

2010 TOWARDS THE FUTURE CONFERENCE AGENDA

Welcome event: Friday evening 11 June

- 5:00 – 6:00pm Registration, *Conference Room Foyer*
- 6:00 – 10:00pm **Welcome to our inaugural conference, *Seaview Rooms A & B***
- **Acknowledgement of country** — Aunty Sylvia Scott, Wiradjuri Elder
 - Meet our international and other special guests and participants
 - A light meal of finger food and beverages will be served
 - Inspirational song by Nina Ward

DAY 1: Saturday 12 June

- 8:00 – 8:30am Meditation or beach walk — meet outside entrance to conference rooms
- 8:15 – 8:40am **Registration and refreshments**
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- 8:40 – 8:50am **Welcome & overview of conference**
Alana Sullivan, President, BEECHAC Inc, *Seaview Rooms A & B*
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- 8:50 – 9:20am **Strength through support—making connections, *Seaview Rooms A & B***
- Nick Weir and Tom Exler
 - Belinda Ward and Misty Blue Foster
 - Nigel Fitzhardinge and Billy Deegan
- Facilitator: Lindy Cassidy
- In this session some of our members will introduce themselves and then introduce representatives of the USA support groups*
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- 9:20 – 9:50am **Panel: Strengthening Our Support Networks, *Seaview Room A & B***
- Joan Hughes, CEO, Carers Australia
 - Lydia Lauder, National Manager, Health Strategic Projects & Publications, Kidney Health Australia
 - Robin Dagwell, Sibling Issues, Spastic Centre, Ryde, NSW
- Facilitator: Professor Kathryn Refshauge
- In this panel representatives from key support agencies will explain what their organisation provides and how we can access their assistance, support and resources.*
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- 9:50 – 10:40am Concurrent Workshops: **Developing strategies & making decisions**
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| a. Issues for Carers & Keeping Kidneys Healthy
<i>Seaview Room A</i>
Joan Hughes, CEO, Carers Australia
Lydia Lauder, Kidney Health Australia
Facilitator: Robin Booth
<i>Strengthening support for family carers and practical approaches to managing kidney health.</i> | or | b. Issues associated with growing older with Bladder Exstrophy, for men & boys
<i>Seaview Room B</i>
Mr. Chris Coombs, Plastic Surgeon; Clinical Associate Professor, University of Melbourne
Facilitator: Professor Katherine Refshauge
<i>Long term post surgical issues and reconstructive options for men, including penile reconstruction — boys aged 12 and over are welcome to attend with parental guidance.</i> |
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10:40 – 11:30am Concurrent Workshops: **Developing strategies & making decisions**

a. **Sibling issues**
Seaview Room A
Robin Dagwell, Sydney Siblings Network
Facilitator: Robin Booth
Support for siblings in the family environment and attending to special needs of siblings experiencing exposure to the health system.

or

b. **Issues associated with growing older with Bladder Exstrophy, for women & girls**
Seaview Room B
Mr. Chris Coombs, Plastic Surgeon; Clinical Associate Professor, University of Melbourne
Facilitator: Professor Katherine Refshauge
Long term post surgical issues and reconstructive options for women including lower body cosmesis — girls aged 12 and over are welcome to attend with parental guidance.

11:30 – 11:45am Morning tea & displays in foyer

11:45 – 12:30am **Strength through support groups: An Australian and International Perspective, *Seaview Room A & B***

- Tom Exler, President, Association for Bladder Exstrophy Community (ABC), USA
- Misty Blue Foster, ABC, USA
- Raylene Gass President, TheWeeKids, Victoria and Rebecca Gass
- Billy Deegan, Executive Director, Hypospadias and Epispadias Association (HEA), USA

Facilitator: Professor Kathryn Refshauge

12:30 – 1:15pm Lunch in Foyer and Seabreeze Room

1:15 – 2:00pm Concurrent Sessions: **Psychosocial issues within holistic care**

a. **Genes, gender & genitalia**
Seaview Room A
Dr William Reiner, Psychiatrist, Oklahoma, USA
Facilitator: Robin Booth
The social development of children and young adolescents with a BEECH condition including school and peer group issues.

or

b. **Late adolescence, adulthood and the family**
Seaview Room B
Billy Deegan, Psychotherapist, New York, USA
Facilitator: Professor Katherine Refshauge
Psychosocial issues — privacy, education and work environments, relationships and family dynamics.

