

BEECHAC

BLADDER
EXSTROPHY
EPISPADIAS
CLOACAL
EXSTROPHY
HYPOSPADIAS
AUSTRALIAN
COMMUNITY

newsletter
issue 2 / March 2011

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BEECHAC recently participated in
WORLD RARE DISEASE DAY on
28TH FEBRUARY 2011
pictured: Steve Waugh with
BEECHAC member Tom Flood at
Sydney Opera House for the WRDD
media launch

MESSAGE FROM THE PRESIDENT: ~

Dear BEECHAC Members and Friends -

A warm Welcome to you all this year - 2011. I'm Katy, a mother of three. My 12 year old son was born in Hawaii, and has BE; our experience of surgery has been at Seattle Children's Hospital, in the USA. We returned to Australia in 2008, and I became involved with BEECHAC soon after.

I'm excited to be working alongside our passionate committee members to carry forward the initiatives achieved so far and develop new directions, including expanding the membership, revamping the website and logo, increasing interaction via social media, developing partnerships with likeminded organisations, compiling health tips and a survival guide for teens, enhancing access to psychological support networks, and connecting with BEECHAC communities worldwide.

Our main goal is to build a supportive community for our members that is inclusive of kids, teens, parents, and adults, while maintaining privacy and providing for individual needs. Together we can make a difference.

~ Aloha, Katy Hargreaves



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We welcome your feedback on this issue, and suggestions & contributions for the next. Please contact us: editor@beechac.org

Future Plans for BEECHAC Inc



Can you help??

At the recent meeting held in Sydney NSW, participants discussed where they would like to see BEECHAC heading in the future:

- Creating more committee positions to involve more people in the running of the organisation, as well as reduce the workload of current committee members. New positions have been created accordingly - see panel p.2
- Creating campaigns in which issues relating to BEECH conditions can be addressed. One campaign is specifically aimed at encouraging companies who manufacture items containing natural rubber latex to include it on the item's label. Another will be in uniting with like-minded support groups under the Rare Disease Day banner to highlight common concerns and lobby for change.
- Organising the next BEECHAC conference including when it will take place, where it will be held, and how BEECHAC can help people attend.
- We are urgently seeking a new Treasurer to join our committee.
- We are also seeking expert assistance with logo, graphics and website design.
- If you have the relevant skills and some time and energy to give, get in touch for more details.

BEECHAC

committee members

2011

As a result of the December Annual General Meeting, the BEECHAC committee has expanded!

We would like to sincerely thank all the previous committee members for their contribution towards making BEECHAC a successful organisation.

Special thanks and acknowledgments to Alana Sullivan, Founding President, Chris Sylva, Founding Secretary, and Inaugural Treasurer Julie Fitzhardinge for their significant roles in BEECHAC's development.

We are delighted to announce the new committee positions:



President

Katy Hargreaves

Vice President

Chris Sylva

Treasurer

TBA

Communications Coordinator

Imogen Yang

Membership Secretary

Ellese Brown

Minutes Secretary

Ashley Matthews

Adult Group Coordinators

Ellese Brown (18-50yrs)

Janet Rankin (50+yrs)

Youth Mentors

Craig Stack (Males)

Ellese Brown (Females)

Health Coordinators

Tom Flood (Adult Males)

TBA (Adult Females)

Alana Sullivan

(Children & Parents)

Fundraising Subcommittee

Coordinator Di Murphy

Website Subcommittee

Coordinators

Lucy Zoric & Darko Zoric

Newsletter Subcommittee

Coordinator Ashley Matthews

State Coordinators

Nigel Fitzhardinge (ACT)

Emma Falconer (VIC)

Chris Sylva (NSW)

Angie Boden (QLD)

Di Murphy & Melanie Clemmans (WA)

Jennifer Hayes (TAS)

Poppy Sylva (NT)

TBA (SA)

Thank you for being a part of BEECHAC Inc.

* BEECHAC Star Profile * Craig Stack *

"I am a 24 year old male; born in the Central Coast and have since re-located to Mildura, Victoria. I was born with Bladder Exstrophy and Gastrochisis, and since birth have had approximately 85 surgeries...

most of these relating to making a bladder out of bowel and expanding it as I grew older.

I was born at Gosford Hospital and immediately sent to Camperdown Hospital for my first surgery which was under the care of Dr. John Harvey.

