is an important factor in treatment success.

### ***Every Voice Matters***

*Every Voice Matters* is a pan-European patient survey of men with advanced prostate cancer and was designed by the *Every Moment Matters* Steering Committee in partnership with Astellas, to determine unmet needs of patients across Europe living with prostate cancer and seen from a



patient's viewpoint.

The survey was comprised of an online questionnaire and was completed by 668 men with a medium age of 65-74. The survey took place between September and December 2014 and replies were received from the UK, the Republic of Ireland, France, Italy and the Netherlands. The most interesting questions and answers or information acquired were as follows:

- 75% were suffering from localized prostate cancer; 17% had locally advanced cancer and 6% had metastatic prostate cancer;

#### **Quality of life**

- Nearly 1 out of 2 replied that what mattered most was maintaining a good quality of life. This was considered as even more important than "being cured". The possibility of "being cured" on the other hand was the priority expressed by only 1 man out of 5;
- 40% of the men with advanced prostate cancer agreed that their quality of life had improved following treatment;
- However, of those men with advanced prostate cancer who had experienced bone pain, nearly half, 2 out of 5, were no longer able to complete day-to-day activities such as shopping and walking due to the pain, and nearly a quarter admitted that they were living with a pain which they felt they could not manage;
- The survey clearly showed that men value being able to live their lives to the full and this means being able to continue to work, continue their hobbies and spend time with their loved ones.

#### **Contributing to society**

- Amongst men aged between 35-54 who are currently taking medication, one third say they sometimes feel too unwell to go to work. However, nearly half (46%) of all survey respondents say they want to continue working as long as possible.

#### **Not the end of intimacy**

- While over half (58%) of the men feel that they have lost some of their masculinity, over two-thirds (67%) feel closer to their partner since their diagnosis.

#### **Communicating with healthcare Professionals**

- Overall, patients feel that communication with their doctors was strong, with 81% obtaining information about the stage of their disease and

treatment options, and over three-quarters (77%) agreed that they were well informed. 38% however complained that there was still a reliance on doctors making decisions and they regretted that they were unable to influence the treatment choice with their doctor.

- It is critical that healthcare professionals treat their patients as individuals and take time to discuss the different treatment options available. "By involving the patients in treatment decisions and understanding what mattered most to them, they could work together to improve the quality of life of their patients and their families," commented Ken Mastris.

When asked about the future of prostate cancer treatment Dr Heather Payne highlighted the importance of an increased focus on the importance of individualized care. "I think the most important factor to note in discussions about the future of prostate cancer treatment is how improvements in medicine and the advent of newer hormonal therapies mean that patients cannot only live longer with prostate cancer, but also maintain their quality of life. This enables them to enjoy time with their family and friends. The *Every Moment Matters* Steering Committee are calling for patients to have the confidence to discuss all aspects of the impact of the disease with their doctors, including quality of life, and thus encourage more informed treatment.

More information regarding the *Every Voice Matters* survey can be found on the *Every Moment Matters* website – [www.everymomentmatters.eu](http://www.everymomentmatters.eu), which also hosts four videos of men across Europe sharing their experience of living with the disease.



## Cancer Care and Support Services in Ireland

By John Dowling, MAC, Ireland

In 2006 the Irish Government adopted an ambitious Cancer Strategy which was implemented despite vigorous popular and political resistance. Cancer services in the Republic of Ireland were already provided in many hospitals across the country. However this meant that specialist skills were spread very thinly; and patient throughput was often too small to maintain high level clinical procedures.

The consolidation of cancer services into 8 designated cancer centres for a population of 4.5 million was intended to address the problems identified. This was the background painted by Donal Buggy, Head of Services in the Irish Cancer Society, in his address to the AGM of Men Against Cancer on 5 May in Dublin.

Mr. Buggy outlined the Society's objectives for the new Cancer Strategy which is now being drawn up by the Department of Health. He wanted to see the patients represented in the process and, so far, at a number of Round Tables with politicians, clinicians, civil servants and advisors, the Society has succeeded in having patient representation at these formative stages.

