

# BEECHAC Inc

Bladder  
Exstrophy  
Epispadias  
Cloacal Exstrophy  
Hypospadias  
Australian  
Community

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## **MEDIA RELEASE - DRAFT ONLY**

FEBRUARY 7TH 2011

# **RARE DISEASE DAY - FEBRUARY 28TH 2011**

## **RARE BUT EQUAL**

~ the need for a national approach ~

In the lead-up to World Rare Disease Day 2011, **BEECHAC** announces its involvement in the **Rare Disease Day Australia** event taking place at the Sydney Opera House on February 28th.

*'We are delighted to be joining forces with the **Steve Waugh Foundation, SMILE Foundation**, representatives from leading medical organisations and other support groups like ours in the call for a coordinated National Approach to Rare Diseases',* says BEECHAC President Katy Hargreaves.

There are 8000 known rare diseases impacting up to 2 million Australians - nearly 10% of our population. Although rare on their own, collectively these conditions affect one in ten households - a very significant sector of the community.

BEECHAC represents adults and children and their families who have life experience of one or more of a spectrum of rare congenital disorders including:

Bladder exstrophy: 1 in 30,000

Epispadias: 1 in 120,000 (males) / 1 in 500,000 (females)

Cloacal exstrophy: 1 in 250,000

*'Many such conditions have no cure, and the ongoing physical, emotional and social impacts are enormous. Yet with high-quality health care and a supportive environment, people do live rich and rewarding lives,'* Katy explains.

There is an urgent need for legislation to provide better access to health and community services for individuals living with rare medical conditions.

*'A common voice is needed now to help raise public awareness and develop national policy. We need to work towards a better future for children and adults living with rare conditions here - Australia is way behind in its commitment to Rare Disease strategy.'*

***'Let's come together as a family - with strength in numbers, and greater recognition, we can all learn from each other and build a stronger, healthier future.'***

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