At the age of 2 and a half, I was referred to Melbourne under the care of Mr. Justin Kelly, and would travel there 4 or 5 times a year for surgeries.

I found that having so many operations made me miss a lot of family and school time. Up until year 7 I was in nappies for leakage, and I was teased and felt alone. I finally had a bladder neck closure procedure and I now catheterise through a hole in my stomach.

I've always loved sports. My father played Rugby League, so my goal growing up was to play Rugby. At age 13 I got the all clear from my doctors to play, and have been playing Rugby ever since.

During years 7 and 8 I had after-school tutoring because I was behind the other students. I worked very hard in high school and came second in my year for Standard English in the HSC.

After High School I moved to Bathurst to attend Charles Sturt University to study a Bachelor of Clinical Practice. I have now finished my degree, and have moved to Mildura to work as a Paramedic.

As a paramedic I see many interesting and sad things: a job not suited to everyone, but I love it. Over the next few years I hope to complete my Intensive Care Degree so that I'll be able to perform more advanced procedures on patients.

I have joined BEECHAC to support other families and individuals who are going through, or who have gone through, similar things as I have myself.

My role as a BEECHAC Youth Mentor is to help the younger people with advice and guidance through any issues they are having.

My contact details are on the website, and I look forward to supporting BEECHAC members in my new role." - Craig Stack



Craig Stack on duty

SNUG Kids' Camp report

Monday 27th September - Friday 1st October 2010 / Myuna Bay, NSW

"The grace of the SNUG Camp is that it provides a space for the most amazing connections to be formed with other families who are walking the same path."
~ BEECHAC parent

Supported by the Steve Waugh Foundation and many volunteers, the SNUG (Special Needs Unlimited Group) project, run by the Family Action Centre, University of Newcastle, provided BEECHAC members with their very own camp designed to bring together geographically isolated families who have a child with special needs. Two of our adult BEECHAC members also participated as volunteers assisting with the program.

SNUG is:

- A family holiday at Myuna Bay in the bushland of beautiful Lake Macquarie.
- Coordinated access to specialist medical, health, dental, neurological and other vital care often not available in rural communities.
- Access to recreational facilities for the whole family and organised fun for special needs children and their siblings, including swimming, tennis, canoeing, archery, mini golf, games, craft, spotlighting, movies, and a bush dance.
- A team of trained volunteers to assist families during their stay.
- Activities for families to get to know each other so that enduring support networks can be formed
- Information to improve knowledge of & access to specialised support services as well as assistance with family coping skills.

"...The SNUG program strengthens families; we need respite, a chance to relax, breathe gently, and be just like all the others..."

[Click here for further information about SNUG camps](#)

MLAK for people with BEECH conditions

During the recent SNUG camp, participants were informed of the **MLAK**

- the **Master Locksmith's Association Key** - that fits into specially designed locks enabling 24hr access to public toilets displaying the MLAK symbol (as shown on right)



Only those who have a disability or who have written authority from a doctor are able to access MLAK-locked toilets. To obtain a key, a written letter from a GP validating eligibility is all that's required.

A MLAK can then be purchased for \$13 from any Master Locksmith.

The MLAK is beneficial for those with BEECH conditions, particularly those who need to catheterise or use stoma bags and require a more hygienic area than regular public toilets.

The MLAK can also be used to access Liberty Swings; specially designed playground swings for use by people in wheelchairs.

Accessible Public toilets bearing the MLAK symbol can be found on the National Public Toilet

Map, at: www.toilemap.gov.au

To locate your nearest Master Locksmith, log on to: www.masterlocksmiths.com.au

Or phone the Master Locksmiths Association of Australasia on 1800 810 698.

EEC and intimacy research project

Participants needed!

Current research into experiences of intimacy for people with Exstrophy-Epispiadias Complex conditions

People aged between 16 and 64 with conditions related to the Exstrophy Epispiadias Complex (bladder exstrophy, epispiadias, cloacal exstrophy and variants) are being invited to take part in an international study on their experiences of intimacy.

This UK-based study is being carried out by Deborah Anderson (trainee clinical psychologist at Lancaster University) as part of her doctoral qualification and in conjunction with the Bladder Exstrophy Service at Royal Manchester Children's Hospital.

Participants would take part in a research interview in which they would describe in their own words their experiences of current and past relationships of importance to them, which could include friends, family members, work colleagues, romantic partners, and sexual partners.

Interviews could be carried out face to face (if participants reside in the UK), via telephone, via online telephone services (e.g. SKYPE) or via online instant messaging (e.g. msn messenger).

