

Orchid: fighting male cancer for over 25 years

Orchid was established in 1996 by a young testicular cancer patient, Colin Osborne MBE, and the oncologist who saved his life, Professor Tim Oliver MD, FRCP. The charity exists to save men's lives from testicular, penile, and prostate cancers and to help those living with a diagnosis. We do this by supporting pioneering, world-class research and through the delivery of nurse-led support services, and education and awareness activities.

We are proud that our track record was recognised when Orchid was a runner up in the 2019 GSK's IMPACT Awards (run in collaboration with The King's Fund) developed to recognise excellence in small charities providing support for health and wellbeing.

Orchid's roots are in research and our current research focus is the Robert Lane Tissue Bank, incorporating the Circulating Tumour Cell project, which is based at the Centre for Molecular Oncology at the Barts Cancer Institute in Charterhouse Square in London. This is a mature tissue bank with specimens for over 13,000 patients, and it has an ongoing collaborative collection of circulating tumour cells with over 1200 blood samples. It is an important link between the laboratory and the clinic, as being able to use or see the actual tissue under a microscope and to know the patient's medical history is key to helping understand male cancers.

The research team, led by Professors Dan Berney and Yong-Jie Lu, collect and validate tissue from male cancers from high quality clinical trials and cohorts to advance understanding of prostate, testicular and penile cancers, creating better prognostic and predictive targets for treatment and diagnosis. The work also helps increase understanding of the molecular mechanisms of prostate cancer development, progression and response to therapies, and the development of biomarkers for the diagnosis, prognosis, and treatment response prediction of prostate cancer, as well as testicular and penile cancers.

Alongside funding research, Orchid identified the need to develop nurse-led services in response to the rising number of male cancer cases each year, and the low awareness of risk factors, signs and symptoms resulting in late diagnoses. Educating men about the risk factors, signs and symptoms to encourage an early diagnosis if needed remains a priority, as does helping those diagnosed better understand their situation, feel less isolated and better able to cope.

Orchid nurse specialists run a Freephone Male Cancer Helpline for anyone worried about male cancers. The hours were increased in March 2020 knowing that our colleagues in the NHS might not have time to answer men's queries, and not surprisingly last year saw an increase in the number and length of calls as many callers raised issues made more complex because of COVID-19.

The Orchid website provides a wealth of information for anyone affected by male cancers, as well as healthcare professionals. Traffic to our website also increased last year, as it did to Orchid's award-winning Testicular Cancer Microsite 'Your Privates', a one stop shop about testicular health and cancer which includes PHSE-accredited educational resources for young people.

Knowing that not all men engage with their health or traditional health services, Orchid reaches out into the heart of communities to pass on health messages via Male Cancer Information Roadshows, Health at Work talks and presentations to community groups. Our Community Engagement Team are skilled at engaging the local community using a range of games and synthetic testicular and prostate models to encourage conversations.

Orchid has developed a portfolio of easy-to-understand paper-based and film resources. These include our discreet, wallet sized



Professor Dan Berney from Robert Lane Tissue Bank.



Robert Cornes, Orchid Male Cancer Information Nurse Specialist, works closely with healthcare professionals and in collaboration with other organisations, offering specialist support and training.

Z-cards about each male cancer which are particularly popular at roadshows, our unique series of leaflets about the different stages of penile cancer, and our recently developed check card to help those with a male cancer concern to prepare for a GP appointment. Films include an animated film, *My Penile Cancer Journey*, and the award-winning *Uncle Mike* which tells the story of a young man and his mentor, and the impact prostate cancer has on their relationship.

Orchid has also delivered targeted projects in response to specific need. These include the Penile Cancer Support Service developed in response to there being increased penile cancer cases in Scotland in comparison to the rest of the UK; a London-based project targeting Black African and Black Caribbean men at increased risk of prostate cancer; and a new project through which Volunteer Community Champions will cascade prostate cancer information in 10 identified locations in England to help overcome the barriers to engaging with prostate cancer.

To complement our male cancer awareness activities, we have been growing our social media presence. Orchid Male Cancer Awareness Week in both 2020 and 2021 (which for the first time ever had a focus on penile cancer) was delivered predominantly digitally, and our followers are increasing and becoming more engaged.

For those living with a male cancer diagnosis, peer support is important, especially for men diagnosed with the rare penile or testicular cancer. Orchid continues to help facilitate opportunities both in person and online. Orchid also refers people to a bespoke telephone-based testicular and penile cancer counselling service it developed.

Recent activities from Orchid include: working with eUrogen / Eurodis (The European Network for Rare Urogenital Diseases), a network of European urologists and institutions whose aim is to improve the treatment of rare urological diseases including penile cancer in Europe; the delivery of a virtual conference on the first International Penile Cancer Awareness Day; and the formation of The Orchid Penile Cancer Steering Group which aims to foster links with anyone throughout the world who actively provides psychological, medical and peer support in order to create a global resource and support network.

For more information about our services, to request or download free resources, or to find details of Orchid's social media, please visit the Orchid website or email.



<https://orchid-cancer.org.uk>



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