# This Register is generously supported by:

Epilepsy Action Australia Epilepsy Society of Australia

**Royal Melbourne Hospital Neuroscience Foundation** 

**UCB** Pharma

Eisai

NHMRC

The Australian Pregnancy Register is a not for profit organisation. Any offer of financial support by way of donation would be greatly appreciated. All donations are tax deductable.

# To make a donation go to – www.apr.org.au

ABN: 38128669797

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# Please contact us.

Your participation will benefit women's and babies' health and may help you and your family in future pregnancies.

Australian Pregnancy Register for Women on Antiepileptic Medication.

# Australian Pregnancy Register (APR)

For pregnant women with epilepsy &/or pregnant women taking antiepileptic meds for other conditions

> 1800 069 722 www.apr.org.au apr@mh.org.au

Find us on



Scan code for more information or to register



The Australian Pregnancy Register is a voluntary, national, telephone based research project that has been running since 1999.

# Antiepileptic Medications (AED's)

Brivaracetam (Briviact®) Carbamazepine (Tegretol®) Clonazepam (Rivotril<sup>®</sup>) Diazepam (Valium®) Ethosuxmide (Zarontin<sup>®</sup>) Gabapentin (Neurontin<sup>®</sup>) Lacosamide (Vimpat<sup>®</sup>) Lamotrigine (Lamictal®) Levetiracetam (Keppra®) Oxcarbazepine (Trileptal®) Perampanel (Fycompa<sup>®</sup>) Pregabalin (Lyrica<sup>®</sup>) Phenobarbitone Phenytoin (Dilantin<sup>®</sup>) Primidone (Mysolin<sup>®</sup>) Sodium Valproate (Epilim®) Sulthiamine (Ospolot<sup>®</sup>) Tiagabine (Gabitril®) Topiramate (Topamax<sup>®</sup>) Vigabatrin (Sabril<sup>®</sup>) Zonisamide (Zonegran<sup>®</sup>)

# **Register Staff**

Prof Frank Vajda Prof Cecile Lander Prof Terence O'Brien Ms Janet Graham Ms Alison Hitchcock Director Principal Investigator Co investigator Research Coordinator Research Coordinator

# Background

From previous research it is believed that women who are taking an AED may have a slightly higher incidence (4-6%) of having babies with birth defects than the general population (2-3%).

After many years of data collection and analysis, there is now some evidence available to determine whether this small increase is related directly to the drugs, the epilepsy itself, or other factors.

As a result from this study we are getting closer to defining safer treatment choices.

**DO NOT STOP** MEDICATIONS WITHOUT FIRST CONSULTING YOUR DOCTOR AS THIS MAY RESULT IN UNCONTROLLED SEIZURES WITH POTENTIALLY SERIOUS CONSEQUENCES FOR BOTH THE MOTHER AND UNBORN BABY.

#### **Our Purpose**

- To evaluate the incidence of birth defects resulting from exposure to AED's
- To determine if certain AED's or combinations are safer than others
- To determine the influence of the seizures, the epilepsy type, the genetic background and environmental factors on outcome
- To study the effectiveness of AED's on seizure protection in pregnancy
- A link to further studies looking at developmental effects on children and or genetic variants in families

# **Target Group**

Pregnant women or mums who have delivered within 1 year with epilepsy:

- taking AED's
- not taking AED's

Pregnant women or mums who have delivered within 1 year taking AED's for other conditions.

## **Enrolment**

All calls or internet enquiries to the Pregnancy Register will be answered by a Research Coordinator.

Enrolment can be initiated by the woman, her family or a health care professional.

# For women calling or completing the enquiry form at www.apr.org.au:

The coordinator will provide information about the Register and ask questions as to your eligibility.

#### For family or health care professionals;

With the woman's permission; call, email or complete enquiry form. Please provide name and telephone contact number. The coordinator will then contact the woman and provide information about the register and enrolment.

If the woman agrees to participate a written information sheet and consent form will be mailed to her to sign.

Following consent (depending upon how far along you are in the pregnancy) there will be six phone interviews:

- Enrolment (10-15 mins)
- Seven months gestation (5 mins)
- One month post delivery (5-10 mins)
- One year following delivery (5 mins)
- Five years old (5 mins)
- Twelve years old (5 mins)

At each phone interview questions will be asked regarding epilepsy, medication, pregnancy, baby and the development of the growing child.

# Call toll free on **1800 069 722** Email apr@mh.org.au Visit www.apr.org for online enquiry form

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