Responses will be analysed using qualitative research methods.

It is hoped that the findings from this study will give health care professionals a better understanding of how people with EEC feel about the possible impact their condition has on their relationships, how this may impact on their overall psychological wellbeing and therefore what services could be put in place to offer effective support.

If you are interested in taking part please email Deborah for a more detailed participant information sheet:

d.anderson1@lancaster.ac.uk

Due to time constraints all interviews must be completed by 13th April. Therefore if you are interested in taking part please contact Deborah as soon as possible.

World Rare Disease Day

28th February 2011

On World Rare Disease Day 2011, BEECHAC was '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', announced 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
Epispiadias:	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 live rich and rewarding lives,' says Katy.

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.'

For more information about the Rare Disease movement around the world go to:

<http://www.rarediseaseday.org>

<http://www.eurordis.org>

For more information about how these foundations can help, go to:

<http://www.stevewaughfoundation.com.au>

<http://www.smilefoundation.com.au>

WESTERN AUSTRALIA

WA group is keeping in regular contact via email and we met up on a couple of occasions after the Conference last year to network and offer support to each other. We plan to strengthen relationships this year and to hold a fundraising event for BEECHAC.

~ Di Murphy diannemurphy@iprimus.com.au

VICTORIA

Planning to get together soon with Adult Group Coordinator Ellese Brown to discuss organising a get-together. I have also started to contact other members in VIC. Several new adult members have joined in VIC, so our numbers are expanding. I plan to ring the RCH in Victoria to see if I can leave some brochures there.

I would also appreciate any ideas in reaching new members from other members.

~ Emma Falconer e.falcone@optusnet.com.au

TASMANIA

I have been in contact with the other mother I know in Tas and we will catch up for coffee. Have been in touch also with Emma Falconer in VIC to suggest that Tassie could join in any get-togethers that Victoria may have.

In an effort to try to find other possible members in Tasmania I have:

- spoken to a nurse who is on the Launceston continence committee - she suggested that I come and speak at their next meeting.

- contacted the Launceston Stomal Therapy nurse and requested that she pass on information about BEECHAC to any relevant patients that she might have, and that she forward the email on to the other stomal therapy nurses in the state, which she did.

- handed out BEECHAC pamphlets to a few paediatricians and doctors, and am currently compiling a list of paediatricians, obstetricians, urologists, and community continence care nurses in the state (27 names so far). I will post out a letter and flyers to these people in the next few weeks.

~ Jennifer Hayes jennifer.hayes@education.tas.gov.au

QUEENSLAND

I was recently contacted by the sibling of a woman whose new baby was born with bladder exstrophy. Several hours on the phone sharing information and offering support resulted in the mother following up with BEECHAC directly, seeking more information about surgeries and doctors in Queensland. We are also able to connect her with another new Mum in another State for ongoing contact and support.

I have been ensuring that I am available to visit children who are BEECHAC members - and their parents - in hospital whenever they are having surgery to offer support and assistance as needed.

I've been in contact with all adult members in QLD that I'm aware of so far, and look forward to meeting more in the months to come.

SNUG camp provided an amazing opportunity for kids, their parents and siblings to get together in a safe and supportive environment. We hope these camps might become annual or biennial events so that other families from around Australia meet and benefit in the future.

A burning issue in QLD is the pursuit of individually allocated funding for children with BEECH special needs in school and after-school care. A future campaign perhaps!

~ Angie Boden braveheartsmum@gmail.com

NSW

For World Rare Disease Day we played an active role in public awareness events in the Sydney CBD, and as an organisational member of the RDD Working Group we look forward to further developing strategy around this campaign for next year. We also made valuable connections with people from similar support groups for other rare conditions in Sydney, with whom we have much in common, and from whom we can learn a lot. We will report back on new developments in Paediatric-to-Adult-Care Transition Programs, a crucial issue for BEECHAC members, and on Post-Traumatic Stress counselling and Patient Empowerment support, other key areas of concern.

~ Imogen Yang imogenyang@beechac.org

The June 2010 conference in Sydney was a great success with over one hundred people attending from all over Australia and New Zealand. Many of the participants had never met anyone with similar conditions before coming to the conference. Friendships and connections were made around similar age groups and similar conditions as well as geographic connections.

