**European Association of Urology – Press release**

# *A quarter of Penis Cancer sufferers don't get recommended treatment – halving the survival rate*

**Embargo until: Fri 16th March 2018 at 00.01 CET (Copenhagen)**

A major international survey has found that around a quarter of patients are not receiving the recommended treatment for cancer of the penis. It also found that these patients had half the survival rate of those who were treated according to guidelines. The study, presented at the EAU conference in Copenhagen, finds that non-adherence is partly due to patients refusing treatment, or doctors being reluctant to treat appropriately or being unfamiliar with the best procedures.

Penis cancer is considered a rare human cancer. Around 1 in 100,000 men contract penis cancer every year in the West (which means that a country such as the UK has around 640 cases per year. The US sees 2320 cases per year), however in recent years this rate has risen by 20% to 25% in many countries[1], especially in older men.

Cancer of the penis is extremely distressing. As the American Cancer Society says "*cancer of the penis can be a frightening prospect. Partially or completely removing the penis is often the most effective way to cure penile cancer, but for many men this cure seems worse than the disease.*"[2]

In this large international survey, researchers found that a significant minority (25%) of patients do not receive the recommended treatment. In part this is due to patients being reluctant to go ahead with surgery which removes all or part of the penis, in part due to doctors not proceeding with the appropriate surgery to treat this rare cancer.

Researchers from 12 centres in Italy, Spain, the USA, Brazil, and Hungary, looked at adherence to the EAU guidelines on treatment of penile cancer. They retrospectively examined the records of 425 patients who had been treated in the 2010-2016 period. Lead author, Dr Luca Cindolo (Abruzzo, Italy) said:

"*We found that most patients were treated in accordance with the gold-standard EAU recommendations[3], but around 25% of patients had not received appropriate treatment. From our work, we see that around twice as many patients survive if they have been treated according to recommended guidelines.*

*In around half of those patients not treated according to guidelines, the decision was made by the doctor, and we suspect that this is because many doctors are unfamiliar with treating this rare, but devastating cancer. In one in 6 cases, the patient, or the patient's carers, made the decision not to be treated according to guidelines. We often find that patients don't want to be treated, or that the patients' carers are unwilling to take the decision to treat*.

*These are often difficult treatment decisions to take, and so they need to be arrived at after open discussion between the patient and the medical team. It's a condition which most urologists don't see very often, so it's best if the medical team is experienced in dealing with the condition. This may*

*mean that the treatment in national or international centres of excellence is the best way to proceed."*

Commenting, Dr Vijay Sangar (Director of Surgery, Christie Hospital, Manchester) said:

*"We often find that patients with rare cancers get short-changed because the cancer is so seldom encountered by doctors. We can suggest that if we treat rare cancers in national or even international centres of excellence, the chances of better management improve. In the UK for example, we centralised the treatment of penis cancer into just 10 centres of excellence, whereas in some countries such as Hungary, Spain, and Italy, these rare urological cancers are still treated locally, which may reflect the lower survival rates. Generally, the more penile cancer a team sees the better they become at managing the disease. The recently established eUROGEN consortium will make a huge difference to European patient care; this gives patients with rare urological diseases access to the best management no matter where they are in Europe."*

*Notes:*

1 England figures https://www.medscape.com/viewarticle/877837. Denmark, https://www.ncbi.nlm.nih.gov/pubmed/22101453

2 https://www.cancer.org/cancer/penile-cancer/after-treatment/emotional-health.html

3 *EAU guidelines on penile cancer: 2014 update. Eur Urol. 2015 Jan;67(1):142-150. doi: 10.1016/j.eururo.2014.10.017*

4 *See* http://eurogen-ern.eu/

**ENDS**

**Notes for Editors**

**PLEASE MENTION THE EUROPEAN ASSOCIATION OF UROLOGY CONGRESS IN ANY STORY RESULTING FROM THIS PRESS RELEASE**

The 33rd European Association of Urology conference takes place in Copenhagen from 16th to 20th March. This is the largest and most important urology congress in Europe, with up to 14,000 expected to attend. Conference website http://eau18.uroweb.org/

**Contact details**

Dr Luca Cindolo: lucacindolo@virgilio.it
Professor Vijay Sangar: vijay.sangar@nhs.net
EAU Press Officer, Tom Parkhill: tom@parkhill.it telephone +39 349 238 8191