The projected increase in some cancers projected for the Irish population over the coming 15 years poses a massive challenge to the health service in terms of the demand on services but also the financial burden of this explosion arising from greater life expectancy and an increasing population. The Cancer Society is seeking to marshal the patient groups into an even more effective and better trained support service. Mr. Buggy went out of his way to emphasize the role which peer-to-peer support work would play in this and he looked forward to working with MAC and others in ensuring that new ways were developed to provide the full range of patient services to those diagnosed with cancer or its recurrence.

The need for support services would grow not only with the ageing population but also with the very success of modern cancer treatments where most people now survive their cancer and die eventually from other causes, but as absolute numbers grow and as primary cancer treatments increase, the

unique role of peer-to-peer volunteers will become vital.

As the largest funder of cancer research in Ireland, the Cancer Society had promoted a range of prostate cancer research projects and had insisted that these projects be carried out on a collaborative basis and a number of research networks have been established as a result.

The patient experience was provided by Dr. Erik Briers, a science writer from Belgium who told the meeting of his experience of being diagnosed with High Risk Prostate Cancer at the age of 50.

The final speaker at the meeting was Mr. Rustom Menecksha, a consultant urologist in Dublin. He gave a presentation of the current state of prostate cancer diagnostics and treatments in Ireland. He explained when and why he could do and not do nerve-sparing prostatectomies and the role of active surveillance in low risk disease. He also compared the benefits and side-effects for the various treatment options. Mr. Menecksha took questions from the audience for more than half an hour. One member of the audience described his presentation as the clearest and most informative presentation on prostate cancer he had heard in over 20 years of attending such meetings and the audience loudly agreed.

### Prostate Cancer and your Sex Life

Prostate Cancer UK has updated their factsheet (12 pages) and booklet (72 pages) on sex and prostate cancer.



The factsheet is for men thinking about having prostate cancer treatment.

The booklet gives more detailed information and comes with a DVD featuring six men talking about how they are dealing with changes to their sex life during and after treatment for prostate cancer.

This booklet and fact sheet are available to download on their website:

<http://prostatecanceruk.org/prostate-information/publications/publications/prostate-cancer-and-your-sex-life>

## East Surrey Hospital apology over care of cancer patients

BBC News Surrey, online, 16 October 2014



Des Holden, Medical director, Surrey and Sussex Healthcare NHS Trust: There are 27 patients where we feel harm occurred

**A health trust has apologised to cancer patients treated by a consultant who was later sacked, saying his treatment "resulted in your harm".**

Letters have been sent to 27 prostate and bladder cancer patients seen by Paul Miller at East Surrey Hospital between 2006 and last December.

Five patients later died, but the trust said "it wouldn't be correct" to connect the deaths to their treatment.

Mr. Miller has described his dismissal as "unjustified".

### Extremely disappointed

The consultant was suspended before being sacked after an internal investigation.

He is now the subject to a formal investigation by the General Medical Council (GMC).

"I am extremely disappointed that the trust has decided to dismiss me," he said.

"I strongly do not believe that this is justified. I welcome the opportunity to co-operate with any investigation into my practice.

"My priority as a consultant for the last 21 years has always been to protect patients' best interests and safety. I cannot comment further due to my duty of patient confidentiality."

Complaints were initially received by the trust in November last year.

In a statement, the trust said based upon each patient's clinical history, an external panel of consultant urologists "found that 27 patients came to harm because of the treatment they received under the former trust urologist's care".

### Treatment not definitive

Des Holden, the trust's medical director, said the affected patients had been left with a higher chance of the cancer returning.

"The initial treatments that were offered to them, they perhaps weren't given the whole range of treatments option and they really weren't told - our external reviewers tell us - they weren't told

the full kind of consequences of the choices they were making, so some did not receive definitive treatment," he said.

The trust said that in addition to the 27 cases, the care of a small number of patients "fell below the standards we would expect".

It said the experts felt they had not been harmed as a consequence.

There were no concerns about the care received by the remaining patients, it added.

The trust said it had conducted an "open and transparent investigation".

### Compensation considered

Mr. Holden said: "On behalf of the trust, I apologise unreservedly for the errors in these patients' treatment.

"I acknowledge and appreciate that the outcome of the clinical review and the content of the letters will be deeply distressing to our patients and their families and I am very sorry."

He said the trust had written to the 27 patients and their families "to enable compensation to be considered and paid".

