

Date: Friday 14th March

Time: 9am to 4pm

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

Recent developments in rare diseases research, health services and policy

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

- ◆ Diagnosis of rare diseases including the latest on genetic testing
- ◆ Health services utility and needs
- ◆ Psychosocial impacts of rare diseases on families
- ◆ The role of rare disease registries to support research and clinical care

Workshop speakers and panel members include:

- ◆ Prof Susan Moloney—President Paediatrics and Child Health RACP, Gold Coast University Hospital
- ◆ A/Prof Yvonne Zurynski—Deputy Director, APSU
- ◆ Dr Sandra Johnson— Developmental Paediatrician
- ◆ Prof Nigel Clarke— Neurogenetic Research, CHW
- ◆ Dr Neil Hime, Research Associate, APSU
- ◆ Prof Hiran Selvadurai—Director, Respiratory Medicine, CHW
- ◆ Ms Lynne Brodie— Network Manager, Agency for Clinical Innovation
- ◆ Ms Sarah Ryan— Transition Care Co-Ordinator, Agency for Clinical Innovation
- ◆ Prof Elizabeth Elliott—Director, APSU
- ◆ Dr Marie Deverell—Senior Research Fellow, APSU
- ◆ Dr Felicity Collins— Head of Clinical Genetics, CHW
- ◆ Ms Kate Dunlop—Director Centre for Genetic Education, NSW Health
- ◆ Prof Adam Jaffe—Director of Respiratory Medicine, SCH, Co-Director Research, SCHN
- ◆ Ms Siobhan Darby— Young person living with a rare condition
- ◆ Ms Madeleine Bridget—Manager, Trapeze Transition Service

Lunch Provided

You MUST register to attend – limited spaces available!!

\$50 Registration fee — Junior Staff and Students are FREE

Registration forms can be found on our website at;

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



Rare Disease Day



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