The attendance of our special guests from around Australia and the USA gave the conference a truly international feeling and enabled our members to feel that we are not alone in our hopes of making life with a BEECH condition a more supported and less isolated experience.

The contribution from **Tom Exler & Misty Blue Foster from the Association for Bladder Exstrophy Community (ABC)** - www.bladderexstrophy.com - in the USA was integral to the success of our conference. Their presentations on resilience throughout their own lives despite many setbacks were moving and inspiring.

We were also so fortunate to have **Dr William Reiner, renowned Child Psychiatrist & Paediatric Urologist** from Oklahoma, and his wife, Irene, at the conference. Dr Reiner worked beyond the call of duty over the two days of the conference as he not only presented several sessions but also offered his time to provide one-to-one sessions with a number of families.

Billy Deegan, Executive Officer of the Hypospadias & Epispadias Association (HEA) - www.heainfo.org - and a Psychotherapist from New York, attended and presented insightful sessions for adults only. Billy facilitated wise and perceptive discussion amongst the group about psychosocial & sexual issues - a unique opportunity for adults living with BEECH conditions.

Having **Tom Flood, President of Ostomy NSW**, presenting at the conference allowed participants to see that our two associations have a lot in common. We hope to work together in the future to more fully support members from both associations. At the conference dinner on the Saturday night Tom Flood was presented with the **"Courage To Shine" award** - for his lifetime of commitment to supporting people with conditions requiring ostomies, many of whom have a BEECH condition and are our members. Congratulations Tom - you are a great role model for many younger people with a BEECH condition.

Like the ABC and HEA, BEECHAC is committed to representing and supporting adults living with a BEECH condition as well as children and their families.

The conference also featured speakers from a range of Australian and state support agencies such as **Carers Australia, Kidney Health Australia, the Siblings Network Australia, the Stomatherapy Association, the Continence Nurses Association, the Anti-Discrimination Board and the General Practitioners Association.**

Two sessions on male and female reconstructive surgery, presented by **Dr Chris Coombs, Melbourne-based Plastic Surgeon**, were very well received by the participants. **Professor Wei Cheng of Monash University** presented a summary of research to date based on his Genetic screening of Bladder Exstrophy project.

Representatives from agencies supporting people with rare medical conditions spoke about the development of an Australian National Plan for Rare Diseases.

We also included practical sessions on health and lifestyle maintenance strategies for ostomies and catheterisation, body image, the benefits of family camps, keeping ourselves healthy in body and mind and resilience strategies.

The children excelled themselves by providing music and singing on the first night and at the conference dinner, and helping to present the Courage to Shine Award. Their energy and enthusiasm were so evident throughout the conference.

The feedback from the conference was very positive and already people are talking about another one in another state sometime in 2012...

On behalf of the BEECHAC Conference Organising committee, thank you to all who attended and participated.

“TOWARDS THE FUTURE” - the BEECHAC conference 2010

A personal perspective
by Di Murphy

Like most parents I know who have children with special needs, over time we become very resourceful & knowledgeable people. Having three special needs children, I quite often feel overwhelmed by the information that's out there and the steps I need to take to make quality improvements to my children's lives.

Over a year ago I found out that an organisation had been set up in the eastern states that was going to provide support to people who lived with Bladder Exstrophy type conditions. My eldest son was born with this congenital disorder. By this time I know most people would now be thinkingWhat's Bladder Exstrophy? and in simplified terms it means the bladder is outside of the body at birth & in most cases, there are other abnormalities of the abdominal skin and wall, pelvic bones and genitalia.

The organisation I refer to - BEECHAC - is incorporated as an Association and was established to provide a national support and advocacy group for individuals throughout Australia with the above conditions as well as to assist health professionals such as doctors, nurses, psychologists and researchers who are interested in finding out more about how to improve their services to those with the conditions, their families and friends.

There has been a lack of support and information in Western Australia and the only people we could liaise with were our surgeons. For years another Mum and I wanted to start some sort of support network but due to our circumstances we didn't have the time to set something up.

Hearing about BEECHAC gave me such a boost, as finally there was something in Australia. I instantly made contact with the secretary, Chris Sylva, and she advised me the committee was organising a conference which would be the first of its kind in Australia to provide information and support specifically related to these medical conditions. Well, I was beside myself at this stage.... In the past, I had so wanted to take Ryan to America for one of their biennial conferences, which are attended by hundreds of people and families, but couldn't afford to take him due to our financial constraints and my husband's and my caring roles. I had tried to search for grants that might assist us, but I hit a brick wall everywhere so to speak. This has always angered me - that carers and families aren't able to apply for assistance to travel to a medical conference in which you can gain knowledge and become part of a network. There's an enormous inequality at times when other people seem to get a green light to attend these types of events as part of an organisation.

