

October 2016, Issue 1



# Message from the Chief Investigator

Dear colleagues,

Welcome to the first edition of the FUTuRE Fertility Research Program Newsletter. The newsletter will be sent out every quarter to provide information about achievements and important updates and developments regarding the Australasian Oncofertility Registry (AOFR) and other research projects associated with the FUTuRE Fertility Research Program.

I would also like to take this opportunity to personally thank you for your ongoing support and commitment to the study.

- Dr Antoinette Anazodo

#### **Staff Changes**

As you may be aware, there has been some changes with the Senior CRA this year; Michael Shum has taken a Management role within Prince of Wales Hospital and Eden Robertson is currently pursuing her PhD. If you could please direct all communication to our new Senior CRA, <u>Debbie Chia</u> at the Kids Cancer Centre. Her contact details can be found below.

<u>Katie O'Neill</u> has recently been appointed as the CRA for South Australia and is the main point of contact for all South Australian sites.

E: Katie.ONeill@flinders.edu.au

Watch this space: we will be recruiting two new part-time CRAs in both Queensland and WA soon!

#### Follow-up

As we are approaching our one year mark of data collection, just a friendly reminder to enter follow-up data if available and ensure each patient's details are up to date. Male patients should be followed on alternate years (blood sample and semen analysis in years 1,3,5) and female patients on an annual basis (blood sample and pelvic ultrasound in years 1-5). If these tests are outside of their required medical care, it is optional and not a requisite for participation in the study.

## Registry Statistics

State	Site	n
NSW	Sydney Children's Hospital	18
	Royal Women's Hospital	5
	Prince of Wales Hospital	10
	St Vincent's Clinic	5
	Genea	1
	IVF Australia	2
VIC	Melbourne IVF	27
NZ	Christchurch Hospital	7
	Wellington Hospital	0
	Starship Children's Hospital	1
QLD	QFG	0
	Monash IVF Auchenflower	0
ACT	Canberra Fertility Centre	0
	Total	76

#### **AOFR Tips!**

Are you having issues entering patient data into the Registry? If the field you require is missing, click 'New Notes' under 'Notes and Attachments' and enter the details in. Please contact Debbie Chia if you have any issues.



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## FUTuRE Fertility Psychological Health Research Study

The FUTuRE Fertility Psychological Health research study aims to prospectively investigate the short and long term fertility related concerns, quality of life and psychological distress that cancer patients of reproductive age (15-44 years), and their families (parents or partners) experience. Additionally, the study is recruiting male and female controls (15-44 years) who do not have cancer but have fertility related concerns or known difficulties as a comparison group. Participants engage in an online survey and qualitative phone interview across three time points (cancer diagnosis, 12 months and 3 years) to capture how fertility concerns and support needs change across time, with reimbursement for participation at each time point.

Cancer patients of any registry participating site who have been recently diagnosed are eligible to be invited into the Future Fertility Psychological Health Study, including those already enrolled onto the registry who have agreed via consent to be contacted about other fertility research studies. Currently the study has recruited 24 cancer patients, 8 parents and 45 control participants onto the study, with a desired sample of n=50 per group. If you would like to find out more about this study please contact the FUTuRE Fertility Clinical Psychologist, Dr Shanna Logan;

E: Shanna.Logan@unsw.edu.au



## **FUTuRE Fertility Website**

We have included new information and resources on the website. Please feel free to view it at: www.futurefertility.com.au

We hope that it will become a helpful useful resource for both clinicians and patients to access oncofertility related information. If you would like to include information on the website please contact Brigitte;

E: Brigitte.Gerstl@health.nsw.gov.au

#### **New International Sites**

We are thrilled to announce that the Children's Hospital of Orange Country (CHOC) have ethics approval to begin recruitment of patients onto the registry. We are also about to launch the study with our Indian colleagues from the Gunasheela Fertility Centre in Bangalore. We will keep you updated with further progress at these sites.

## Suggestions

If you would like to contribute news or information in the next Newsletter edition, or have suggestions that you would like included, please feel to email Debbie Chia;

E: Debbie.Chia@health.nsw.gov.au

# Follow us on:



@futurefertility



@ANZoncofert

#### **Study contacts**

Chief Investigator:

Dr Antoinette Anazodo P: (02) 9382 1733

E:Antoinette.Anazodo@health.nsw.gov.au E: Brigitte.Gerstl@health.nsw.gov.au

National Project Manager:

Brigitte Gerstl P: 0404 082 190

Senior Clinical Research Associate:

Debbie Chia P: (02) 9382 3119

E: Debbie.Chia@health.nsw.gov.au