It has set up a helpline and has urged patients and their families to call if they have any concerns.

Mr. Miller also worked at Spire Gatwick Park Hospital in Horley, Surrey.

Its director, John Crisp, said: "Spire suspended Mr. Miller in December 2013 as soon as the trust notified us of their investigation into Mr Miller and he has not undertaken any surgery or held clinics at our hospital since."

## Prostate cancer sufferer: "It's either buy the drugs, or die"

**A desperately sick man faces financial ruin because the NHS won't fund his medication**

*By Ruth Wood, The Telegraph online, October 13, 2014*



Peter Smith, at home on Teesside: "I feel like I'm trapped in an Orwellian nightmare".

Prostate cancer patient Peter Smith is caught in a cruel catch 22. He has responded "astonishingly

well” to a new cancer drug that could prolong his life by as much as 18 months, according to his consultant. But because the NHS will not pay for him to have it, he is buying the pills himself direct from the manufacturer, at a cost so far of £15,000.

Mr. Smith’s modest life savings are almost used up, and he is desperate. He had hoped that if he could prove the drug was working, the state would step in and pick up the bill before he went bankrupt. Instead, he’s been told that self-funding has probably only hardened the case against him, because the NHS disapproves of the advantage it gives better-off patients.

“I feel like I’m trapped in an Orwellian nightmare,” says the grandfather-of-one from Teesside. “I’ve barely cost the NHS a penny in 75 years. I’m a non-smoking fitness fanatic, and, until I was diagnosed with prostate cancer 10 years ago, I’d never even been in a hospital, except to visit people. Now, at the very moment I need the NHS, it’s not there for me.”

Mr. Smith’s battle centres on enzalutamide, a new hormone treatment that blocks the action of androgens (male hormones such as testosterone) that stimulate prostate cancer cells. Licensed last year, it can extend life by between five and 18 months in men with advanced prostate cancer.

Initially, prescriptions for enzalutamide were paid for by the Cancer Drugs Fund, the Government’s £280 million-a-year pot for cancer drugs that are not routinely available on the NHS. Then, a year ago, the National Institute for Health and Care Excellence (Nice) approved the drug for all men whose prostate cancer had spread and who were no longer responding to other hormone therapy, or to chemotherapy.

Patients rejoiced – but not for long. In February, Nice issued an update saying that the NHS should not fund enzalutamide for patients who had previously tried another new drug called abiraterone, because there was insufficient evidence it was effective in this group.

Overnight, the recommendation stripped Mr. Smith and thousands of other men across England of a lifeline because they had taken abiraterone. Following an outcry from cancer charities such as Tackle and Prostate Cancer UK, Nice performed a U-turn in May, removing the restriction. But, in its final guidance published in July, it merely said

there was not enough evidence to make a recommendation either way.

NHS England and NHS Wales have responded by ruling out enzalutamide for men who have previously taken abiraterone, and vice versa. Only men found to be intolerant to one of these drugs within three months are permitted to try the alternative. The health service in Northern Ireland is likely to follow suit, while men in Scotland can have the drug without restriction.

Even the Cancer Drugs Fund is limiting patients to trying just one of the drugs.

“It’s outrageous,” says Mr. Smith, who still works part-time as an associate lecturer for the Open University. “The cancer hasn’t spread to my bones and I feel super-fit. Until recently, I was still playing squash twice a week.

“My consultant says I’ve responded astonishingly well to enzalutamide. The NHS should be delighted that it’s keeping me on my feet, contributing to society as a taxpayer, not languishing on a hospital ward.

“Instead, it’s financially crippling me by forcing me to pay £3,000 a month for a drug that others don’t pay a penny for.”

The NHS can buy enzalutamide at a discounted price, but Mr. Smith has paid the retail price for the drug since June.

His voice cracks with emotion when asked how far he would go to self-fund the drug. “Well, I have a house,” he says. But understandably, he is reluctant to sell the semi he has shared with his wife Helen for 45 years, which she will need when he is gone.

Mr. Smith was diagnosed with prostate cancer, the most common type in men, in 2004 at the age of 65. Brachytherapy, a type of radiation treatment, was unsuccessful. Surgery or cryotherapy – freezing the cancer cells – was ruled out after a biopsy showed the cancer had spread to his pelvis.