I discussed attending the conference with my husband and we decided I was definitely going to take Ryan. The reality was, travelling as a family was out of the question: it would have cost us a fortune for airfares, accommodation and we'd need to take a couple of carers with us to support our other two kids. There's an old saying - "where there's a will there's a way" - this was an opportunity of a lifetime for our son, and I was going to take him, even if I had to work two or three jobs to do it.

The inaugural BEECHAC Conference was held in June and yes, we managed to attend it. The conference was called "Towards the Future" and it was everything we hoped it would be. In case you're thinking 'did she work two jobs to get there?', I actually cashed in some of my long service leave and the Commonwealth Carelink Centre funded our registration fee, which had been organised by our Local Area Coordinator, Elisha Johnson.

Before I touch on the conference, I wanted to share how complex it can be for a person with a medical condition to travel. There were a lot of preparations beforehand. We needed medical clearance for Ryan to fly and had to get our surgeon to complete the form. We also needed to ensure we took enough supplies with us for daily doses of medications, catheters, drainage bags, equipment in case we had any medical problems and reports from the last year detailing what surgeries and infections Ryan has had. We needed special permission for Ryan to be seated near the toilet due to his frequent catheterisations and my suitcase was practically full due to all the supplies I needed to carry for him. I was a travelling pharmacy!



BEECHAC Co-founder
Chris Sylva with Di Murphy at
the Sydney 2010 conference

The welcome event at the Conference was a finger-food type event that encouraged us all to mingle with each other. I was so impressed with the number of families who had travelled from all parts of Australia. Besides us, another two families had travelled from WA and there were special guests from the USA who had come over to present. One of them was Dr Billy Deegan, the Executive Director of an organisation called HEA - Hypospadias & Epispadias Association. He also has a private counselling practice in New York City and focuses on addictions and post-traumatic stress. HEA ensures that educational and supportive information is available to adults and families living with genital differences, with the goal of bringing all disorders that have similarity to advocate together under one large financially solvent and politically savvy umbrella. Dr Deegan's expertise was most certainly appreciated as we don't have anyone as specialised (concentrating on one similar condition such as this) here in Australia.

Another special guest was Tom Exler. Tom is the President of another Bladder Exstrophy support network - ABC - in America. Tom was also born with this condition and Tom's Mum and his surgeon founded a support group many years ago which supported people living with ostomy and intestinal or urinary diversions. Tom has given many speeches over the years and we were grateful that he came to Australia to share his experiences and highlight strength through support groups.

Over the next few days we met many people and attended numerous sessions. Although each session was fantastic, some information was quite overwhelming. One session in particular was from Melbourne based Clinical Associate Professor Mr Chris Coombs (University of Melbourne), a Plastic Surgeon who specialises in genital reconstruction. The questions asked by parents afterwards were quite amazing. We spoke about transplants, other complex reconstructive surgeries, medications, psychological issues of what was happening with stem cells (one of my questions). After this session was finished, I looked around the room and felt extremely proud of us parents. Not only were we living an already difficult life with our child with the condition but we sounded like professionals in the field and had all accumulated a vast knowledge of reconstructive and post surgical issues.

“TOWARDS THE FUTURE”

A personal perspective
- the BEECHAC conference 2010

cont'd from p.5...

Ryan attended some sessions designed for the kids and one of the sessions was with a specialised Psychiatrist from America, Dr William Reiner, (who later told me that Ryan has a very special quality about him and he was sure he would become a great advocate in the future). Dr Reiner is a faculty member at Johns Hopkins Medical Institute in Baltimore USA, is Board Certified in Urology, Psychiatry and Child & Adolescent Psychiatry, and is part of a team of investigators that includes Doctors Brad Kropp and John Gearhart who specialise in Bladder Exstrophy in America. Dr Reiner provided one on one consultations over the weekend with families and we were so very grateful for this. Ryan and I had a very long chat with him and we felt so lucky to have not only had this opportunity, but to have met him and his lovely wife. He'll certainly be remembered by all those who attended.

