The Chromosome 18 Registry & Research Society Conference
21-23 April 2017
Novotel Twin Waters Resort
Twin Waters Queensland Australia

It is with great pleasure that The Chromosome 18 Registry & Research Society invites you to join them on the Sunshine Coast at the Novotel Twin Waters Resort, Twin Waters Queensland in April 2017 for their Family Conference.

The conference provides an opportunity for parents, affected individuals, family, friends, caregivers, health professionals and doctors to come together to network and share their Chromosome 18 experiences. Chromosome 18 genetic disorders include 18q, 18p-, Ring 18, Tetrasomy 18p, Trisomy 18, Pitt-Hopkins Syndrome (mutated or deleted TCF4 gene) and other rearrangements on chromosome 18.

Key Presenters

- Professor Jannine Cody - the Founder and President of The Chromosome 18 Registry & Research Society and the Chromosome 18 Clinical Research Center. San Antonio Texas USA
- Dr Daniel Hale - Paediatric Endocrinologist and Medical Director of the Chromosome 18 Clinical Research Center.
- Mr Rick Guidotti – Positive Exposure, New York USA
- Dr Jonathon Mason - D Clin. Psych *Lond*., PhD *Kent*, BSc Psychology *Lond*. - Senior Lecturer, Clinical Psychology, University of the Sunshine Coast Queensland.

Topics

- Chromosome 18 research
- Chromosome 18 support network
- Endocrinology
- Evidence-based approaches to managing challenging behaviour and developing psychological therapy services for people with disabilities.
- Chromosome 18 parents and siblings share their experiences
- Chromosome 18 individuals sharing their stories
- Breakouts sessions for the various syndrome groups

Conference Venue - Novotel Twin Waters Resort, Twin Waters Queensland
Ocean Drive
Twin Waters Queensland 4564
Tel (+61)7.54488000 - Fax (+61)7.54488064.
Web: www.twinwatersresort.com.au

The Conference will be held on Saturday 22nd and Sunday 23rd April in the Mudjimba Ballroom. The Child Care Room will be located in the Maroochy Room.

Novotel Twin Waters has a Non- Smoking policy which includes all indoor conference areas. The Committee would also like to ask those attending to refrain from wearing heavily scented perfumes and aftershave. This is for the health of those individuals that are sensitive to fragrances. Please do not bring peanut/nut snacks into the conference rooms as there will be individuals attending who are highly allergic to these products.

There is a Deli café and convenience shop which is open from 7am. They offer a limited menu which includes muffins, sandwiches, breakfast items. See Twin Waters website for other dining options.

Car parking is available onsite at no charge.

Accommodation – Novotel Twin Waters Resort Sunshine Coast

Attendees will need to make their own reservations for accommodation. Please see the booking form which is attached. Reservations phone number is +61.7.5450 9591 or email groups@twinwatersresort.com.au.

You may choose to look elsewhere for accommodation on the Sunshine Coast.

Transport
The Novotel Twin Waters Resort is located 5 minutes by car from The Sunshine Coast (Maroochydore) Airport and is 112 kms from the Brisbane Domestic and International Airport. A bus service is available from Brisbane Domestic and International Airports. Airport transfers can be arranged through the hotel's Discovery Desk at the guest's own expense. To book, please call +61.7.5450 9569 or email info@exploresunshinecoast.com Other shuttle services are available –Con-x-ion is another company offering services. Their contact number is 1300 856 531 and their website is: https://www.con-x-ion.com/services/sunshine-coast-airport-transfers

Conference Registration Fees
It is expected by The Registry & the Novotel Twin Waters that anyone accessing any of the Conference Rooms ie Mudjimba Rooms, Ninderry Rooms, Maroochy Room and foyers associated with our Conference, must pay. We are offering a 2 day Conference Package, which includes morning and afternoon teas and lunches on Saturday and Sunday. The Friday night and Saturday night dinners are an additional option which can be selected on the Registration Form.

Our Registry is voluntarily run and receives no government subsidies. Since the Conference falls into the 2016-2017 financial year, these subsided prices are for Chromosome 18 families that have paid or are going to be financially active for at least the 2016-2017 membership year or beyond. Please note that Registration fees have been estimated at approximately $500 per person at minimum numbers. The Registry has subsidised the Member Registration fee to minimise your cost and we are charging $220 per Adult (17 years and over), $60 for children aged 5-17 years, no charge for children 4 years and under for the 2-day package. Chromosome 18 families that are not financially active with their membership will need to purchase their registrations at the non-member rate of $310 per person.
Chromosome 18 affected individuals registered with our Registry here in Australia, will not be required to pay the conference registration fee. Please contact us if you have any further enquiries.