Since then, his only hope has been to control the disease rather than attempt to cure it, and Mr. Smith has tried a succession of hormonal treatments, each of which has worked for a while before failing, as is the norm.

Cancer is like water,” he said. “You can hold it back for so long, but eventually it finds a way through.”

In early 2013, he was prescribed abiraterone, another new hormone therapy, which worked well initially, but after six months the cancerous cells were on the rise again. In June, he was told enzalutamide was his last hope – but he wouldn't get it on the NHS. His only option was to pay for the drugs himself.

The main yardstick for measuring the success of prostate cancer drugs is their impact on blood levels of prostate specific antigen (PSA), a protein produced by the prostate gland. When he was first diagnosed, Mr. Smith's PSA was 16 nanograms per millilitre (ng/ml), slightly above average. By June this year, it had risen to an all-time high of 771 and was rising dangerously fast. But, within five months of taking enzalutamide, it has plummeted to 100 – the biggest improvement he's ever had from treatment.

Armed with these results, he appealed unsuccessfully via his consultant to both the Cancer Drugs Fund and his local Care Commissioning Group for NHS funding.

He even had a letter to his MP from Sir Andrew Dillon, the CEO of Nice, intimating that he may have a case, "especially as Mr. Smith has responded well to enzalutamide". But neither the letter nor his PSA results were accepted as evidence. In fact, his appeal was screened out before it even reached his regional Cancer Drugs Fund panel.

Though it wasn't given as a reason for rejection, Mr. Smith has also been told by two consultants that the NHS looks unfavourably on patients who go outside the system to buy treatment and then ask the NHS to take over funding, as it creates a two-tier system. "But I had no choice," said Mr Smith. "It was either buy the drugs myself or die."

A spokesman for NHS England, which controls the Cancer Drugs Fund, said: "We look at applications to the fund on a case-by-case basis, based on clinical need. And that's the only consideration.

"Doctors and specialists have reviewed enzalutamide and found that there is not enough evidence to prove that it can be effective for patients who have previously received abiraterone. Although both drugs are effective when used separately, that does not mean that they will be effective when used one after the other – the

benefit to patients of sequential use of these drugs needs to be better understood."

At the root of the controversy is a selection of small, observational studies by Astellas, the manufacturer of enzalutamide. In these, between 10 and 46 per cent of patients who had previously taken abiraterone had a decline in PSA of at least 50 per cent after taking enzalutamide. Nice concluded these studies were too small to give any meaningful insight. But NHS England interpreted them to mean that post-abiraterone enzalutamide was not clinically or cost-effective.

Sandy Tyndale-Biscoe, chairman of the prostate cancer charity Tackle, says the NHS should at least allow all patients to try enzalutamide for a couple of months to see if they respond well to it. "It should be a clinical decision, not a political decision," he says.

Consultant oncologist Prof. Nick James, director of the cancer research unit at the University of Warwick, said he could see both sides of the argument.

"Although there is a lack of formal trial data, what we are hearing is that enzalutamide only works for about 20 per cent of people who have tried abiraterone. That means that in four out of five cases, the NHS would be wasting its money. But if you are one of the 20 per cent, you obviously want the drug.

"The other issue for the NHS is that if you self-fund a drug and have a good response, it gives you an advantage over people who can't afford to buy it. It sets a precedent.

"That said, I have huge sympathy for Mr. Smith. These drugs do enable people to stay at home having a fairly good quality of life until the end. The drugs are expensive but there are big savings for the health service in preventing patients coming into hospital for palliative treatment as they used to 10 years ago. I don't think that has been taken into account."

Meanwhile, time ticks on for Mr. Smith, his wife, their three children and granddaughter. "I despair of the inflexibility of the decision-making process," says Mrs. Smith. "Especially when there are lives at stake."

## Pictures of our booth in the EAU congress in Madrid last March 20-24, 2015)



From left to right: Joaquim da Cruz Domingos (webmaster) and Maria Luisa Dinis Domingos (booth manager).



Our Polish delegates Tadeusz Wlodarczyk and Tadeusz Rudzinski were our special guests as they will host our Europa Uomo seminar next June 19-20, 2015 in Warsaw.



