



# spanc

Study of the Prevention of Anal Cancer



## ISSUE 7 DECEMBER 2014

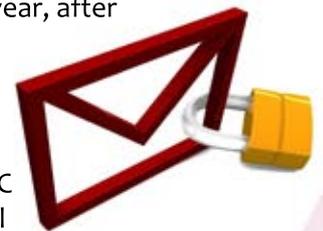
Season's Greetings and a big thank you to the 470 participants now enrolled in SPANC. Without your generosity, patience and endurance SPANC would not be the success it is today. This SPANC year hasn't been without its hurdles but we have come out the other end older and wiser – more about that inside! And just a reminder, SPANC will be recruiting right up until July 2015 (when enrolments must cease) so don't forget to tell your friends they will miss out if they don't join soon. We particularly welcome more HIV positive participants in the study.

## What's new in SPANC...

- ▶ New procedures in place for addressing confidentiality issues when sending group emails
- ▶ The SPANC Information Night
- ▶ Q&A - Our doctors answer some of the questions you have raised in your survey feedback.
- ▶ Media attention on the results of SPANC - Gay news network 29 July 2014

## SPANC is taking new measures to ensure participants' email confidentiality

You will all be aware of the email error that occurred in September. In late October this year, after an extensive review of procedures that we were using to send out group emails (such as this Newsletter), a new method of communicating with SPANC participants via email was approved by St Vincent's Hospital Human Research Ethics Committee.



With this new procedure in place you will no longer receive any group emails from SPANC staff using the cc or bcc functions. These same new procedures have been adopted by all Kirby Institute staff who have contact with their study participants. The Kirby Institute has adopted a University of NSW IT mail-out system called 'Mailman' that makes it impossible for group emails to be sent out showing multiple email addresses, thus making the use of cc or bcc functions obsolete. The UNSW Mailman mailing list service is used by UNSW Departments and Schools for any mailing lists that contain non-UNSW email addresses. This service is provided, maintained and secured by the UNSW Central IT Department. The recipient sees just a single email address i.e. Kirby-spancmm@kirby.unsw.edu.au, so there is no possibility for a recipient to expand the distribution list to see any individual addresses. In this way the privacy of the recipients' email addresses is secured.

The SPANC team thank you for your patience and understanding during this review period and we apologise again for any problems that may have arisen from the inadvertent breach of your privacy.



## Fair Day - 22 February 2015

The SPANC team will be at Fair Day so pop in and say 'hello' at the SPANC stall. We'll be giving away sunscreen generously donated by Banana Boat, Ego Sun Sense & Hamilton.

## SPANC Information Night

On Wednesday 25th March 2015 we will be hosting a SPANC Information Night for SPANC participants. The purpose of this evening is to provide you with interim study findings, current ideas about and approaches towards anal cancer prevention and the projected directions for SPANC until the final follow up of our last participants in 2018 and beyond. There will be a Q&A format included, some surprises throughout the evening, and refreshments will also be served.

You may be concerned about your privacy at an event like this. Please be assured that the only people invited to attend this event will be SPANC participants (and a partner or friend if you would like to bring them along), frontline SPANC staff that you may have met during your SPANC visits or talked to on the phone, Study Investigators & a few representatives of community organisations, some of whom will be presenting data on the night.

The event will be held at the Function room located in St Vincent's Clinic, Darlinghurst (next to St Vincent's Private Hospital)

**Time:** 6.30pm

**Date:** Wednesday 25th March 2015

**Place:** Function Room, St Vincent's Clinic  
406 Victoria Street, Darlinghurst NSW 2010

**RSVP** as soon as convenient

To help us with catering requirements, would you please email [SPANC@kirby.unsw.edu.au](mailto:SPANC@kirby.unsw.edu.au) simply noting "SPANC night", "yes" and "1" or "2" (for example, the number attending including yourself)



### HONOUR AWARD (health and wellbeing category) - 2014



Professor Andrew Grulich

**GNN Gay news network 21 Sept 2014** - For over two decades, Prof. Andrew Grulich has been one of Australia's leading HIV researchers and public health physicians. He has initiated and/or collaborated on some of Australia's most important studies relating to HIV prevention, HIV transmission and gay men's health, has published hundreds of highly influential research articles, and has engaged in cutting edge research that crosses boundaries between epidemiology, clinical, behavioural and social research. He has also made significant contributions over many years to HIV and LGBTI community organisations through board and committee memberships.

