thePOSNOCstudy

PARTICIPANT NEWSLETTER - SE

POSNOC

POsitive Sentinel NOde: adjuvant therapy alone versus adjuvant therapy plus Clearance or axillary radiotherapy

Welcome

Welcome to the second edition of the POSNOC participant newsletter! We thought it would be a good time to get in contact and let you know what's been going on with the trial. There have been some important and exciting developments since the last newsletter and we're looking forward to telling you all about them. We hope you find the time to read this leaflet and find it both useful and enjoyable.

Website re-launch

The POSNOC website has recently undergone a re-vamp to update the appearance of the page as



well as the information, making the website far more user friendly. The website will be a hub for all POSNOC updates, trial developments and any other information that is relevant and interesting to participants, healthcare professionals and the interested general public. There is now a section where you can easily access our Twitter page – so please feel free to have a tweet with us! There are useful links to various documents and websites that

could be of interest to you, your friends and family. Please take a look and explore the new website at...

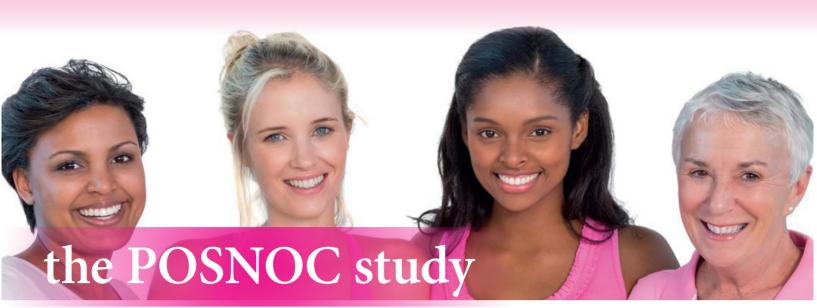
Australia & New Zealand Derby Teaching Hospitals Australia & New Zealand Derby Teaching Hospitals Australia & SHORE Stress Field October Reserve to 10





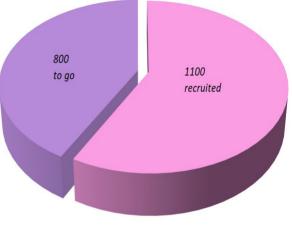
AUGUST 2018





Current recruitment

We are extremely proud to report that we have recruited over 1000 participants onto the trial! This is a huge trial milestone which we achieved back in April this year. Whilst we still have a way to go to reach our 1900 participant target it is still a fantastic achievement. We'd like to thank each and every one of you for helping us achieve this milestone and for your continuing commitment and passion for improving the standards of breast cancer care for women everywhere.



recruitment figure correct as of July 2018

Since achieving our 1000th participant milestone we have recruited steadily and are pleased to confirm that we have now recruited over 1100 participants onto the trial. Thank you again for your continued support.

The trial has been extended

We are pleased to announce that POSNOC has now received approval to extend the recruitment period up until 31 August 2021. Whilst this will not affect your trial visit schedule, it is important to know that if you have consented to receive the results at the end of the trial, that these will now be distributed during 2027. The extended end date allows us more time to achieve our total recruitment target of 1900 participants.

AUGUST 2021						
SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31)			



POSNOC study follow-up visits

We appreciate that balancing life alongside participating in a long running clinical trial can be tricky at the best of times, and that after a few years the follow-up visits can become increasingly difficult to manage with work and life commitments. Just as a reminder the POSNOC trial involves 5



years of follow-up, which for the first three years requests completion of questionnaires and participation in clinical and telephone consultations. For us to be able to report the most accurate result at the end of the trial we need to have as much of the follow-up data completed as possible so any information you can provide when requested by your local research team is hugely appreciated.

Please contact your local research team with any questions you may have regarding your visit schedule and to enquire about what you can expect from these follow up visits. Together we hope that we can help improve the treatment and care of breast cancer for the better.

Your voice...

We are very interested to hear about the your experience of the POSNOC trial and your journey as a participant. We hope that these newsletters can serve as a forum for the POSNOC community, and where possible, we would love to share individual POSNOC participant stories. Please contact us if you have a story you would be willing to share with the rest of the community. In this edition we have heard from Kierstan, who joined the trial back in April 2015:

"I've been taking part in the study since shortly after my diagnosis in April 2015, aged 40.

My treatment went well and finished in January 2016. It all feels very much behind me and I am in very good health.

I have always been happy to be involved in the POSNOC study - it feels as though it is something positive to come out of a challenging period. And a tiny contribution on my part to medical science / treatment research - for which I am enormously grateful."



- Kierstan



A message from the Chief Investigator:



Amit Goyal

"More than 1100 women have joined the study! Thanks a lot for making the study a success. The study is monitored closely and it is reassuring that no concerns were identified by the oversight committees. I would like to encourage all women to complete the questionnaires and attend the follow up visits when requested so that the study can generate good quality data allowing to change the lives of future breast cancer patients worldwide.

We are looking for participants who are willing to be ambassadors for the study and help raise awareness of the study and the side effects or armpit treatment in their own way e.g. twitter, facebook, local patient support groups.

Together we can reduce the unpleasant side effects of cancer treatment and #makelymphoedemahistory"

And from the Australia and New Zealand Investigator:

"Breast units from around Australia and New Zealand were delighted to learn of the extension time granted to POSNOC to ensure full accrual. We have all our sites open, and are considering extending POSNOC to one or two more sites. Despite commentary from North America that the question of axillary management has been resolved by the ACOSOG Z0011 trial, Australian and New Zealand clinicians remain unconvinced, with most patients with macrometastases still being advised (or choosing) to have axillary treatment. Interest in POSNOC remains high, although it is proving difficult to recruit patients, as many of our patients choose axillary treatment. We are confident that we will continue to recruit patients to this vital clinical trial"



Bruce Mann



Have your say...

If you would like to share your POSNOC story, we would love to hear about your experiences and view of the study. Please contact us using the details below if you would like to be included on our next newsletter or on the POSNOC website.

Please be sure to get in touch with your local research team if you have any concerns about your treatment.

For any general trial queries please get in touch with your study coordinating team:

UK: Nottingham Clinical Trials Unit Email: <u>POSNOC@nottingham.ac.uk</u>

ANZ: Breast Cancer Trials breastcancertrials.org.au

Visit our website at www.posnoc.co.uk



Follow us on Twitter @POSNOC

#makelymphoedemahistory

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