Anja Vancauwenbergh (Secretariat & Newsletter Secretary) & Malcolm Duncan (Board Member & Newsletter Editor).

## The hippocratic corner: “On Prostates and Hormones”

*By Prof. Louis Denis, Strategic Consultant EUomo*

Castration, in medical terms a bilateral orchiectomy, removes the testicles from the male mammal through a surgical incision which is a much feared word in the treatment of prostate diseases. The procedure was already used on domesticated animals when our prehistoric hunter society turned to agriculture and raising cattle to sustain their life needs.

The side-effects were very clear and straightforward. Castrated animals became more obedient, became calmer and gained weight. A typical example is the age old Antwerp tradition of the Fat Ox. In this 1933 picture we can see a photo of the prize winning animal, named Louis, with an imposing weight of 1,201 kilograms (Fig.1). The fact that these overfed animals sometimes dropped dead during the ceremony was noted without much further thought.

Figure 1:



Even little piglets were castrated to improve the taste of the meat and most citizens approved the castration of all cats to prevent disturbing sex parties in the spring season each year. This last side-effect, quit libido and impotence, came in handy to select eunuchs to guard a harem in order to prevent potential misunderstanding. Castration was also a favored procedure in young male singers to safeguard their falsetto voice. Though most castrati were impotent and lost interest in copulation an incident is recorded in the Vatican library where one of the castrati asked the Pope for his permission to marry. He was short of luck as the Pope had a scientific mind and wrote in the margin of the letter of request “Castrate him properly”. The recognition of the prostate as a secondary sex organ came much later when the great Leonardo

da Vinci drew anatomical sketches in dissected cattle where the prostate was missing. We realize that he was correct.

Indeed the anatomical drawing was of an ox where previous castration had reduced the prostate to a minimal layer of tissue. It was our famous Flemish Andreas Vesalius who left us in 1538 in his *Tabulae Anatomicae* a realistic and clear description of the prostate as part of the male genito-urinary system. The testicles always feature prominently in one treatise on the factors that regulate prostate growth and functioning. John Hunter described more than 200 years ago the close relation of the testicles to the prostate. The prostate will atrophy if the testicles are removed. Automatically it looked like a worthwhile experiment to treat pathological growth of the prostate by castration. Indeed this effect was clearly demonstrated in the benign growth of the prostate. Still it was a surprise after the second world war that Charles Huggins and his colleagues laid the basis of castration as a primary treatment in prostate cancer by a series of scientific experiments on the prostate secretion in dogs. He received the Noble prize somewhat belatedly in 1966.

It is important to read how careful and modest he remained in his publications of these experiments on dogs and men. An example for many publications in recent times. Dogs are the ideal experimental animals as it is the only animal similar to the human male where the urethra (piss channel) and seminal tubes run through the prostate tissue and where spontaneous growth is noted with increasing age. It was known that this growth does not occur in men that were castrated in their youth providing evidence that these conditions only could develop on an adequate supply of circulating testosterone concurrent with increasing age.

Of practical clinical importance was his demonstration that prostate cancer cells kept their dependence on male hormones in casu testosterone and that castration or female hormones in casu diethylstilboestrol (DES) by decreasing the phosphatase markers in the blood and that they relieved pain and many of the symptoms of metastatic advanced prostate cancer while male hormones increased the markers and the symptoms (Huggins & Hodges, *Cancer Research* 1, 1941: 293-297).

### Definition of a hormone:

A chemical substance produced in the human body (peptide, protein or steroid structure) that stimulates organs or tissues via the blood circulation.

It is of interest to note that Huggins and colleagues had already published their results of castration in benign prostatic growth and that the pharmaceutical industry in casu Schering Corporation and EH Squib and sons were able to deliver the needed hormonal agents. This marked the start of the medical discipline of endocrinology, the science that studies the hormonal milieu and the interrelation of endocrine organs including the brain.

### Did you know?

**The prostate is classified as a secondary male sex hormone but it plays no role in a sexual relation. Erection and sexual activities are possible after removal of the prostate.**

**The missing detail is the ejaculation as this projected fluid during the sexual climax is almost completely made up of the prostatic secretions. It serves as a logistic DHL package delivery of the sperm evacuated from the seminal vesicles.**

For most of us it is amazing to learn that a simple change of one methyl group and a few double bindings in a steroid molecule leads to very different biological outcomes (Fig.2).

