

**Did You Know? – N°4 – December 2015**

## **The voice of prostate cancer patients across Europe**

In warm appreciation of your support during 2015, we extend our best wishes for a happy Holiday Season and a New Year filled with Peace, Joy and Success.

Europa Uomo



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### **Editorial**

by Malcolm G. Duncan, the Newsletter Editor

This number of our Newsletter more or less coincides with incredible news from America. While we are discussing the importance of early screening in order to detect the presence of prostate cancer in its early stage, the United States of America are evaluating the usefulness of the PSA and are in the process of conducting a public inquiry on line asking the opinion of the general public. This inquiry ended on 20th November. If the majority of responses are negative, PSA screening stands to be abolished and doctors guilty of prescribing it in future would be exposed to financial penalties. On the other side, prostate cancer patients would risk being totally unaware of their predicament of a prostate cancer silently growing in their bodies probably until a few months prior to their unexpected death.

It is even more incredible when it is generally thought that patient awareness still needs much improvement. This mortal disease is also still taboo in many countries and ethical communities.

On the contrary, Europe has decided to tackle this problem of general unawareness with the creation of EUPATI which has recently established in-depth Patient Expert Training Courses, which are also available in many different European languages. This will surely favour a major patients' viewpoint at all medical levels.

In a similar manner, Alberto Costa, Scientific Director of the European School of Oncology (ESO), in his article entitled "Arrivederci or Good-bye", has emphasized the urgent need for Centres of Excellence all over Europe where specialization is limited to a small number of cancers in order to assure the best possible treatment of patients.

Reporting from Germany, Gunter Feick emphasizes the important role now realized by the Germany medical authorities of patient advocacy groups like Europa Uomo in assuring the best treatment of PC, and expresses thanks to the authorities active monitoring of reimbursement decisions and the optimal exploitation of the Active Surveillance therapy.

The Finnish oncologist, Petteri Hervonen, also warns us of the misleading habit of treating PC as one disease which is not the case. His Finnish colleague Kari Tikkinen however reassures us of a certain improvement in the knowledge of PC as well as the positive change in the attitude of physicians vis-à-vis their patients. This medical issue ends with a warning of care to not overdo the use of hormonal treatment. A danger confirmed by a 2009 Swedish analysis of 30,642 P.C. patients.

Our Secretary, John Dowling, describes the difference in PC treatment in the Republic of Ireland and North Ireland, which is part of the UK. The treatment of patients in the first named State statistically appears more successful thanks to early screening and the availability of new and expensive drugs to all patients, which is not always the case in North Ireland which is under the supervision of the British NHS public health system.

The Patients' Mailbox continues to thrive and some of the questions are this time posed by wives and regard the problem of intimacy. The same author, Tania Estapé, a Spanish psychologist, has written an article on the problem of Denial which is very common in men suffering from PC.

This number informs our readers of further awards granted to Prof. Louis Denis, one of the leading figures in the development of Europa Uomo over the last 12 years, who assures us that, based on ongoing research, PC will be a chronic and no longer a mortal disease within the next few decades.

In the spirit of Christmas, I have briefly mentioned an annual cancer fund raising event in Milan called "The Race of Hope" which is a non competitive marathon for kids and grown-ups, in memory of a disabled Canadian boy, Terry Fox, who, in 1980, ran across the Canadian continent in order to get funds for cancer research.

## The Chairman's Letter

by Ken Mastris

First and foremost, may I wish you all a most enjoyable Christmas and, above all, a most healthy New Year.

The Board has been very busy and has just returned from its Barcelona meeting where it was invited to attend two conferences organized by ESO and EMUC. The Board is most concerned about the inequalities of treatment which exist in some parts of Europe. We strongly believe in the importance of Centres of Excellence throughout the continent, but it is still a pipe dream in many member States due to cost implications. And in many cases even better new drugs are not always available for local patients.

Patient awareness still needs improving, especially in advanced prostate cancer and that is one of the goals of our quarterly Newsletter "Did You Know?" which we trust you circulate as much as possible to all potentially interested parties: patients, medical institutions, the authorities and the press. Unfortunately prostate cancer is still regarded like a taboo in several countries and ethical communities. This is in fact another aspired goal of Europa Uomo together with the attainment of personalized medical treatment.

We must not forget our most sincere appreciation for the help, encouragement and co-operation provided to us by EAU and ESO as well as by our medical and pharmaceutical supporters.

I would be most happy and grateful if you were to write to me through the secretariat on issues which are of importance to you and your association of Europa Uomo and which may be included in the topics for discussion at our forthcoming General

Assembly. You may also externalize such feelings by writing to the Newsletter editor, as there is a specific space reserved for letters from the Newsletter readers.

Finally may I express the sincere hope and pleasure of the Board and myself to see you all on the occasion of our next General Assembly in June 2016 which promises to be of great interest with a much needed extension in the number of participants who are called to actively contribute to the successful attainment of Europa Uomo's goals. Details will arrive in good time.



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

## Raising the Cancer Patients' Voice

by Günter Feick

Reimbursements for medications in the EU states are incumbent upon the results of health technology assessments (HTA) in the EU member states.

Reimbursement decisions are affecting the prices of medication and consequently the cost of national public health systems and pharmaceutical company decisions on whether to market a product or not.



There was a recent case where EMA and the Committee for Medical Products for Human Use (CHMP) had duly recommended the marketing of a medical product called Sipuleucel-T while, on the contrary, the company concerned withdrew the product from Europe, which might have been influenced by HTA assessments in several European states.

An example for current differences among HTA assessments in Europe is manifested in the Prostate Cancer Diagnosis and Treatment Guidelines of the National Institute for Health and Care Excellence (NICE) of Great Britain published January 2014: <https://www.nice.org.uk/guidance/cg175/chapter/recommendations>. Table II Protocol for Active Surveillance recommends "If there is concern about clinical or PSA changes at any time during active surveillance, reassess with multiparametric MRI and/or rebiopsy." Other European countries are not recommending this diagnostic method which is causing differences in administering Active Surveillance at the expense of optimal and equal patient treatment throughout Europe.

The coordination of the decisions of the various independent HTA national authorities, in co-operation with EMA, is quite a complicated procedure in order to assure that the proposed medicines have a positive risk-benefit outcome in favour of the patients and is still rather underdeveloped at this moment. The following indicated paper:

[http://www.ema.europa.eu/docs/en\\_GB/document\\_library/Minutes/2015/07/WC500189013.pdf](http://www.ema.europa.eu/docs/en_GB/document_library/Minutes/2015/07/WC500189013.pdf) clarifies this aspect and provides insight on the complications involved.

