



**Responding to the common problem of rare diseases**

To mark International Rare Diseases Day 2010, APSU will host a workshop to:

- raise awareness of the impacts of rare diseases
- provide information about resources for clinicians and families
- encourage comment on the draft National Plan for Rare Diseases.

**Saturday 27<sup>th</sup> February 2010; 12noon to 5:15pm**

**Venue:** Kids Research Institute, Meeting Room 1, The Children’s Hospital at Westmead, Sydney

The workshop is provided **FREE** with the support of the Australian Research Alliance for Children & Youth (ARACY), the Steve Waugh Foundation, Kids Research Institute and the APSU.

**To register contact:** Karen Pattinson at 02 98453005 or [APSU@chw.edu.au](mailto:APSU@chw.edu.au)

The impacts of rare diseases go beyond affected individuals. There are approximately 8000 rare diseases and taken collectively they have a huge impact on clinicians, the health system and families. Rare Diseases Day is an annual, awareness-raising event co-ordinated by EURORDIS and NORD at the international level and this workshop contributes to this international effort.

**Convenors:** Dr Yvonne Zurynski and Prof Elizabeth Elliott

	<b>PROGRAM</b>
1200 - 1255	<b>Registration And Lunch</b>
1255 – 1300	<b>Welcome</b> Prof Elizabeth Elliott – Director, APSU
1300-1500	<b>Impacts on Clinicians and Patients</b> <ul style="list-style-type: none"> <li>• Rare diseases in Australia: an overview of research and other initiatives <i>Dr Yvonne Zurynski, APSU</i></li> <li>• Rare respiratory diseases in children – impacts on health professionals and health services <i>Prof Adam Jaffe, Head Respiratory Medicine, Sydney Children’s Hospital</i></li> <li>• Living with ChILD: Children's Interstitial Lung Disease <i>The Walker Family</i></li> <li>• Zebras on the commons? Rare diseases in general practice <i>Dr. Andrew Knight, General Practitioner, The Upper Mountains Medical Centre</i></li> <li>• Helping families affected by rare diseases <i>Lisa Smith, Genetic Counsellor (TBC)</i></li> <li>• General discussion – gaps and needs</li> </ul>
1500 – 1520	<b>AFTERNOON TEA</b>
1520 – 1715	<b>Resources for Health Professionals and Patients</b> <ul style="list-style-type: none"> <li>• Benefits of multidisciplinary clinics for rare diseases <i>Prof David Sillence, Medical Geneticist, The Children’s Hospital at Westmead</i></li> <li>• Providing support and education for people affected by rare diseases <i>Mrs Dianne Petrie, AGSA</i></li> <li>• SNUG camps for children affected by rare diseases: A dose of respite <i>Graeme Stuart, SNUG</i></li> <li>• National plan for rare diseases <i>Prof Elizabeth Elliott, Director APSU and Paediatrician, The Children’s Hospital at Westmead</i></li> <li>• Discussion and comments on the Draft National Plan</li> </ul>
1715	<b>END</b>