2:00 – 2:45pm Concurrent discussion groups: **Psychosocial issues within holistic care**

a. **Genitalia, gender & genes**
Seaview Room A
Dr William Reiner, Psychiatrist, Oklahoma, USA
Facilitator: Robin Booth
In depth discussion of psychosocial issues facing young people with a BEECH condition — peer relationships, school, camps, who to tell, how to tell and maintaining a healthy wellbeing within the family and the community.

or

b. **Late adolescence, adulthood and the family**
Seaview Room B
Billy Deegan, Psychotherapist, New York, USA
Facilitator: Professor Katherine Refshauge
In depth discussion of psychosocial issues facing late adolescents and adults with a BEECH condition — personal relationships, education and employment environments, who to tell, how to tell and maintaining a healthy wellbeing within the family and the community

2:45 – 3:15pm Afternoon Tea & displays in foyer

3:15 – 4:00pm Concurrent sessions

a. **Recent Research Findings**

Seaview Room A

Professor Wei Cheng, Monash University, Melbourne
Dr Natasha Nassar, Sydney University

Facilitator: Professor Kathryn Refshauge

Genetics based research on Bladder Exstrophy/Epispadias Syndrome and Hypospadias.

or

b. **Talking circle**

Seaview Room B

Billy Deegan,
Psychotherapist

Facilitator: Lindy Cassidy

For adults 18 years and over with a BEECH condition — an opportunity for unstructured discussion of psychosocial issues.

or

c. **Talking circle**

Seabreeze Room

Dr. William Reiner,
Psychiatrist

For children and young adolescents — an opportunity for unstructured discussion about psychosocial issues. Come and have a wine!

4:00 – 4:45pm

Panel: Draft National Plan for Rare Diseases, *Seaview Rooms A & B*

- Dr Yvonne Zurynski, Australian Paediatric Surveillance Unit (APSU)
- Andrew Rowley, Steve Waugh Foundation
- Jane Dinte, SMILE Foundation
- Di Petrie, Australasian Genetic Support Association (AGSA)

Facilitator: Professor Kathryn Refshauge

Key representatives will discuss how their agencies support people with rare diseases and explain participation in development of the draft plan — feedback is encouraged to assist in progressing the plan to federal government level, establish an umbrella rare diseases strategy, and increase access to funding and resources.

5:00 – 5:15pm

Summary of the day, *Seaview Rooms A & B*

Facilitator: Alana Sullivan

5:15 – 7:00pm

Wine tasting, *Foyer*

7:00 – 11:00pm

Conference Dinner, *Seaview Rooms A & B*

- Speaker: Tom Exler on The 'Courage To Shine' Awards
- Songs by Nina Ward and Nick Weir

Dancing & music!

DAY 2: Sunday 13 June

8:00 – 8:30am Beach walk, meditation, registration and refreshments

8:45 – 9:00am **Welcome & overview of day 2, *Seaview Rooms A & B***
Alana Sullivan, President, BEECHAC Inc

9:00 – 9:30am **Strengthening resilience and wellbeing, *Seaview Rooms A & B***

- Misty Blue Foster, ABC, USA
- Tom Exler, ABC, USA

Facilitator: Alana Sullivan

9:30 – 10:15am Concurrent sessions: **Psychosexual issues within holistic care**

a. **Sexuality, kids & medical care**
Seaview Room A

Dr William Reiner

Facilitator: Prof. Kathryn Refshauge

The psychosexual development of young people with a BEECH condition.

or

b. **Late adolescence, adulthood and the family**
Seaview Room B

Billy Deegan

Facilitator: Lindy Cassidy

Psychosexual issues for adults with a BEECH condition — disclosure, sexual relationships and interpersonal dynamics, work and education environments.