I envisage that a HTA composite body will eventually substitute the role at present covered by the national HTA organizations. However the problem of the different financial capabilities of the individual national health systems in Europe would still remain unsolved. It appears indispensable that competent patient advocacy groups are involved in the activities of both EMA and the HTA organisations.

The four year long working experience with HTA in the German Federal Joint Committee: <http://www.english.g-ba.de/benefitassessment/information/> has shown how vital is the participation of patient groups in the improvement and financing of the German public health system.

## The Race of Hope

(La Corsa della Speranza)

by Malcolm Duncan

This annual Milanese event goes back over 20 years and was originally inspired by an event called "The Marathon of Hope", which amounted to a race across Canada from coast to coast organized by a young disabled boy with a prosthesis in his right leg called Terry Fox in order to collect funds for cancer research.



The Milanese event amounts to two non competitive weekend races respectively for kids (600 metres) and adults (6 km), and in the two preceding Saturdays gymnastics and games are organized by trainers and specialised personnel, including a magician, much to the delight of the young participants.

The funds obtained from the participants and sponsoring institutions like Europa Uomo are promptly donated to Dynamo Camp which is a



Tuscan body which regularly organizes recreational sojourns in Tuscany for kids suffering from some form of cancer.



All Europa Uomo associations are strongly invited to inform the Newsletter of similar social events organized in their country and in which they offer their co-operation.

### Sponsoring Associations and Institutes

Amgen GmbH	IPSEN Pharma SAS
Astellas	Janssen Pharmaceutica NV
Bayer Pharma AG	Oncology Centre Antwerp (OCA)
European Association of Urology (EAU)	
European School of Oncology (ESO)	
Sanofi	

### Prof. Louis Denis awarded

Our 2015 strategic consultant continues to collect awards for his outstanding contributions to the progress of cancer treatment.

Last year he received the Frans Debruyne Life Time Achievement Award by the European Association of Urology in Stockholm. This year he received the Klaus Meier Award from the European Society of Oncology Pharmacy in Vienna at the ECCO Congress.



These awards confirm his continuing dedication to the art and science of health care and form a well merited addition to the medals already received from the Maria Sklodowska-Curie Memorial Cancer Institute; the Folke Edsmyr Memorial Award from the Karolinska Institute; and the Silver Medal from the Danish Surgical Society.

Congratulations from the Europa Uomo Newsletter for the honour justly conferred to one of our most cherished contributors.

## NEWS FLASHES

**Metastatic Cancer:** Christopher J. Sweeney of Dana-Farber's Lank Centre has recently announced that a combination of chemotherapy and hormone blockers has considerably increased the average survival of patients. Testing of the new treatment was conducted by the American ECO G-ACRIN Cancer Research Group (See [CanceComment.com](http://CanceComment.com)).

**Abiraterone and Radium 223** will shortly no longer be provided to English advanced cancer patients by CDF (Cancer Drugs Fund). A forthcoming ruling by NICE\* will limit their availability to patients who have had chemotherapy. This will exclude about 60% of the patients. Such forthcoming limitations will not apply to Scotland. Abiraterone and Radium 223 treatments have an annual cost per patient respectively of £36,000 and £24,000 (*The Sunday Times*).

\*The National Institute for Health & Care Excellence.

*The Guardian* reveals that many British pharmaceutical companies object to the proposal of the British Health Research Authority which calls for **the prior registration of all new drug trials**. That is in order to assure the safety of all patients.

**Incredible!** Following a recommendation by the US Preventive Services Task Force (USPSTF) against any further PSA screening, the American authority CMS (Centers of Medicare & Medicaid Services) is asking for public comment on the proposal by means of an online questionnaire to be answered no later than 20th November 2015. For further details contact [Darryl@malecare.org](mailto:Darryl@malecare.org).

If this proposal passes, doctors advising PSA screening will in future risk financial penalties. On the patients' side thousands of PC patients risk being totally unaware about advanced prostate cancer till a few months before their unexpected death.

**Unbelievable!**

**The Guardian reports** that while the NHS is prepared to pay for expensive new drugs during trial periods, they are not prepared to reimburse the cost of drugs in use which NICE considers to be somewhat inflated in price and do not appear to respect cost-effective standards.

## Back to nature

by Hannu Tavio

We have read a lot about the latest news on developments in PCa research and new methods and possibilities of treatment.

After these huge steps forward it might be a good idea to stop for a while and try to look at basics.

Looking for an ideal title, I am not considering forests, lakes or mountains. I mean considering prostate cancer from a patients' perspective and studying prostate cancer, its diagnosis and choices of treatment from a patient's viewpoint.

In this Europa Uomo's informative Newsletter called "Did You Know?" we can read oncologist Petteri Hervonen's very valuable article on C61 justly entitled "One diagnosis – many diseases". We read that speaking about prostate cancer as one disease is misleading and wrong. In his article we learn a lot about the nature of PCa which amounts to many variations in different men.

Making a diagnosis is not simply a technique as the disease differs greatly from one man to the next.

- earlier detections may disclose variations in the disease due to different backgrounds.
- Most diagnoses are initially made simply based only on PC's microscopic character – and its histological grading – Gleason;
- It is no longer limited to PC's biological behaviour and clinical picture (WHO-grading) or to what the patients tell us.

The correct treatment choice is another matter. It is no longer simply the result of a doctor/patient consultation.

Diagnosed men are now expected to take an active part in the treatment choice. Together with professionals they take part in this very complicated decision.

- Men are not often informed of treatment options which should lead to equally good results.
- Do men need more than one specialist and his/her advice? That is a second opinion.
- Do men have enough knowledge of PCa to take part in this optimal case of multiprofessional (-disciplinary) decision-making?
- Do men realise that the primary radical treatment choice may be a once in the lifetime decision?

The urologist Kari Tikkinen, who chairs many large groups, writes in his information letter how they

evaluate decision making choices that also take into account patients' values and preferences when making treatment decisions which will ensure that individual patients get the treatment that is right for them.

I am convinced that as a patient organisation Europa Uomo should speak more about its activities and goals and not be satisfied simply by its special nature only and narrow professional views.