There were so many speakers & guests who touched our hearts. Presenters living with the condition who shared their stories, their ups and downs; and all reiterated to make the most out of each and every day. Life is difficult at times; it's not easy going to hospital; but this is your life and you do the best that you can. Speakers such as this have empowered our children living with the condition too.

During this conference we met so many families who live similar lives to us; we shared our struggles, our hopes and our dreams for our kids. We felt encouraged and gained strength from the wonderful people living with these medical conditions. But most of all, we don't feel so alone. This conference brought a lot of us together and together we are many. We have met newfound friends from Australia and overseas and this means we now have a network.

That's thanks to some absolutely wonderful women in Sydney who had a shared vision of creating an organisation to support all of us. These inspirational women - who have experienced so much already in life such as the loss of a child and loved one, and the challenges in life faced with having a loved one with a medical condition. I'm so grateful. I feel so very lucky and blessed to have now met these women and will gain the momentum with them to move BEECHAC forward. I know that we're now part of something very special.

One thing I didn't mention about the Conference was that it was held in Coogee in Sydney - a place that's dear to my heart. It felt like an omen to attend because Coogee is where Shaun and I lived for 4 years prior to moving to Perth and we returned there 17 years ago to marry. After the Conference, I took Ryan to the Park where his Daddy and I married. We stood there in the Gazebo and enjoyed the ocean view & never did I think that I would come full circle, marrying a wonderful man and returning with our child to attend an event that will enhance our lives.

Watch this space because attending this event has inspired me to once again bring our strengthening network of people together by hosting a BEECHAC Conference in the West in the coming years.

Di Murphy was recently elected to the BEECHAC committee as a coordinator for Western Australia and coordinator of the Fundraising sub-committee.

BEECHAC member
Ryan Murphy at
Coogee Beach, Sydney
2010



message board

—Original Message—

From: Betty Engel [<mailto:betty@heainfo.org>]

Sent: Monday, 7 March 2011 12:46 PM

Subject: pen pals for children with epispadias (especially girls)

Hi everyone,

As you might remember, I'm Betty Engel, the webmaster for the HEA website. This email is being sent (via blind carbon copy to maintain your privacy) to parents of children with epispadias, women with epispadias, and epispadias support givers. I'm writing to ask for your help.

I've been receiving some inquiries from parents of children with epispadias. These parents' children (especially the girls) want to "meet" other children with this condition by exchanging emails. It might be helpful for these children to exchange emails with adult or teenage women with this condition, too, especially since female epispadias is so rare that it might be difficult to find children. I'd like to help find some pen pals for girls with epispadias while keeping these children safe and maintaining individual confidentiality. Children under 13 years of age are not supposed to post to our message board or use our chat rooms, so it seems that email (supervised by the child's parent) is the best way to help these kids reduce their isolation.

Do you have a child (girl or boy) who would be willing to share emails (under your supervision) with a girl with epispadias? If you have female epispadias yourself, would you be willing to share emails with a child with female epispadias? Do you know of any children with female epispadias who might want to be a pen pal? If you're a parent of a child with epispadias, would you like to have email contact with other parents of children with epispadias? Can you think of other ways we can help out these girls and/or their parents?

Please reply to this email if you want to help. Thanks!

Betty Engel

HEA Webmaster

The Australian Paediatric Surveillance Unit - APSU

- a unit of the Royal Australasian College of Physicians - in conjunction with **International Rare Disease Day** February 28th, 2011, needs your help:

***** Do you support a national plan for rare diseases for Australia? Register your support by completing our brief [survey](#) here:**

<http://surveys.med.usyd.edu.au/limesurvey/index.php>

The impacts of rare diseases go beyond affected individuals. There are approximately 8000 rare diseases and taken collectively they have a huge impact on families, clinicians, and the health system. Rare Disease Day is an annual, international, awareness-raising event that provides the opportunity to highlight the urgent need for a National Plan to address rare diseases in Australia, to facilitate a coordinated response to service development, carer support and health, professional and community education, and support research and promote advocacy on behalf of affected children and adults and their families.

***** APSU is also helping to coordinate an international symposium to be held in Fremantle, WA, April 18 - 20:**

Awakening Australia to Rare Diseases: Global perspectives on establishing a coordinated approach to a national plan

This symposium will bring international experts on rare diseases together with stakeholders nationally to work towards a rare disease strategy for Australia. BEECHAC members are invited to attend. See www.raredisease.com.au for more information. N.B. Full program and Funding assistance application form also available at http://www.beechac.org/conferences_13.html