



Australian Paediatric Surveillance Unit

A Unit of the Royal Australasian College of Physicians, Paediatrics and Child Health Division
Supported by the Department of Health and Ageing and the Faculty of Medicine of the University of Sydney

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Did you know that rare diseases are actually common? There are about 8000 rare diseases affecting an estimated 1.2 million Australians, including about 300,000 Australian children. The impacts of rare diseases go beyond affected individuals, and taken collectively they have a huge impact on health professionals, the health system and families.

The European Union, Canada, the UK and New Zealand have recognised the complex problems of rare diseases and are responding by implementing national plans for rare diseases, establishing national integrated support organisations for rare diseases, by making rare diseases a public health and a research priority and by developing integrated clinics that pool expertise to enable quicker diagnosis and better access to treatments and interventions.

The Australian Paediatric Surveillance Unit convened a Rare Diseases Working Group on the 9th of February 2009 to discuss the need for a more co-ordinated approach to providing health care and support for Australians affected by rare diseases. This group has produced a Draft National Plan to address the many impacts of rare diseases.

We value your views and opinions. Please take the time to read the attached Draft National Plan and provide your feedback by the 31st of March 2010, by completing the attached Feedback Form. You may return the form via e-mail, fax or post.

Your feedback will be incorporated into the draft plan before presenting it policy-makers to initiate discussion about the implementation of the plan. The more support we have the better the chance of the plan being adopted.

We look forward to your comments

Yours Sincerely

Yvonne Zurynski
Deputy Director, APSU

Elizabeth Elliott
Director, APSU

on Behalf of the Rare Diseases Working Party

Attachments:

1. Draft National Plan for Rare Diseases
2. Feedback Form
3. List of members of the Rare Diseases Working Group

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