## Media attention on the results of SPANC - GNN Gay news network 29 July 2014

### 'PRELIMINARY RESULTS OF SPANC STUDY REVEAL ANAL LESIONS MAY SPONTANEOUSLY RESOLVE'

At the International AIDs conference in Melbourne this year Professor Andrew Grulich from the Kirby Institute presented preliminary results from the Institute's Study of the Prevention of Anal Cancer (SPANC) which measured the prevalence of anal lesions and cancers in gay men who have HIV.

While the study has shown that anal lesions and high grade anal dysplasia (see explanation in next paragraph) is common among gay men and men who have sex with men (MSM) who are living with HIV, Professor Grulich's findings have revealed the lesions often resolve spontaneously and routine treatment may be unnecessary.

Anal cancer and its precursors, anal dysplasia and neoplasia (abnormal cell growth and tissue changes), are more common among people living with HIV – especially men who have sex with men – than in the general population.

Grulich's 'natural history' study was designed to learn more about the role anal human papillomavirus (HPV) infection and anal cancer precursors in HIV-positive and HIV-negative gay men plays in incident, risk factors and occurrence.

Some high risk types of HPV can lead to anal and cervical cancer, often first manifesting as intraepithelial lesions (LSIL), which can progress to high-grade lesions (HSIL).

However HPV does not always cause abnormal changes and Grulich's study has shown that HSIL is quite common in gay men and frequently resolves without any treatment. To find out more please visit the SPANC website and look under 'reports'...

### New resource for anal cancer information

[www.thebottomline.org.au](http://www.thebottomline.org.au)

This website produced by the Australian Federation of AIDS Organisations (AFAO) is intended as a resource for gay and other men who have sex with men. The resource contains detailed information about how anal cancer affects gay men. For more information check out this new resource now.



SPANC's recruiting until July 2015 - don't forget to tell your friends they will miss out if they don't join soon.

Did you know that a new group called "Friends of SPANC" has been formed this year? They have been working on helping with raising funds for equipment used in SPANC. The first item that has been received from a Friend of SPANC (picture) is the beautiful ergonomic surgical chair for the procedures in SPANC. Please note that there is a colour theme emerging for SPANC ... All different shades of PINK! Dr Carmella Law has indicated that she will offer pink carpet treatment from now on rather than red carpet treatment. SPANC participants are encouraged to ask for this when they book their appointments.



### Thank you for helping out

Some of you have been asked when you've come into the clinic for your visit if you'd mind having another doctor being present in the procedure room for the purposes of training and standardisation of our procedures. As you can imagine training other doctors in these specialised procedures is important but we also acknowledge that this can also be confronting for some participants. Thank you to those who were able to assist us during these training days. Your assistance has been most appreciated.

# Q & A

## Our doctors answer some of your questions...

**Q:** I noticed that my hemorrhoids were painful for 72 hours post-examination. Is this normal?

**A:** Haemorrhoids, although sometimes painful, are just slightly enlarged veins, which can sometimes occur following the anoscopy procedure. In the majority of cases this does not last for more than a few hours. Anal pain lasting for more than 72 hours may be due to other causes, so that needs to be checked by your local doctor or, failing that, by your SPANC doctor.

### Test results after my SPANC visit.

From time to time some of you have phoned asking why you haven't received your SPANC results yet.

We aim to deliver your test results within 28 days of your SPANC appointment. Blood results come back sooner, but results from the swab or biopsy (if any were taken) can take up to 3 weeks or more, so the nurse waits until they are all back rather than calling you multiple times.