## Patients' values and preferences incorporated into treatment decisions

*Taking patients' values and preferences into account when making treatment decisions can ensure that individual patients*

*get the treatment that is right for them. Physicians increasingly listen to the patients' desires*



*when negotiating treatments. However, shared decision-making is difficult, and clinicians need help.*

**Kari Tikkinen**, a Finnish academic and clinical researcher from the Department of Urology at Helsinki University Hospital, has investigated decision-making related to the treatment of prostate cancer as an interaction process between physicians and patients. In particular, his research has focused on decision aids given to patients when planning treatment. The material includes brochures and websites explaining the illness, treatment options and their benefits and harms. The study was completed as an international collaboration,

including researchers from the university hospitals of Helsinki and Tampere, McMaster University, the University of Western Ontario, the University of Minnesota and the Mayo Clinic. The project was conducted under the auspices of the Clinical Urology and Epidemiology (CLUE) Working Group and its results were published last spring in a scientific journal with the world's highest impact factor, *CA: A Cancer Journal for Clinicians* of the American Cancer Society.

The systematic review of the available literature included 14 randomised studies that had assessed the impact of decision aids in patients making the treatment decision regarding their localised prostate cancer. A total of 70 per cent of the studies were North American, while the rest had been conducted in Europe and Australia. In all, the studies included 3,377 patients.

Key treatment options for the treatment of localised prostate cancer include active surveillance, surgery and radiation therapy. Some previous studies focusing on illnesses other than prostate cancer have shown that patients who used decision aids were more likely to choose non-invasive treatments. In the case of prostate cancer, this would have been active surveillance. However, this wasn't the case in our study. "This may be due to the fact that the studies used in the meta-analysis were primarily from the US, where active surveillance as a treatment strategy of prostate cancer is less commonly used than in Europe," explains Tikkinen.

"A notable observation in our study was that, after treatment, patients were less likely to regret the treatment decisions they had made if they had used decision aids when selecting the treatment. Additionally, aids seemed to increase satisfaction with the treatments and improve knowledge of the disease, treatment options and their risks." Tikkinen's group also found that the use of decision aids did not increase or reduce the selection of any single treatment option.

### **Risk assessment and value mapping**

Tikkinen works both as a researcher and as a urologist in practical patient work. Meeting patients, reaching a diagnosis and discussing treatment options are all familiar to him from his daily work as a physician.

"Patients should be given time. The treatment decision doesn't have to be made on the first post-diagnosis visit to the doctor. Rather, the patient should be allowed to think the decision over.

Decision aids could be utilised in this context so that the patient would receive material to take home, and there would also be material to review together with the doctor. This could increase the chances that the patient fully understands the alternatives and possible good and bad consequences."

According to Tikkinen, genuine physician-patient cooperation takes into consideration the patients' values and preferences. Doctors and patients should together consider the outcomes that patients value in their lives. For example, in the treatment of localised prostate cancer, different treatment options can have different impacts on patients, such as erection problems as well as urination and intestinal symptoms.

"Similar to many other diseases, when selecting the treatment for prostate cancer, the risk needs to be assessed and the values mapped. In the worst case, the cancer may spread and the patient may die. On the other hand, it may stay localised and under control without any invasive treatments. Therefore, we have to balance the potential benefits and risks. What are the health and quality-of-life risks of the selected treatments in relation to the effectiveness of the treatments?"

Tikkinen emphasises that patients today are more aware of diseases and their treatment modalities than before. Furthermore, doctors are not the same kind of authority figures as they once were. "Many studies have shown that patients feel better when they have taken part in deciding on their treatment. They also better adhere to post-operative care."

"I hope that the correct form of treatment could be found for every patient, and this can mean different decisions to different people. At its best, patients have key issues specific to them explained so that they understand them, while taking into account evidence and the patients' values and choices. This doesn't mean that doctors are trying to avoid their responsibility."

### **Towards sensible diagnosis and treatment**

According to Tikkinen, decision aids can be increasingly utilised by developing online versions. Together with his colleagues, he is currently working on a Finnish version of a proven North American decision aid website.

Tikkinen became interested in evidence-based medicine particularly during his postdoctoral period at McMaster University in Canada, where he worked in a group led by a pioneer in the field, distinguished Professor Gordon Guyatt. "Evidence-based medicine

includes three key principles. You must reach the correct diagnosis, be aware of the evidence regarding benefits and risks of the alternative treatments, and then consider the trade-offs between the benefits and risks. For this last principle, you need information on the patient's values and choices."

In his work as a clinical researcher, Kari Tikkinen finds it intriguing that in the practical work you understand what the treatment practices are based on and can also develop these practices yourself. "I find that I can promote good things in this work. A sensible use of healthcare resources is important to me, and I think disease and health should not be the target of hard business at the expense of society. Work for the benefit of the patients and for sensible diagnostics and treatment is meaningful."

*Original Finnish text by Riitta Tirronen.*

*Photo by Marjo Aaltomaa.*

## **C61. One diagnosis – many diseases**

### **Prostate Cancer has many faces**

Petteri Hervonen, M.D., P.h.D., Docrates Cancer Center, Helsinki Finland & Tampere University Hospital, Tampere, Finland



The disease is classified under one code C61 in the international diagnosis classification, but every prostate cancer is different and every patient with prostate cancer is unique. The support of your fellow patient is priceless, but his prostate cancer cells are nevertheless different to yours.

Prostate cancer is a broad spectrum of differently behaving diseases with varying prognosis and need for treatment. At one end of the spectrum there are indolent, hidden, un-symptomatic cancer cells that do not ever need to be treated. The other extreme is a younger man's aggressive, uncontrollable wild malignancy that requires every means of treatment to even slow down for a few months.

Between the two extremes are most men with prostate cancer with a chronic, slowly progressing disease, predominantly affecting the bones.

The treatment modalities of a local prostate cancer, surgery and radiation therapy have developed with huge steps in the last few years.

Robotic-assisted surgery spares healthy tissues and increases the accuracy of the operating surgeon. The modern radiation equipment gives a higher and more precise dose of radiation without compromising the function of the surrounding organs.

The development of new tracers such as PSMA for the PET scan enhances the reliability of the treatment decision. Magnetic resonance imaging (MRI) can be considered a golden standard in pre-operative staging of the tumor.

The treatment of castration resistant metastatic prostate cancer evolves with great velocity. Most men with metastatic prostate cancer are treated initially with hormonal therapy. A new generation of hormonal therapy is widely accepted as being more effective and less toxic to the patient when compared to conventional chemotherapy regimens. Other new treatments include a powerful chemotherapy drug cabazitaxel and an effective radio-pharmaceutical, radium-223.

In addition to these new drugs and many more that are on the way, we have learned to use the established treatments in a more efficient and tolerable fashion.