10:15 – 11:00am Concurrent workshops: **Psychosexual issues within holistic care**

a. **Sexuality, kids & medical care**
Seaview Room A

Dr William Reiner

Facilitator: Professor Kathryn Refshauge

In depth discussion of psychosexual issues facing young people with a BEECH condition — body awareness, genital difference and peer relationships.

or

b. **Late adolescence, adulthood and the family**
Seaview Room B

Billy Deegan

Facilitator: Lindy Cassidy

In depth discussion of psychosexual issues facing late adolescents and adults with a BEECH condition — personal relationships, dating, genital difference and fertility.

11:00 – 11:30am Morning Tea & displays in Seabreeze Room

11:30 – 12:15pm **Panel: Strengthening our support networks, *Seaview Rooms A & B***

- Tom Flood, President, Ostomy NSW
- Carol Stott, Stomatherapy Association
- Joanne Lawrence, NSW Continence Nurses Association

Facilitator: Lindy Cassidy

A showcase of support agencies that provide specialised advice, equipment and resources.

12:15 – 1:00pm Concurrent workshops: **Practical maintenance strategies**

a. **Ostomy/Stomatherapy**
Seaview Room A

Tom Flood & Carol Stott

Facilitator: Alana Sullivan

Practical advice and information about ostomy and stoma care.

or

b. **Catheterisation maintenance**
Seaview Room B

Joanne Lawrence

Facilitator: Katy Hargreaves

Practical advice and information about catheterisation methods and avoiding infection.

1:00 – 1:45pm Lunch & displays in Seabreeze Room

1:45 – 2:30pm **Panel: Knowing Your Rights, *Seaview Rooms A & B***

- Claire Williams, NSW Anti-Discrimination Board
- Diana Murphy, R/Leader, Access & Participation, Disabilities Unit, DET NSW
- Andrew Knight, General Practitioners Association

Facilitator: Lindy Cassidy

Promoting a proactive approach to asserting your rights in education and medical contexts.

2:30 – 3:15pm Concurrent workshops: **Working together — Knowing your rights**

a. **Anti-discrimination policies in the workplace**

Seaview Room A

Claire Williams

Facilitator: Lindy Cassidy

Strategies to deal with discrimination and disadvantage in the work place.

or

b. **The GP as part of the team & your right to choose a second opinion**

Seaview Room B

Andrew Knight

Facilitator: Chris Sylva

The essential role and responsibility of the GP in providing quality care.

or

c. **School health procedures**

Seabreeze Room

Diana Murphy

Facilitator: Katy Hargreaves

Procedures that ensure a supportive school environment in NSW public schools.

3:15 – 3:30pm Afternoon Tea & displays in Seabreeze Room

3:30 – 4:15pm Concurrent workshops: **Healthy bodies, minds and wellbeing**

a. **Healthy body image**

Seaview Room A

Carol Stott

Facilitator: Chris Sylva

or

b. **The benefit of camps for kids and their families**

Seaview Room B

Heather Hawe, Special Needs Unlimited Group (SNUG)

Lisa Kimpton, Stomatherapy Nurse

Facilitator: Katy Hargreaves

or

c. **Taking control**

Seabreeze Room

Belinda Ward

Workshop for adult participants with BEECH conditions only — *a talking circle initiated by Belinda, sharing her experience of health and wellbeing and living with Bladder Ectopia*

"it is about the position you assume in your own life and taking control of your own medical condition".

4:15pm – 4:45pm **Ten steps to resilience and wellbeing, *Seaview Rooms A & B***

- Alana Sullivan

Facilitator: Lindy Cassidy

4:45pm – 5:15pm

Farewell

Feedback on conference, network arrangements, DVD overview of conference
Songs by Nina Ward and Nick Weir

6:45pm Dinner in Hotel Garden