

Forum for Young People Living with Rare Disease:

The challenges of the many
transitions to adulthood!

Date: Saturday 23rd February 2013;
8.30AM TO 2.30PM

Venue: The University of Sydney, New
Law Building, Camperdown

Cost: **FREE!** Morning tea and lunch
provided.

- ☐ Do you have a rare disease or
medical condition?
- ☐ 15 to 21 years old?
- ☐ Yes? Then we need to hear
from YOU!



- ☐ Connect with other young people
with similar experiences
- ☐ Share your views and focus
attention on issues that matter to
you
- ☐ This is your opportunity to
contribute to advocacy for better
health and community services for
young people living with rare
disease
- ☐ Hear from inspiring young people
living with a rare condition

This forum is for young
people. Parents/Carers
welcome to attend first
session and to network with
other parents



TO REGISTER OR FOR MORE INFORMATION

Phone: 02 9845 3005

e-mail: apsu@chw.edu.au

Web: www.apsu.org.au

**You MUST register to
attend - numbers
limited!**

Proudly supported by: Australian Paediatric Surveillance Unit; Rare Voices Australia; Smile Foundation;
The University of Sydney; and Transition Care Agency for Clinical Innovation



Forum for Young People Living with Rare Disease: The challenges of the many transitions to adulthood!

Saturday 23rd February 2013
University of Sydney, New Law School Building

Programme

Aims:

To document the issues experienced by young people living with rare diseases when transitioning from child health services to adult health services.

To develop advocacy tools proposing changes or improvements in transition services.

Expected Outcome:

A report summarising the forum findings will be published. The report will be made available to service providers, government agencies, rare disease organisations and the rare disease community, and will support advocacy for improved transition services.

Forum organisers: Australian Paediatric Surveillance Unit
Rare Voices Australia
ACI Transition Care, Agency for Clinical Innovation

Time	Title	Speaker/Facilitator
8.30-9.00	Coffee/registration	
9.00-9.05	Welcome	A/Prof Yvonne Zurynski
9.05-9.15	Rare diseases – unique needs	Prof Elizabeth Elliott
9.15-9.45	Transition services in NSW	Ms Lynne Brodie, and Ms Jude Foster
9.45-10.00	The need for family support and advocacy	Ms Tam Johnston CEO SMILE Foundation and Ms Megan Fookes RVA
10.00-10.20	My Transition Journey with Cystic Fibrosis	Ms Catherine Gasparini
10.20-10.40	Morning tea	
10.40-10.50	Briefing for breakout group discussion	A/Prof Yvonne Zurynski
10.50-12.30	Group discussions	*Facilitator for each group
	4-5 break-out groups	
12.30-1.00	Lunch	
1.00-2.00	Feedback from Groups	
2.00-2.30	Summing up	Prof Elizabeth Elliott

Breakout group discussion will include but will not be limited to the following:

- Navigating the adult health system – getting the care you need
- Need for transition coaches or mentors – do they exist? Are they needed?
- Challenges of study or work
- Relationships – with parents, friends, partners

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