The optimal treatment decision for the right patient at the right time is a challenging task that requires knowledge and experience of new treatment options and determination, sometimes even a bit of courage.

The basic right of every prostate cancer patient is to have a timely discussion with a prostate cancer specialist, a medical oncologist or urologist and a trustworthy, long-lasting relationship with the expert responsible for the treatment plan.

Every patient is entitled to the best possible treatment regardless of country, city or town of origin. First and foremost he needs reliable information about his disease.

You have prostate cancer. Your world stops for a moment, but then you take a deep breath and decide to fight back.

Prostate cancer research does not stop either. A lot is to be done for you. Your oncologist and the new medical innovations are there for you in different stages of the disease.



## Goodbye or arrivederci?

***Our new vocabulary – gene, genome, molecular, targeted, personalized – no longer inspires the confidence it once did, and as the cancer community prepares to gather at the 18th ECCO - 40th ESMO European Cancer Congress in Vienna, there is a real sense of uncertainty about where the next major progress will come from, writes Alberto Costa in this editorial.***



by Dr. Alberto Costa

Where will European oncology go from here? This is a question many of us will be asking as the ECCO–ESMO congress convenes in Vienna. There's a diffuse sense of uncertainty, coming mainly from the laboratories, where many promising cutting edge innovations still seem to be in the air. Our new vocabulary – gene, genome, molecular, targeted, personalised – has lost its novelty and its shine. What will be the next clinical trial to have us all breathlessly awaiting the results? What innovation will be the next to radically change our clinical practice? A second generation of Da Vinci robots for everybody? Intraoperative radiotherapy? Immuno-oncology? Alopecia preventing devices?

With this in mind, the thoughtful ECCO–ESMO participants will also be worrying about the endless list of cost issues that intrude on clinical decisions. This is not something we were prepared for; we never studied pharmaco-economics (or device-economics) at medical school. How can clinical oncologists take these decisions? Is what we do even still clinical oncology, or is it a highly complex combination of medicine, nursing, ethics, sociology, economics and politics?

On top of this, many of our friends participating in ECCO–ESMO will want to attend sessions that address questions about how and where care should be delivered to their patients. Questions like: should I send all my breast and prostate cancer patients to the nearest certified breast or prostate unit? It's now accepted that all patients with rare cancers must be referred to the nearest centre of excellence, but what about other patients? Can I, a surgical oncologist, continue to practice as I have done for the last 20 years? Is it still OK to 'do' a lung cancer one morning and a liver cancer the next? Can I, a medical

oncologist, safely treat a patient with an advanced colorectal cancer, a bone sarcoma and maybe a lymphoma, all within the same outpatient clinic?

These are our common concerns and the things that really matter to all of us who are proud to attend the ECCO–ESMO conference. The Americans have decided to keep well separated the physician researchers (AACR), the cancer doctors (ASCO), the nurses (ONS) and the patient advocates. Here in Europe we have a long tradition of working together, but the will to continue to do so is now in danger.

The details of how ECCO and ESMO should collaborate may be of no great interest to participants at the Vienna conference, but the great majority will undoubtedly feel that staying together is the right thing to do, both for cancer health professionals and patients. Cancer has become all about collaboration, and it's too late for any single specialty to work in isolation.

When we leave Vienna, we want it to be with an *arrivederci* and not a goodbye.

*Originally published in Cancer World magazine*  
[www.cancerworld.org](http://www.cancerworld.org).

## Denial

by Dr. Tania Estapé, FEFOC Barcelona

Denial is a normal psychological state of mind. We deny the existence of famine in the world when we eat every day despite knowing that there is hunger in the world or when having problems or negative situations in our lives go out and carry on a normal life. Denial is defined by psychologists as a "coping strategy consisting in omission of facts which could be painful if they were conscientiously accepted". It seems that the human beings need to refuse some negative facts to survive, at least psychologically, from stressful events.

One of the areas where denying is common is disease, overall serious diseases, those that will substantially change the life of the affected persons. Sometimes it occurs as a first reaction to the diagnosis. However we find denial in many stages of the disease. In cancer it is not infrequent. Denial can occur even before diagnosis of prostate cancer, overlook signs or evidence and show reluctance to check doubts by doctor visits. Some people are barred mentally to pain, discomfort or changes in vital functions and simply say "nothing has happened", "let me go", or based on previous experiences ("I had a pain last year and it turned out



to be nothing "or" my brother had that, and in the end it was just nonsense"). In diseases such as cancer a paradox occurs even though the time spent in this situation, relying on other treatment options, may lead to an uncontrolled growth of the tumour and therefore endanger healing.

As on diagnosis it is not uncommon to find patients that are blocked by the information and pass a denial phase based on disbelief ("it cannot be true", "it was not going to be me" or "you must be mistaken, I feel great"). This last example may be because the disease is often detected in very early stages thanks to current developments, but then the person has not had disease check-ups and has kept on denying. In prostate cancer there is another factor added to this. In some patients, symptoms may be confounded with other normal situations such as old age. Some men and even their wives/companions and families label these symptoms as normal, usual or not strange if they have urinary or sexual problems. It is not exactly a denying attitude, because some truly think of these problems as normal at their age. However if it persists long in time then men may be denying worrying about it.

### Types of denial

Denial can take various forms:

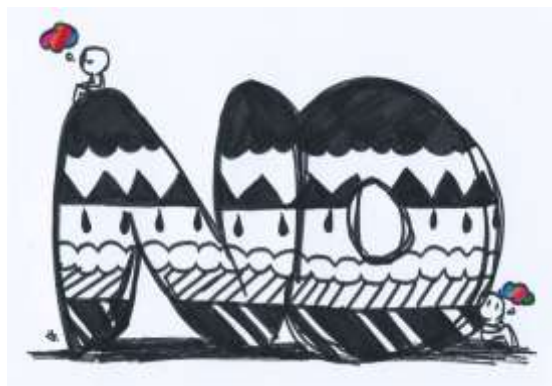
**TOTAL:** It is rare today because there is a lot of information in the media about oncological diseases. However, we still find men who do not initiate conversations about what is happening to them or ask or express any curiosity. This extreme reaction could be a problem if it leads to refusing treatment. Some years ago it was more typical of patients who received information about prostate cancer as being a benign inflammation or breast cancer as a benign lump of fat. If these alternatives were used with the intention to ease the problem, it often resulted in rejections to undergo any treatment, In such cases it was necessary to change the information in order to have a truer interpretation of the situation.