Figure 2:

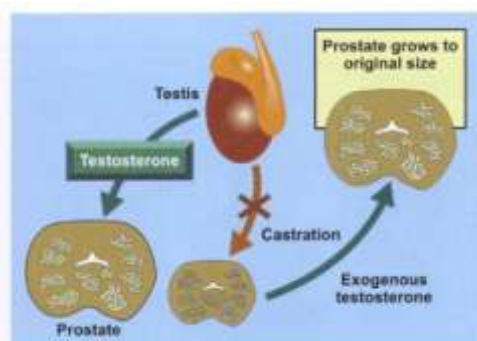


One picture is more informative than a thousand words.

To avoid any misunderstanding we like to emphasize that male hormones regulate the growth and function of the prostate but do not cause prostate cancer as a single factor. Ageing is the most important prognostic factor: a period in a man's life where male hormone levels decline over time.

Dog experiments show evidence that castration diminishes the volume of the prostate and that administration of exogenous testosterone causes regrowth of the gland but only to its original size (Fig.3).

Figure 3:



Still the level of circulating androgens is a key factor in the treatment of prostate cancer.

Can we give exogenous testosterone to patients with prostate cancer? A complex question where the dose of the testosterone and the stage of the cancer are important. Small doses may support the ageing male with one of these ubiquitous latent micro cancers but think of Charley Huggins before you give any dose of testosterone to advanced hormone sensitive metastatic prostate cancer.

These observations led to a tsunami of castration by surgery or female hormones as a first treatment in newly diagnosed prostate cancer.

#### **Did you know?**

***Around the same time, in 1936, Dodds was able to synthesize a new steroid, diethylstilboestrol (DES), as effective as the natural steroids. A dirt cheap molecule that can be compared to the effects of castration, with more breast formation, and should be listed as the first successful chemotherapeutic agent. It is too cheap and no surprise that it is never properly evaluated in phase III studies. The promising Veterans Administration trials of the 1950's were terminated after an increase in cardio-vascular deaths was noted after a 5mg dose.***

It should be no surprise that men are uncomfortable with a diagnosis of prostate cancer and that urologists share the discomfort of advising castration. One of the reasons why they are so eager to find cancer in its localized stages where cure is possible without castration.

The colleagues that resist any form of early

diagnosis and/or screening are not the ones that have to ask their patients to make a choice between Scylla and Charibdis.

Even subcapsular orchiectomy (removal of a testicle) where only the glandular tissue is removed remains a permanent, mutilating form of surgery with concurrent psychological problems. It became more difficult as it soon became very clear that castration is able to bring relief especially of pain in metastatic diseases in 80% of the patients but that this beneficial effect fades after a few years followed by a clinical relapse of the cancer. That simple castration really equates palliative treatment still remains disappointing for both patients and doctors at the final stage of the disease called Castration Resistant Prostate Cancer (CRPC). This is the stage where all hands are on deck to provide updated, multidisciplinary treatment.

#### **Did you know?**

***1mg of DES was considered as an effective dose of PCa treatment by the uro-genital group of the EORTC but randomized phase III trials were never started. Veteran onco-urologists still try it in cases of relapse for the unexpected benefit that is sometimes observed.***

New research in the last quarter of the previous century explained the action of DES and all related estrogens or progestogens through the inhibition of two hormones in the hypophysis, the luteinizing hormone (LH) and the follicle stimulating hormone (FSH) also called gonadotropin hormones (GnRH). These hormones stimulate the gonads (testicles and ovarium) to produce testosterone and estrogen. High, continuous doses of their derivated forms stop the production of gonadotropines after an initial stimulation; a normal reaction of mother nature to keep the balance in its hormonal functions.

Simultaneous the hormonal production of the surrenal glands is elucidated. These organs are stimulated by the adrenocorticotrophic hormone (ACTH) again from the hypophysis. This source of androgens and estrogens is particular in humans and they may stimulate prostate growth in their own pathway starting from cholesterol.

