

# NRAMP Newsletter



For Participants

## NRAMP Newsletter for Participants

### Welcome to NRAMP

#### (The National Register of Antipsychotic Medication in Pregnancy)

We are delighted to join you once more, and to bring you up to date with 'all things NRAMP'. Welcome to all our consented participants and to those amongst you who may be considering taking part in our study. We always welcome your queries, comments and suggestions, and would encourage you to discuss the study with your family, friends and healthcare professionals if that would be helpful in your decision-making process.

### Brochure for Potential Participants

We have recently developed a quick reference guide, in the form of a brochure, for potential participants and other interested parties who would like to learn more about NRAMP. The following notes have been taken from the brochure, for your information.

### What is NRAMP?

- ◆ An observational, nationwide study which follows the journey of mother and baby during pregnancy, birth and for the first 12 months of the baby's life.
- ◆ Has been developed to gather information from women across Australia who are taking, or have taken, antipsychotic medication during pregnancy.
- ◆ Collects and records information on maternal and infant health and wellbeing.
- ◆ Plans to develop evidence-based guidelines for the best use and effect of antipsychotic medication during pregnancy, birth and the postnatal phase.
- ◆ Will enable healthcare professionals and women with mental illness to make informed decisions about appropriate treatment options, and encourage safer outcomes for both mother and baby.
- ◆ Provides an opportunity for women to 'share their story' in a confidential manner, with compassionate research personnel.
- ◆ Is not designed to provide treatment recommendations, make mental health diagnoses or pass judgement on any individual.

### Who can take part in NRAMP?

- ◆ Women who are taking, or have taken, antipsychotic medication during pregnancy.
- ◆ Women who are pregnant or have had a baby in the last 12 months.
- ◆ Women who reside in Australia
- ◆ Women who are able to provide informed consent.

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# News Flash

We are delighted to report  
the birth of **116** healthy babies so far,  
to mothers involved with **NRAMP**

## Possible benefits of taking part in **NRAMP**?

Participants will be contributing directly towards the best use and effect of antipsychotic medication during pregnancy, for the benefit of present and future generations. Other benefits include the development of an ongoing contact and relationship with **NRAMP** research personnel, who will provide a 'friendly, non-judgemental ear', so that participants can feel at ease when discussing personal issues.

## How can I become involved in **NRAMP**?

Women may be referred to **NRAMP** by their healthcare professionals (doctor, nurse, psychiatrist, psychologist, social worker etc). Women may also refer themselves to **NRAMP**.

Participants are required to give written consent to take part in **NRAMP**, which includes a General Consent form and a Medical Consent form. The Medical Consent form allows **NRAMP** research personnel to contact healthcare professionals for further information, if required.

## Is participation in **NRAMP** voluntary?

Participation in **NRAMP** is completely voluntary, as for any research study, which also means that participants may withdraw from the study at any time.

## Will my privacy and confidentiality be protected?

Any information obtained in connection with this study, and which can identify any individual, will remain confidential. It will be disclosed with your permission only, except as required by law. In any **NRAMP** publication, information will be provided in such a way that individuals cannot be identified. Personal participant information is stored securely in a locked research office, which is accessed by **NRAMP** research personnel only. Participant information which has been entered onto the **NRAMP** database is completely de-identified, with a code number, so that any one individual cannot be identified.

## What about ethical issues?

The ethical aspects of **NRAMP** have been approved by the Human Research Ethics Committee of Alfred Health, and numerous other Human Research Ethics Committees Australia-wide. **NRAMP** is also carried out according to the *National Statement on Ethical Conduct in Human Research* (2007), produced by the National Health & Medical Research Council of Australia. This protects the interests of those who agree to take part in human research studies.

## Sharing your story

We encourage you to share your story with us by becoming a part of the study. In this way you will be able to talk about your personal experiences with the study co-ordinator, who provides a friendly, non-judgmental ear, facilitating an ease of discussion in a comfortable and confidential manner. Anecdotal reports from participants indicate a high degree of positive response throughout their involvement in the study, which they describe as the ability to speak freely and share their story in this particular forum, when there may be few opportunities to do so in their regular circle of support persons.

We look forward to journeying with you during your pregnancy and for the first 12 months of your baby's life. Whether you are having your first baby or have had previous pregnancies, the information you so willingly provide is essential to the development of treatment guidelines for the best care of women who take antipsychotic medication during pregnancy. We are infinitely grateful for your participation in **NRAMP**.

## Writing your story

Would you be interested in writing your story in your own words and sharing it with the **NRAMP** Team? You may find this process to be beneficial as it could provide an outlet for your thoughts and experiences. Any identifying details would be removed to protect the privacy and confidentiality of your personal information. You may like to contact the **NRAMP** personnel for more information, or if you have any queries or comments. Any involvement in this activity is completely voluntary.

## Baby Photo Board

The **NRAMP** Team have established a Baby Photo Board, which currently displays approximately 25 photos of beautiful babies born to mothers who have consented to take part in the study. What a wonderful sight to be greeted with each morning when arriving at work. All photos are displayed anonymously. We would like to encourage mothers to share their baby photos with us, if they wish to do so. They provide a wonderful motivation for the continuation of our work here.