**PARTIAL:** It is quite frequent. There are patients that support the diagnosis but not entirely. They underestimate an initial diagnosis especially if it is a fairly small tumour in the prostate. They deny the possibility of no recovery. What they are denying is the possible consequences of not taking the matter seriously. The crux of the issue is therefore the prognosis.

**INTELLECTUALIZED:** This model is growing. The current trend is to give a lot of information, including jargon which means that the diagnosis is not clear for

several patients. We find, for example, men with prostate cancer who respond automatically with expressions learned by heart such as "prostate carcinoma" when asked if they have any information, and even give a detailed explanation of their Gleason number or other medical characteristics. The way to respond with words learnt by heart makes us realize that they have not entirely comprehended the meaning of those words. The information given to the patient should be adapted to the capabilities of comprehension of each patient. Much care is required in the case of advanced stages of the disease. It is likely that if patients are given a huge amount of information and/or it is formulated in an excessively technical language, so it is unlikely that it will be fully understood by the patient.

Denial is a dynamic state of the mind. Some men begin the illness process by denying it, and after a period of time (especially if anxiety decreases) they are more prone to assume it is a prostate cancer. Other persons accept it from the start, but begin to deny when the illness reappears, sometimes when it means they won't be cured. In other men it never appears or in others denial is a constant phenomenon during the entire clinical course.



Picture by Mercè Estapé

### Denial of psychological suffering

Until now we have been referring to the nature of medical information, but there is a more complex form of denial: the denial of psychological distress due to prostate cancer. Some patients refuse to admit the fear, anxiety and uncertainty that they feel. In prostate cancer this kind of denial is quite frequent. Men are told to be strong, not to be frail or verbalize negative emotions and cry much less. That is nothing that could mean weakness. Even if this trend is changing, it persists in our societies, depending on cultural backgrounds. In this sense they are at risk of not having their needs met in terms of psychological support not only professionally, but also by their families and friends. It is difficult to seek for help without verbalising aloud feelings, anxiety or

having fear or feeling that their self-esteem as men has been damaged. Men are more used to explaining corporal body and physical discomfort than psychological or emotional feelings. Some even try to have a positive look, which is not bad if they really feel that way. Although it is not a correct attitude to risk life as it could have subsequent psychological consequences for the patients and also for their wives and families. Some of these prostate cancer patients express bad emotional feelings and not only at home. In any case, if they refuse emotional or psychological problems due to cancer they are neglecting the need for help or specialized support.

### Can Denial be a positive attitude?

Some authors regard denial as a way to positively avoid suffering. It means that some prostate cancer patients may prefer to live their lives without contact with their illness and, especially when they are cured, try to enjoy life to its fullest. In this case, denial is not a bad attitude, but a different way to live and cope with cancer. If men don't flee from reality and go regularly to their doctor, and do PSA tests when they are needed, we would say that denial is not a problem. Therefore the author regards this attitude as positive. It doesn't lead to avoid being aware of the monitoring requirements in the clinical course or after treatment. They are people who respect their medical needs, and new possible symptoms, but do not engage in prostate cancer or supporting groups, and the subject is not part of their normal activities. Psychological reactions to prostate cancer are individual and unique to each man and should be respected as such. However, when these lead to abandoning medical or psychological monitoring, we can say they definitively need some help.

## One Island - Two Experiences of Prostate Cancer

by John Dowling

The island of Ireland has two legal jurisdictions. The Republic of Ireland, often incorrectly called Southern Ireland, which now has a population of 4.6m. Northern Ireland is part of the United Kingdom and has a population of 1.8m (2011 Census).

The health service in the Republic is part Public and part Private. The health service in Northern Ireland is part of the British National Health Service (NHS) and follows NHS guidelines and practices.

With regard to prostate cancer there is no national screening programme in either jurisdiction, but

medical practice in the Republic uses opportunistic PSA screening to a marked extent whereas in Northern Ireland the practice is not so widespread with regard to younger men, being confined for this cohort to using PSA testing for higher risk men such as those with familial prostate cancer history and those of African or Afro-Caribbean origin.

### The Facts

Time Line	Incidence			Age
	Numbers & percentages	Per 100,000	Overall Population	Median age
Cases Diagnosed (RoI 2010-12) (NI 2009-13)	3,384 1,038	157.3 165.1	4.5m 1.5m	67 years 71 years
Deaths from PCa Republic of Ireland (2012) Northern Ireland (2013)	519 268	22.9* 29.9*		80 years 78 approx
5 Year survival rate 1994-99 (RoI) 1993-98 (NI)	66.1% 55.6%			
5 Year survival rate 2000-2004 (RoI) 1999-04 (NI)	85.4% 72.2%			
5 Year survival rate 2008-2012 (RoI) 2004-2008 (NI)	91.9% 87.0%**			

\* Crude mortality rate per 100,000

\*\* Age Standardised Net Survival Estimate

Statistics from the National Cancer Registry Ireland and the Northern Ireland Cancer Registry

For those who don't like statistical tables what do the above figures tell us?

- The incidence of Prostate Cancer diagnosis is higher in Northern Ireland than in the Republic (165.1 compared with 157.3 per 100,000).
- The age at which men are diagnosed with prostate cancer is 67 in the Republic as against 71 in Northern Ireland.
- Republic of Ireland residents with prostate cancer have a median age of 80 on death, whereas their Northern Ireland comparators tend to die about 2 years earlier.
- The 5-year survival rates are higher for the Republic, but both jurisdictions are showing major improvement in survival over the past two decades.
- The 5-year survival rates over the past 20 years or so have been consistently higher in the Republic than in Northern Ireland.
- The death rate from Prostate Cancer is higher in Northern Ireland than in the Republic (22.9-29.9 per 100,000).

## Why?

The question which arises is why is there such a difference between two sub-populations on the one island. With statistics, things are often not quite what they seem. We know that within the Republic there are marked differences in the incidence of prostate cancer between the different regions of the country. So it is not of itself remarkable that the two larger populations on the island also have differences. Within Northern Ireland there are differences also. In the Republic the incidence of prostate cancer is highest in the west of Ireland which is also the poorest region, with weaker demographic factors (especially the age of men) compared to the east. Cork in the far south is an anomaly. It has higher than average incidence and it is a comparatively prosperous county with a balanced demographic profile.

There is anecdotal evidence that the culture in the medical profession at both general practitioner level and among consultant specialists in urology, radiation and medical oncology in the Republic may be influenced by the fact that a higher proportion of Irish medical graduates who pursue higher-level training do so in the US whereas in Northern Ireland this is often done in England or Scotland.

