



## Australian Paediatric Surveillance Unit Rare Disease Workshop

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

**You MUST  
register to attend  
– limited spaces  
available!!**

**Saturday 15<sup>th</sup> March 2014; 10am to 4pm**

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

This workshop is specifically designed for parents, carers and support groups. The theme is **Exploring the impacts of rare diseases – your child, your family and the health system**. Preliminary results from a family survey on the impacts of rare diseases conducted under the APSU ARC Linkage Grant will be presented. There will be information stalls from organisations that support families. The afternoon session will include focus group discussions about the out-of-pocket expenses incurred by families while caring for a child with a rare chronic condition and financial support needs of families. Please see the programme on the next page.

For more information please call Jade or Kirrilee at the APSU on (02) 9845 3005.

*All parents and carers are welcome no matter which disease or condition your child has. Please note that CHILDCARE will not be provided – this is an educational workshop for parents, carers and support group representatives.*

**REGISTRATION FORM** - To register please complete the form below or call the APSU on (02) 9845 3005

<b>Name:</b>		
<b>Address:</b>		
<b>Phone:</b>	<b>Mobile:</b>	<b>Email:</b>
<b>Dietary requirements:</b>		
<p><b>Please tick which sessions you will be attending:</b></p> <p> <input type="checkbox"/> Both sessions  <input type="checkbox"/> Morning educational session ONLY  <input type="checkbox"/> Afternoon discussion groups ONLY         </p> <p>Lunch and refreshments will be provided for all attending</p>		



Please return completed registration form  
to the **APSU** either via fax on (02) 9845 3082  
or by email at [apsu@chw.edu.au](mailto:apsu@chw.edu.au)



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**Programme - Saturday 15<sup>th</sup> of March**

Time	Title	Speaker
1000-1010	Welcome and icebreaker	
1010-1030	Responding to Rare Diseases – Recent Developments in Australia and Internationally	Prof Elizabeth Elliott
1030-1100	The economic and psychosocial impacts of rare diseases on families (including a screening of a movie of a family living with rare disease)	A/Prof Yvonne Zurynski
1100-1120	The role of genetic counsellors in supporting families	Ms Lyndal Douglas (TBC)
1120-1140	How can support groups and rare disease foundations assist families	Ms Dianne Petrie (TBC)
1140 - 1300	Lunch and networking Information stalls from support groups and information providers, and advocacy groups	
<b><i>The financial costs of rare diseases (this session includes focus group discussions)</i></b>		
1300-1315	The cost of rare diseases – health services use and out of pocket expenses	Dr Marie Deverell
1315-1330	Health services costs – a case study of a child with Children's Interstitial Lung Disease birth to 7 years of age	Dr Neil Hime
1330-1345	Out-of-pocket health costs for families living with rare disease - Focus Group Briefing	A/Prof Yvonne Zurynski
1345-1500	Focus Group discussion (4 groups)	Group facilitators
1500-1530	Feedback from group spokes-persons, summing up and close	A/Prof Yvonne Zurynski and Dr Marie Deverell



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