- If you haven't received your results within 28 days, please phone the study nurses on 8382 3106 or email [spanclinical@stvincents.com.au](mailto:spanclinical@stvincents.com.au) for St Vincent's, and 9515 1200 for RPA Sexual Health.

- If you've elected to receive your results by email, please add [spanclinical@stvincents.com.au](mailto:spanclinical@stvincents.com.au) to your email address book – this will stop our emails ending up in your 'junk mail'

- If you've received your results by email, please hit reply adding a quick 'yes' to indicate you have received them.

**Q:** My 2nd results came back as abnormal. This has caused significant distress, but there is little I can do until my next anal test.

**A:** Abnormal results are very common in the SPANC study, as we are using extremely sensitive tests that pick up even minor changes. Most abnormal results are of fairly minor importance. However, if you are worried about anything, please call 02 8382 3106 to speak to the SPANC study nurse, who will put you on to the doctor if required.

**Q:** What services for anal cancer screening will be available for the study participants when the SPANC study concludes?

**A:** When participants in SPANC attend for their 6th visits they are given a summary of all their results throughout the study, and a rough estimate of their possible risk of anal cancer. Those with higher levels of risk are scheduled to have 1-3 year follow up anoscopies in the Dysplasia and Anal Cancer Services (DACS) clinic at St Vincent's hospital, with Dr Richard Hillman.

**Q:** Is there a short video link as to what to expect with exam as I know for me, as I am bad at reading ALL the info sent but short video or picture's may be quicker/easier for some??

**A:** Thank you for your suggestion! We can definitely consider putting a video on the SPANC website to give you a visual image of what to expect when you attend for your SPANC visit. This will be a project for the early part of 2015. Watch this space ....

**Q:** What about a reclining chair/couch that the Doctor spoke about?

**A:** This is on the top of the wishlist for SPANC and there are some "friends of SPANC" who are working on putting

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# Q & A

*...continued from page 4*

••together donations for the chair. But this is likely to be a longer term project ... unless we get enough funds suddenly. The doctor is optimistic and can't wait till you guys get to be examined on the "dream couch", just like the patients in San Francisco!

**Q:** Can you keep researching new ways of examining the anus that can be far more comfortable, and enable the anus to relax far more?

**A:** Several of the doctors have just been at an advanced technical course in anoscopy and have come back with more ideas to try out to make your procedure more comfortable.

**Q:** Could I have had a reaction to the staining process?

**A:** A very small percentage of people feel stinging when the iodine is put on. That is why the doctors wash off the iodine after the examination. Sensitivity to the vinegar solution is less common, but again the doctors can wash off the vinegar if you feel stinging when it is applied. Please tell the doctor or nurse on your next visit if you think you are reacting to either of the 2 solutions.

**Q:** Is my partner not allowed in the room to be with me? We share everything in our lives - except anal screening?

**A:** The examination room is quite small and cramped, and we need to prioritise space for the doctor, nurse and equipment. However, if you feel strongly about your partner being present, please raise it with the research assistant when you are booking your appointment and he can discuss it with the doctor and nurse and get back to you with confirmation.

**Q:** Is it possible to follow up more detailed results – maybe a letter – something in writing may be?

**A:** SPANC policy is to email results to every participant and also call all participants with high grade changes (in their Pap smear and/or biopsies). This means that there is always provision for discussion with the nurse. If you do feel that you need to speak to the doctor, the nurse is able to refer you on. If you would like more than this, please let the nurse or doctor know or ask the research assistants to pass on the message. Next year the workload will be significantly increased as we head towards 500 and then 600 participants with only a slight increment in staffing levels. We will always do our very best to respond to requests from participants, but sometimes our staffing levels may make it a little difficult for us.

SPANC is funded through the Australian Government's chief medical research agency, the National Health and Medical Research Council and the Cancer Council of NSW. The total through these two sources is over \$3 million.

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[spanc.org.au](http://spanc.org.au)

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*"Thank you for your support"*