**Abstract (AM18-2684), poster session 03.**

**The adherence to the EAU Guidelines dramatically influences the survival of patients with penile cancer: Result from a retrospective international study (PECAD Study)**

**Authors**
Cindolo L. [1], Bada M. [1], Nyirády P. [2], Varga J. [2], Spiess P. [3], Chipollini J. [3], Ditonno P. [4], Battaglia M. [4], Chiodini P. [5], De Nunzio C. [6], Tema G. [6], Veccia A. [7], Antonelli A. [7], Musi G. [8], De Cobelli O. [8], Conti A. [8], Micali S. [9], Alvarez Maestro M. [10], Quesada Olarte J. [10], Diogenes E. [11], Valima M. [11], Tracey A. [12], Guruli G. [12], Autorino R. [12], Schips L. [1]
[1]ASL Abruzzo, Dept. of Urology, Chieti, Italy, [2]Hospital of Budapest, Dept. of Urology, Budapest, Hungary, [3]Moffitt Cancer Center, Dept. of Genitourinary Oncology, Tampa, United States of America, [4]University of Bari, Dept. of Urology and Andrology Unit II, Bari, Italy, [5]University , Medical Statistics Unit, Naples, Italy, [6]Hospital "Sant'Andrea", Sapienza

University, Dept. of Urology, Rome, Italy, [7]Hospital “Spedali Civili”, Dept. of Urology, Brescia, Italy, [8]Istituto Europeo Oncologia, Dept. of Urology, Milan, Italy, [9]University of Modena & Reggio Emilia, Baggiovara Hospital, Dept. of Urology, Baggiovara, Italy, [10]Hospital Universitario La Paz, Dept. of Urology, Madrid, Spain, [11]Ceara Cancer Institute , Dept. of Urology, Fortaleza, Brazil, [12]Virginia Commonwealth University, Dept. of Urology, Richmond, United States of America

**Introduction & Objectives**

To evaluate the adherence to the EAU guidelines on penile cancer (PC) in terms of primary treatment and lymphadenectomy; and to weight the impact of the adherence on survival outcomes.

**Materials & Methods**

We retrospectively reviewed the clinical charts of patients underwent penile surgery for neoplasms in 12 Euro-American Centres (2010-2016). Demographics, patient’s comorbidity, circumcision, site of primary lesion, perioperative and histopathological data were collected and analysed. The follow-up was updated by recall of all patients.
For each case the theoretical adherence to 2016 EAU Guidelines for the primary surgery and the lymphadenectomy were evaluated. A comparison between theoretical and practical surgical approach was done in order to evaluate the adherence rate. The TNM 2009 was used to classify stage and grade. Descriptive, univariate and multivariate analyses were performed to evaluate the impact of the adherence on survival. Kaplan-Meier curves were estimated.

**Results**

425 patients were enrolled (median age 65y +/-13). 58% was uncircumcised. The lesions were located at the glans, the prepuce and on both sites in 65%, 10% and 25%, respectively. The surgical approaches adopted were radical circumcision, tumour excision, glansectomy, penile partial amputation, total emasculation in 6.3%, 22.8%, 9.4%, 48%, 13.4%, respectively. All PC were squamous carcinoma. The staging was 14.3% The adherence to the EAU guidelines for primary treatment was respected in 74.8% of patients. In non-adherent cases the reasons for discrepancy was a choice of the patient in 17%, of the surgeon in 52% and other causes of 31%. The adherence to the EAU guidelines in terms of LY was respected in 73% of patients.
Survival estimates showed that the adherence to the EAU Guidelines on Primary Surgery, after adjustments for age, TNM stage and LY significantly influences the overall survival (HR 0.47 (95% CI 0.22-0.97, p=0.037)). Moreover the adherence to the EAU Guidelines for LY, after adjustments for age, TNM stage, Palpable Nodes and Grade, significantly influences the overall survival (HR 0.46 (95% CI 0.23-0.92, p<0.023)). The adherence to EAU Guidelines showed a trend of statistical significance on Progression Free Survival.

**Conclusions**

Our data showed that the adherence to the EAU Guidelines on PC:

- is quite optimal across 12 Euro-American Centres;
- strongly influences the survival outcomes;
- should be reinforced, endorsed and encouraged in all the centres treating PC.