It is suggested that the greater propensity among medical practitioners in the US to use opportunistic PSA screening had its effect on Irish doctors who returned later to take up positions in the health sector in the Republic of Ireland. Whether this is so or not, there is little doubt that opportunistic screening has been the norm in the Republic for some time and as a result the age of initial diagnosis for prostate cancer has been dropping and is below that in Northern Ireland. It should also be noted that a higher proportion of men die in Northern Ireland compared with those across the border and at a slightly earlier age. These are all indicators which are in accord with the European Randomised Prostate Screening Study which reported in 2009 and for which there is now much more extensive follow-up now available with 10-year survival data.

There are also other, more recent factors, which may also have some marginal impact on mortality rates and curves. In the Republic the reimbursement of new treatments for metastatic Castrate Resistant Prostate Cancer (mCRPC) such as Abiraterone Acetate and Enzalutamide is available on a national basis whereas in the UK generally there is significant variation on the availability of these expensive drugs – the so called post code lottery. This may have an

influence on mortality age and survival rates.

In the Republic about two-thirds of prostate cancer diagnoses now take place in the six Rapid Access Prostate Cancer Clinics which are in public hospitals. The Minister for Health, Leo Varadkar, recently signed an acceptance agreement which introduced new Clinical Guidelines for the Treatment and Diagnosis of Prostate Cancer which will mean a uniform practice across the public hospitals and because many senior clinicians in public hospitals also work in the private sector, the new evidence-based guidelines will undoubtedly become the norm across the country very quickly. There is some concern that the speed with which the Rapid Access Clinics function in terms of follow-up PSA and initial biopsy followed within two weeks by a multi-disciplinary-team treatment recommendations that men are being “sucked” into undertaking radical treatments when some of the low risk patients might at least consider the active surveillance option.

The reorganisation of cancer diagnosis and treatments into a much smaller number of hospitals took place less than five years ago and it will be some time before we can assess whether these changes will impact on the existing differences between the Republic and the North. The big gain of the past two decades for the patient and practitioner has the establishment and resourcing of good Cancer Registries in both the Republic and in the North. There is little doubt that the epidemiologists now have a rich vein of statistics on incidence, survival and mortality to fully inform public policy formation into the future.



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## The Patients' MailBox

by Tania Estape

*1) I feel very tired since I finished radiotherapy, unwilling to do anything, even things that I liked to do. I only want to be at home, alone and doing nothing ... My wife tells me that maybe it is depression. How can I know?*

Comment: Anticancer treatments have side effects like fatigue that sometimes produces symptoms

similar to depression. You need to consult a specialist if this persists. The question is whether cognitions (thoughts) are depressing (e.g. life is not worth living, I'm a mess, and so on). In that case perhaps you need psycho-oncological support. Find a professional that is trained in cancer patients and if possible in prostate cancer patients.

*2) I sense a feeling of distance from my old friends. It seems as if I have had an experience following the diagnosis of cancer that has placed me in another dimension.*

Comment: This is normal and is a frequent comment among cancer patients. The experience of the illness and the resultant treatment represent a difficult personal experience that leaves no-one immune. That is why you think your friends are now in another world. It may be important to try to find people who you note seem to understand you, perhaps some group of cancer patients. Some people say that there is something invisible that unites them and then they begin to talk and explain their feelings in spite of the fact that they didn't know one another previously. But I recommend you to keep in touch with your old friends. Even if you feel that they act somewhat differently. Sure ! there are things that unite you and you can still share with them. Meeting only people who are prostate cancer patients can be a kind of shared isolation that is not right for anyone.

*3) I'd rather not explain to my colleagues that I'm suffering from prostate cancer. I think I'm not ready for that. Is this a perfectly normal reaction or does it mean that I'm not able to accept the diagnosis?*

Comment: The diagnosis of cancer is nearly always difficult to accept. Taboo connotations of disease-related death and suffering accompany this state of mind. Notwithstanding the diagnosis of prostate cancer we still have to work, because sometimes hiding the fact has an impact on the quality of life, that makes men feel little inclined to explain what is happening. Men in general tend to be more reluctant to talk about aspects of their health or any negative feelings. Cancer is not usually immediately an acute illness and the impact it has on the patient's life is normally a long process and varies from one man to the next. Every man needs time to adapt to the new situation and challenges which emerge over time. Therefore there is no magic formula. You must decide and know when and to whom you prefer to talk about it. Otherwise you will not feel at ease.

*4) My husband has been diagnosed with prostate cancer. He has undergone radical prostatectomy and now has no erections. Our sexual life is of importance*

*to both of us, and my husband even fears that I might leave him in spite of my repeated reassurances.*

Comment: The loss of the power of erection is very stressful for men and has a very negative impact on them, as they feel that their masculinity and sexual life have been completely destroyed. In certain cases men do not admit that there may be another type of sexuality and believe the same thing may even happen to their wives. Surely the over-riding desire of the couples is that the husband survives and the sexual problem is something to cope with later. She may think about other options for physical closeness and intimacy. It is important to show their affection to their husbands or life companions and take every opportunity to talk openly and intimately about their feelings. Any request for help or expression of how necessary they are to their wives will surely benefit their confidence that their relationship with their wives is much stronger than they previously imagined.

*5) Each time I have to go through a PSA test I experience a terrible feeling of anxiety. I remain extremely nervous all the day long. I can hardly think of anything else. What can I do?*

Comment: Many people experience great anxiety as the time approaches for periodic diagnostic tests and the time span in order to be informed of the results. It is normal for the fear that the results of the test may show an aggravation of the disease. This is quite coherent, whereas no anxiety fruit of the imagination is unlikely. It is difficult to give guidelines to a situational anxiety caused by anguish while awaiting the test results. However you can try the technique of relaxation and deep breathing. If you have time therapies which focus on the present can also help to divert attention away from anxiety. This must be done with trained professional help. It is not something which can be improvised. It is something that can help you on many similar occasions.

*6) I have just been diagnosed as suffering from prostate cancer. I can not sleep at night. My mind is obsessed by the disease and the fear that I may die. What will happen to my family and will I suffer very much?*

Comment: Insomnia is very common in people diagnosed with any form of cancer. It is logical that the diagnosis will have an impact on our life and we all know the probable consequences. Sleep is one of our most susceptible functions to stressful or traumatic events. Sometimes people temporarily consume any form of psychotropic drugs. However there are ways to at least try to get a more relaxed sleep. Sleep is a natural continuation of wakeful



hours, so the more relaxed you are in the day, the more you will sleep at night. Therefore, on preparing to go to sleep, you should do every thing possible to reduce any stimulation. Try dimming the lights, reducing the volume of sounds (speak in a calm voice, avoid high or loud music .....), eat light and try not to watch TV from the bedroom, read or anything else but, above all, go to bed. These are some guidelines of sleep hygiene but other phenomena may prove beneficial provided that you don't have a natural tendency to suffer from insomnia.