## Emotional Health and Wellbeing before and after birth

(Excerpts from 'Becoming a Parent. Emotional Health and Wellbeing', produced by the Department of Health, Western Australia, 2009)

### Ways to support yourself during pregnancy:

- ◆ If you have a partner, talk about the difference a baby will make to your lives
- ◆ Don't expect too much of yourself - make time to slow down, rest and relax
- ◆ Set up extra support, if possible, for the first few weeks after the baby's birth. If you can, arrange for both parents to be at home for the first week or two
- ◆ Talk to someone you trust about your feelings. Simply sharing your concerns can be really helpful
- ◆ Extend your support network - other new parents can be a valuable resource
- ◆ Don't be afraid to ask questions when you visit your GP, psychiatrist, obstetrician or midwife
- ◆ Be careful what you read - some websites and articles might only make you feel worse. Look at who is writing it
- ◆ Be aware of changes from how you normally feel. If your emotions are starting to interrupt your day-to-day life, talk to your GP, psychiatrist, obstetrician or midwife - the earlier the better.

### Ways to support yourself after your baby is born:

- ◆ Value your role as a parent - it's a very important job to do
- ◆ Make time to enjoy doing something fun with your baby, like cuddling them or playing with them
- ◆ Remind yourself - there is no 'right' way to parent
- ◆ Don't expect your baby to just fit in to your routine - you will need to work around your baby
- ◆ Remember - babies adapt to different way of parenting, so it's ok if your partner does things differently to you
- ◆ Plan to have additional support in the first few months and accept all reasonable offers of help
- ◆ Share the household chores as much as possible between yourself and your partner. Also, remember - you don't need to have a 'perfect' house
- ◆ Try not to make any major life changes in the first few months after having your baby (like moving house or changing jobs) unless it is absolutely necessary
- ◆ Share your feelings and concerns with someone you trust
- ◆ Try not to spend all day in your pyjamas. Getting showered and dressed can help you feel good
- ◆ Get to know your local resources, like crèches and playgroups
- ◆ Try to sleep or rest when your baby is sleeping. This is not the time to catch up on household chores
- ◆ Give yourself 'time out' each day and learn ways to relax
- ◆ Try to maintain a social life. Have contact with friends or family members who are supportive and positive

- ◆ Plan some quality time alone with your partner each week. Extend your support systems and find someone you can trust and rely on who can babysit for you
- ◆ Take care of your health, including your diet, exercise and rest patterns
- ◆ Have regular check-ups with your local child health nurse and/or GP and/or psychiatrist, and don't be afraid to ask them questions
- ◆ Be aware of any changes from how you normally feel or behave. If you notice any major or long-term changes, seek help and advice your GP, psychiatrist and/or child health nurse

## Introducing the *NRAMP* Website

We invite you to peruse our new *NRAMP* website, which is available at [www.maprc.org.au/nramp](http://www.maprc.org.au/nramp) and contains useful information about the structure and function of the study.

By clicking on each drop-down box, you can read about:

- ◆ [What is \*NRAMP\*?](#) An overview of *NRAMP*, including the aims, development and purpose
- ◆ [Participation in \*NRAMP\*](#) Discusses the *NRAMP* Inclusion Criteria, the interview process, and informed consent. Study documents are also available and can be downloaded
- ◆ [Confidentiality, ethics and consent](#) Information relating to the protection of confidential and private information
- ◆ [FAQs](#) Frequently Asked Questions
- ◆ [Contact Us](#) Study Co-ordinator contact details, for referrals, queries, comments and suggestions
- ◆ [Useful Links](#) Provides links to health-related sites
- ◆ [Newsletters and Updates](#) *NRAMP* Participant Newsletters are available for downloading if required

Have you heard about the  
***NRAMP* Website**  
[www.maprc.org.au/nramp](http://www.maprc.org.au/nramp)

## Funding Support

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## Who do I contact about *NRAMP*?

The *NRAMP* Team includes Professor Jayashri Kulkarni, the Chief Investigator, and Ms Heather Gilbert, the study co-ordinator. Please contact the *NRAMP* Team, as below, for further information.

### Parent Helplines:

**VIC:** 132-289  
**NSW:** Karitane Care Line: 1300-227-464  
 Tresillian: 1800-637-357  
**SA:** 1300-364-100  
**WA:** 1800-654-432  
**TAS:** 1800-808-178  
**ACT:** (02) 6287-3833  
**QLD & NT:** 1300-301-300  
**Smoking Quit Line:** 131-848

**Ms Heather Gilbert**  
**RN Division 1/Research Nurse**  
**Monash Alfred Psychiatry Research Centre (MAPrc)**  
**Alfred Hospital, Melbourne, Victoria, 3004**  
**Ph: (03) 9076-6591**  
**Fax: (03) 9076-6588**  
**Email: [H.Gilbert@alfred.org.au](mailto:H.Gilbert@alfred.org.au)**