

Date: Saturday 15th March

Time: 10am to 4pm

Kids Research Institute, Children's Hospital at Westmead
Cnr Hawkesbury Rd & Hainsworth St
Westmead NSW 2145

Exploring the impacts of rare diseases – your child, your family and the health system

The Australian Paediatric Surveillance Unit will host a Rare Disease Day workshop that will include:

- ◆ Preliminary results from a family survey on the impacts of rare diseases conducted under the APSU ARC Linkage Grant.
- ◆ Information stalls from organisations that support families.
- ◆ Focus group discussions about the out-of-pocket expenses incurred by families whilst caring for a child with a rare chronic condition and financial support needs of families.

Workshop speakers include:

- ◆ Prof Elizabeth Elliott—Australian Paediatric Surveillance Unit
- ◆ A/Prof Yvonne Zurynski—Australian Paediatric Surveillance Unit
- ◆ Ms Lyndal Douglas— Children's Hospital Westmead
- ◆ Ms Dianne Petrie—Association of Genetic Support of Australasia
- ◆ Dr Marie Deverell—Australian Paediatric Surveillance Unit
- ◆ Dr Neil Hime—Australian Paediatric Surveillance Unit

Lunch
Provided

You MUST register to attend – limited spaces available!!

Registration is FREE!!!

Registration forms can be found on our website at;

<http://www.apsu.org.au//home/rare-disease-workshop/>



Rare Disease Day



Australian Paediatric Surveillance Unit



Please return completed registration forms to the APSU either via fax on (02) 9845 3082 or by email at apsu@chw.edu.au or contact APSU by phone on 9845 3005