EUomo booth, EMUC, Barcelona, Nov. 2015

## EUPATI – training programmes for patient advocates

by John Dowling

It has been long realised that the patient organisations had to do more than demand “a seat at the table”. It is also necessary to make an effective contribution when the door to the table is eventually prised open. Many patient organisations have made huge efforts to upgrade the knowledge and skills of their patient advocates but as most patient organisations are small and with very limited resources they often fall short in terms of numbers and the levels of expertise achieved.

The formation of EUPATI – The European Patient Academy for Therapy and Innovation – was an initiative to address this. EUPATI is a pan-European Innovative Medicines Initiative project of 33 organizations, led by the European Patients' Forum, with partners from patient organisations (the European Genetic Alliance, the European AIDS Treatment Group, and EURORDIS, universities and

not-for-profit organisations, along with a number of European pharmaceutical companies.

EUPATI aims to help patient representatives be more educated and involved in the research and development process of new medicines by offering reliable, objective, comprehensive lay-friendly information and training on the research and development process of medicines. EUPATI hopes that it will increase the capacity of patients to be effective advocates with meaningful involvement in areas like drug discovery and non-clinical testing, planning and conduct of clinical trials, regulatory affairs, assessment of safety of medicines, benefit-risk assessment, as well as principles of health technology assessment.

### PATIENT TOOLBOX DUE SHORTLY

EUPATI launched the in-depth Patient Expert Training Course in October 2014 and we are launching a web-based educational toolbox, hosting educational material in English, Italian, Spanish, Polish, German, French and Russian from January 2016, aiming to reach 12,000 patient advocates across Europe.

The first cohort of patient expert trainees are now completing their course and the second cohort commenced their course on 7th October. Among the 60 trainees in the second cohort is Europa Uomo Secretary John Dowling. “I am hoping that the course will consolidate my understanding of the medicine research and development process and when completed that I will be able to work with others to transfer that knowledge to patient organisations generally and to my own organisations.”

Dowling says that the organisers claim that participants will spend 250 hours availing themselves of the on-line tuition as well as two weeks of face-to-face workshops held in Barcelona, but those of the first cohort whom he knows are now completing their programme say that the real time is closer to 400 hours. He says that there were four Irish participants in the first cohort and another four in the second. The Irish Patient Platform (IPPOSI) has formed a participants group for the eight Irish trainees and the group have already had a meeting and are using conference calls and Webinars to assist the development of the group. It is hoped that through the agency of IPPOSI this EUPATI group will act as a coordinator of training initiatives for Irish patient groups.

The EUPATI patient experts course is delivered on-line in six modules over 14 months with two face-to-face sessions each about 4 days in duration held in

Barcelona.

MODULE 1: Discovery of Medicines and Planning of Medicines Development

MODULE 2: Non-Clinical Testing and Pharmaceutical Development

MODULE 3: Exploratory and Confirmatory Clinical Development

MODULE 4: Clinical Trials

MODULE 5: Regulatory Affairs, Medicinal Product Safety, Pharmacovigilance and Pharmaco-epidemiology

MODULE 6: Health Technology Assessment (HTA) principles and practices

EUPATI hopes that upon completing the course the trainees will have, among other things, in-depth knowledge of:

The medicines development process from pre-clinical research through approval and post-marketing follow-up. The language and terms used by the different stakeholders involved in medicines development and the relevance of guidelines set by the regulatory authorities and professional organisations

- Personalised and predictive medicine
- How the benefit versus the risk of medicines are assessed and guaranteed
- Pharmacoeconomics, health economics and pricing/costs/reimbursement
- How are clinical trials designed, and by whom?
- How can patients be involved in the development of new medicines

This course has been designed in such a way as to encourage all participants to apply knowledge and skills acquired via three main areas:

- Patient Representation: EUPATI Patient Experts will be able to actively engage in representing a patient perspective in the medicines development process by interacting with scientific committees, Health Technology Assessment agencies, industry, regulatory bodies, academia and other relevant stakeholders.
- Communication: EUPATI Patient Experts will be able to contribute to raising awareness on patient involvement in medicines research and development amongst lay patients, hard-to-reach patients and the lay public. Some examples of activities: writing articles and press releases; organising press conferences; facilitating cooperation with media; being a

spokesperson in TV and radio programmes; utilising social networks and blogs.

- Education/Training: EUPATI Patient Experts will be able to play the role of facilitators/trainers by engaging in activities supporting the dissemination of the education and information programmes for both patient advocates and lay patients and the general public in their countries, through their patient communities and networks. Some examples of activities: providing training to patient advocates; leading workshops; running information sessions for people interested in participating in clinical trials or wanting to learn more.

## About Prostate and Hormones III: A new direction?

by Prof. Louis Denis

The blind belief in hormonal treatment as beneficial for all cases of prostate cancer is over. We do know that hormonal treatment causes increased morbidity and mortality by cardio-vascular incidents in long-term hormonal treatment. A Swedish analysis of 30.642 prostate cancer patients, analysed in 2009, confirmed the new concept. Hormonal treatment is indicated on specific situations (always in symptomatic advanced prostate cancer as primary treatment) and not just to bring T and PSA values down as effective treatment. This explains the popularity of intermittent hormonal treatment as compared to continuous androgen depletion treatment (ADT).

A number of studies confirmed the equivalent of intermittent ADT (IADT) in primary endpoints as survival. The patient suffered fewer side-effects (sexual response) and the treatment is cheaper. A limiting factor is the immediate response to the start of the treatment. A PSA decline to < 4 ng/ml is a prognostic sign of responsive IADT. Again we discuss symptomatic prostate cancer as the jury is out on early or delayed hormonal treatment in advanced cancer.

Personally I believe that a near total drop in PSA values as a reaction to primary hormonal treatment (castration, anti-androgens or both) is a good omen to promise the patient a number of years of treating PCa as a chronic disease. However exemptions are rare but do appear as I believe that a number of CRPC is already present in about 20 percent of cases as part of the cancer cells.