These observations led again to new treatments as bilateral surrenalectomy or the destruction of the hypophysis. Aggressive surgery that was quickly



abandoned in the light of new discoveries. Prolactin and growth hormone were also extensively studied but did not lead to new treatments.

A major breakthrough was the discovery of a small (10 amino acid) peptide, produced in the hypothalamus (part of our brain) the key to the gonadotropic production of the hypophysis.

This luteotropic or gonadotropic releasing hormone (LHRH or GnRH) stimulates the hypophysis in regular intervals to secrete the gonadotropins. A change in amino 6 or 10 makes an LHRH analog (LHRHA) that stops the secretion of the gonadotropin cells after an initial stimulation. A refined form of castration. It led to Andrew Schally being awarded a Nobel prize in 1977.

#### ***Did you know?***

***The hypophysis is a small gland beneath the brain, the size of a pea resting in a hole in the base of the skull, playing an important role as conductor of an hormonal symphony in our body.***

The hypothalamus is part of the brain. It controls our autonomous nervous system and endocrine production. It plays a crucial role in our behavior and survival -of the individual through nurture, fighting, flying and yes sex. It also plays a role in the stabilization of body temperature.

While the first clinical research focused on the minimal daily dose for a permanent stop of the LHRH production as long as the dose was repeated we have now two decades later long-term preparations available that guarantee castrated values of testosterone for 3, 6 and even 12 months.

The biggest advantage of this treatment is not only its efficiency and safety but it is also reversible. If one stops the medication, the testosterone production comes back.

One disadvantage as reported above is the initial stimulation resulting in a testosterone surge. Wherever this happens in localized cancer it is no big deal but this phenomenon, called clinical flare, can have a disastrous effect in metastatic cancer and lead to a vertebral collapse. The golden rule is that LHRHA is contra indicated in patients diagnosed with far advanced cancer. The clinicians avoided these side-effects by giving steroids or androgen receptor blockers (see part 2) in the first weeks of treatment. About 3 years ago a direct blockade of the gonadotropins by molecules

(LHRH antagonists) was introduced to avoid this flare.

So we have now, in 2015, a refined form of castration which is now cautiously termed as Androgen Deprivation Therapy (ADT). What is the difference? The term is correct as we diminish the testosterone production in the testicles (about 95% of the total daily production) leaving only the production in the adrenal glands and the prostate itself. The side-effects are the same as a surgical castration: sexual problems and diminished libido, decrease of muscle mass and increase of fat deposits, heat waves and annoying transpiration, decreasing bone density, metabolic disturbances and mood changes as well as an increased risk for cardio-vascular problems including death. This long list can be very different in individual patients but serves as a reminder that ADT is a serious treatment decision to be taken on the proper indication. There is a consensual trend to avoid invasive treatment including ADT in low risk disease where active surveillance is an accepted indication of first treatment.

The key word is treatment.

#### ***Did you know?***

***There is agreement that asymptomatic, low volume, low risk prostate cancer should not be treated whenever the patient has a shorter life expectancy than 10 years. In these men one should not look for prostate cancer. This decision is called watchful waiting where nothing is done until symptoms appear. In active surveillance a regular follow-up ensures the possibility of cure by delayed intervention.***

A reversible ADT is indicated in the simultaneous treatment with external radiotherapy especially T3 stages. The preventive action in ADT patients consists of clear, updated and objective information where exercises and an healthy lifestyle helps the quality of life.

Our next chapter on hormones will deal with anti-androgens, 5-alfa-reductase blockers (5-ARI's) and blockers of the cortisone cascade. Therapeutic indications run from primary treatment to avoid the castration effect, blocking the specific prostate hormone (dihydrotestosterone, DHT) as well as the glucocorticoid receptors.

A combination of castration and anti-androgens as primary treatment has been the cause of debate

for more than a decade.

We like to finish with these simple conclusions:

1. Hormonal treatment (in case ADT) in a patient with prostate cancer should be decided on objective criteria, treatment responses and objective patient information.
2. First line castration in localized prostate cancer does not improve overall survival (on the contrary) nor specific survival (death caused by prostate cancer).
3. Indications for hormonal treatment are clearly explained in the guidelines of the professional and patient associations.

Read before you act.