**Table 2:** Choice of approach to treatment

**Indications of ADT with tested medications:**

1. Not in cases of localised cancer followed by watchful waiting and active surveillance.
2. An evidence-based exception: Radiotherapy and a restricted ADT treatment have synergistic results in primary endpoints.
3. With positive glands (except minimal) in a radical prostatectomy.
4. Always in symptomatic prostate cancer.
5. At this moment in time. Individualised treatment
  - LHRH A & anti-androgens, anti-androgens, oestrogens
  - Intermittent treatment (IADT)
  - Delayed hormonal treatment
  - New treatments
    - Enzalutamide
    - Abiraterone
    - Chemotherapy taxanes
    - Radium-223

It is clear that watchful waiting indicated in patients with a short life expectancy (classic < 10 years) due to co-morbidity only receive treatment when symptoms appear. A grain of salt, common sense and the opinion of the cardiologist/general practitioner is basic to this decision. In active surveillance the main drive is an option to curative treatment if needed. The best and sometimes spectacular results are obtained in symptomatic patients usually suffering from vertebral metastatic disease. Monotherapy in localised cancer never led to increased overall or specific survival. Recent progress and interest is noted in the use of oestrogens, corticosteroids (dexamethasone) and their effect on the cell metabolism, the new kids in the block enzalutamide and abiraterone and last but not least the heralded precision medication in CRPC. The concept is promising but the effective practice will require more time (in years).

**Salvage Hormonal Treatment**

It is evident that after some time (years) hormonal treatment wears out in controlling cancer progression. The accepted term is castration resistant prostate cancer (CRPC).

The diagnosis is defined as:

1. Castrate level of serum T < 50 ng/ml or 1.7 nmol/L (new proposed limit < 20 ng/ml or 1.0 nmol/L).
2. Biochemical progression 3x PSA increase over the nadir (lowest value).
3. Radiologic progression with 2 or more new lesions or size increase of soft tissue tumours.

Once confirmed we consider this alarm phase red. Mostly the hormonal treatment is maintained and if not done yet a multidisciplinary consultation of the tumour board is useful and needed. Non-hormonal salvage treatment are possible options such as chemotherapy, immunotherapy, radium-223 as well as palliative treatment.

These treatments are best performed in the frame of clinical trials combined with research on new specific biomarkers and individualised molecular treatment.

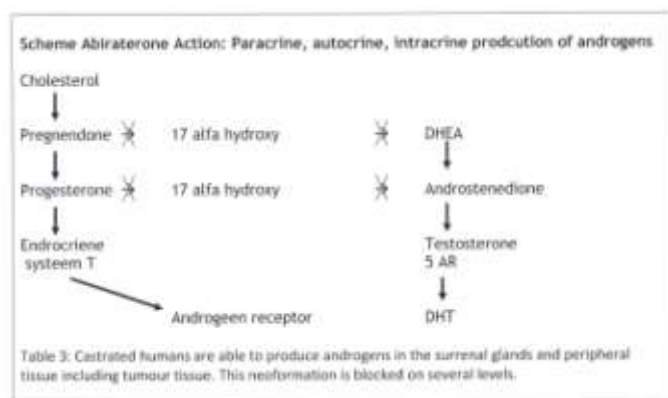
We believe that enzalutamide and abiraterone fall in the realm of hormonal treatment and should be given in a continuing scheme of attacking the cancer cells responsive to hormonal changes.

Recent research is focused on androgen production in the tumour cells (paracrine, autocrine, intracrine) and changes in the AR signalisation (mutations, variations and simple amplification).

**Abiraterone**

Abiraterone Acetate (AA) blocks the production of androgens in the surrenal glands and peripheral tissues (included the tumour tissue) by their inhibition of the progesterone derivatives of cholesterol to androgens.

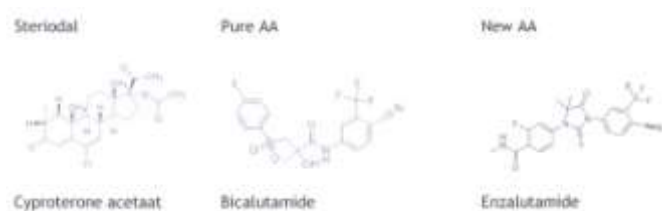
AA is accepted as effective treatment in CRPC and replaces the earlier ketaconazole and liarozole. Administration is combined with prednisone and has shown to increase survival and improvement in the quality of life of the patient. Prednisone (or dexamethasone) serve to restrict the overproduction of mineralocorticoiden (hypokalemia, hypertension and oedema).



**Enzalutamide**

Belongs to the new class of anti-androgens. It has a greater affinity in ligand building and does not lead to AR nuclear translocation. Again increased survival and longer remissions were demonstrated. Some side-effects were reported such as fatigue and rare epileptic incidents (0.6 percent). Enzalutamide is being introduced as primary treatment. See figure 4.

Figure 4: The best known anti-androgens



The indicated treatment for CRPC is in evolution and clinical studies are required to guide the new concepts. Prostate cancer is still a chronic disease but we are getting closer to its solution.

### Conclusions:

Anti-androgens of the first generation (bicalutamide) or the new line (enzalutamide) inhibit the cancer cells from progressing by their action on the androgen receptors (AR). In hormone-response tumours with limited tumour volume they can compete with castration with fewer side-effects on the sexual response. They cause breast formation by the increase of circulating T. The role of enzalutamide is being prepared for routine use in chemo-naïve patients. The definite choice of primary hormonal treatment (a contradiction in terminis) in CRPD between enzalutamide and abiraterone or a combination will depend on ongoing clinical trials. In hormone-responsive cancers there is no debate that ADT by whatever treatment is a first choice when indicated. In castration or worse hormone-resistant tumours, there is a trend towards individualised treatment and personalised care. Progress is shown in controlling the morbidity and mortality of prostate cancer but there is some light at the end of the tunnel. Just as the urologists were able to control the mortality and morbidity of benign prostatic hyperplasia in the previous century, earning their nickname of plumbers, we are confident to limit prostate cancer to a chronic disease in senior citizens in the next few decades.

May we end by reconfirming that US TOO and Europa Uomo will not condone any clinical trials in prostate cancer that omit quality of life and cost-effectiveness as end-parameters.

### Abbreviations:

CRPC	Castration Resistant Prostate Cancer
DHT	Dihydrotestosterone
IADT	Intermittent ADT
LH	Luteinizing Hormone
LHRH	Luteinizing Hormone-Releasing Hormone
MAB	Maximal Androgen Blockade
T	Testosterone

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