## New Subscriptions

Please send your request by email to the attention of Anja Vancauwenbergh at [europauomo@skynet.be](mailto:europauomo@skynet.be), the Newsletter secretary, with the following information:

Name: .....

Organisation/Working place: .....

Country: .....

E-mail address:.....

Pertinent category (see below).....

.....

Any comment or suggestion, in your e-mail, would be much appreciated:

.....

.....

Here are the following categories you may belong to:

- |                                   |                       |
|-----------------------------------|-----------------------|
| Patient                           | Medical association   |
| Ex patient                        | Public administration |
| GP (family doctor)                | Charity organization  |
| Scientific Committee              | Politician            |
| Pharmaceutical company            | TV or press           |
| Medical research institute        |                       |
| Multi-Disciplinary Centre/PC Unit |                       |
| Other (please specify)            |                       |



**MISSION**

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

To support national organizations to deliver services effectively, efficiently and in line with national priorities.

**DON'T STICK YOUR HEAD IN THE SAND, GET INFORMED ON YOUR PROSTATE**



[www.europa-uomo.org](http://www.europa-uomo.org)  
centraloffice@europa-uomo.org

*"The views expressed in this newsletter are not necessarily the views of Europa Uomo"*

### "Did You Know?" European Newsletter contacts and email addresses

**Austria:** Ekkehard Büchler, [efb@gmx.com](mailto:efb@gmx.com); **Belgium:** Henk Van daele, [henk.vandaele@telenet.be](mailto:henk.vandaele@telenet.be); **Bulgaria:** Alexander Marinov, [alpamarinov@abv.bg](mailto:alpamarinov@abv.bg); **Cyprus:** Andreas Moysesos, [andreas.moyesos@cytanet.com.cy](mailto:andreas.moyesos@cytanet.com.cy); **Czech Republic:** Dalibor Pacik, [dpacik@fnbrno.cz](mailto:dpacik@fnbrno.cz); **Denmark:** K.B. Madsen, [madsenk@mail.dk](mailto:madsenk@mail.dk); **Finland:** Hannu Tavio, [hannu.tavio@gmail.com](mailto:hannu.tavio@gmail.com); **France:** Roland Muntz, [info@anamacap.fr](mailto:info@anamacap.fr); **Germany:** Günter Feick, [g-feick@gmx.de](mailto:g-feick@gmx.de); **Hungary:** Dr. Tamás Simon MD. Ph.D., [simon@rakliga.hu](mailto:simon@rakliga.hu); **Ireland:** John Dowling, [johndeclandowling@gmail.com](mailto:johndeclandowling@gmail.com); **Italy:** Malcolm Galloway Duncan, [mgi@hotmail.co.uk](mailto:mgi@hotmail.co.uk) - [europauomo.italy@virgilio.it](mailto:europauomo.italy@virgilio.it); **Lithuania:** Zygimantas Kardelis, [karzygis@gmail.com](mailto:karzygis@gmail.com); **Norway:** Tor Tausvik, [tor@tausvik.no](mailto:tor@tausvik.no); **Poland:** Tadeusz Rudzinski, [stowarzyszenie.gladiator@poczta.fm](mailto:stowarzyszenie.gladiator@poczta.fm); **Portugal:** Joaquim da Cruz Domingos, [cruzdomingos@outlook.pt](mailto:cruzdomingos@outlook.pt); **Romania:** Toma Catalin Marinescu, [rokapro@yahoo.com](mailto:rokapro@yahoo.com); **Slovak Republic:** Josef Blazek, [josef.blazek@vsbm.sk](mailto:josef.blazek@vsbm.sk) - [uomosk.3@gmail.com](mailto:uomosk.3@gmail.com); **Spain:** Jordi Estapé, [jestape@fefoc.org](mailto:jestape@fefoc.org); **Sweden:** Calle Waller, [calle.waller@partnershipforeurope.se](mailto:calle.waller@partnershipforeurope.se); **Switzerland:** Max Lippuner, [info@europa-uomo.ch](mailto:info@europa-uomo.ch); **The Netherlands:** Kees van den Berg, [voorzitter@prostaatkankerstichting.nl](mailto:voorzitter@prostaatkankerstichting.nl); **United Kingdom:** Ken Mastris, [ken.mastris@btinternet.com](mailto:ken.mastris@btinternet.com).