If you are accessing any meeting rooms and not eating with us, the registration fees will still apply. We know from past events that head counts are done regularly and any discrepancies are billed back to us. These are costs we can ill afford. Please be aware that any additional costs will be forwarded on to the respective family.

Attendance is by prior registration for the weekend. RSVP is Tuesday 21st March, 2017.

Membership Fees
Membership fees are due 1st August 2016. Due to the increase of administration work involved with this conference, could you please help us by paying the 2016-2017 Membership Fee with your Conference Registration. Payment from prospective attendees must be received with the Registration Form to access the discounts outlined above.

Donations
This conference is taking place because of prior fundraising events. If you, your business or work place would like to help, please contact us. There are still areas in our program where we can utilise funds. We are a registered charity so donations $2 and over are tax-deductible in Australia. Your donations and sponsorships will be acknowledged.

Payments
Payments are accepted by Direct Deposit, Cheque, Money Order or by Visa/Mastercard Credit Cards. Please ensure your full Reference Name is included with the Direct Deposits. All payments are to be made in Australian Dollars.

Payment must accompany your registration form by post. Please include the Payment Summary sheet along with the Registration Form, Membership Form and the Childcare form if applicable.

Program
A tentative program is enclosed and this will give you an idea of how the weekend will flow. The final Program will be forwarded to Attendees closer to the time of the event.

Registration Desk
The Registration desk will open on Friday 21st April between 4-6pm in the Foyer. If possible, it is recommended that you register your attendance on this day. We would like to avoid congestion on Saturday morning so that we may begin our proceedings on time. Registrations and general enquiries will take place outside the Conference Room on Saturday and Sunday mornings.

Friday 21st April
A 'Pizza and Pasta Night' has been arranged for Friday evening for families who would like to attend. A jukebox has been hired so we can enjoy the music, sing and dance. Parents and carers of these individuals are most welcome to attend, though, you are required to pay for your own meals and drinks. A Cash Bar for all beverages will be available. The evening will be held in the Mudjimba Ballroom. Price for adults is $25 per person. Children 5-12 years is $12. Children 4 and under are free.

Saturday 22nd April Conference Dinner – *Mind Your Ps and Qs*
At previous conferences we have held a dinner and everyone has enjoyed the evening. Our conference dinner will be no different this time round and we invite you to dress in theme as part of our "Mind Your P's and Q's" fun. You may wish to simply dress in "P"ink or "P"urple or come as a Queen, a Prince, a Pumpkin or a Quince. It's over to you to let your imagination and sense of fun guide you. Prizes for the best dressed on the night! Entertainment will be provided by The Outsiders Band – a local Sunshine Coast Band including a member of the local Chromosome 18 community. This is a time where we can relax and socialise over a meal. It's an ideal time to meet some of the other Registry members or catch up with the ones that you already know. We welcome all conference attendees to join together for this social event. Cost is $45 per adult and $15 per child (5 – 17 years). Children 4 and under are free. A Cash Bar for all beverages, including alcoholic and non-alcoholic will be available on the night.

Sunday Dinner
This is an informal night and we will endeavour to book tables at the resort. Please indicate on arrival if you would like to be included for this night.

Respite Carers
Parents will need to make their own arrangements for personal carers. The Chromosome 18 Registry is unable to provide any respite service. If you require respite, it is suggested that you contact your local Commonwealth Respite and Carelink Centre on 1800-052-222.

Families that have access to funding may choose to use other respite carer agencies.

The information following is to assist you make choices. The agencies listed are some that we are aware of. By listing these agencies is not a recommendation as we are unaware of their competence or performance. Any choices are solely yours to make.

Here is some information about Support Carers to get you started on how to plan and book a support worker/carer for your chromosome 18 child/adult for our conference in April 2017.
Contact Commonwealth Respite (CR) on 1800-059-059.

- If you are using your home landline you will be directed to your local CR
- If using your mobile you will be directed to the closest CR, not necessarily your local CR

Either way, they will direct you to the appropriate district.
Commonwealth Respite will need to register you as a client and set you up in their system. They will need intake information about you and your child/adult e.g. diagnosis and caring roles. They will discuss with you any fees and contributions applicable. This will depend whether the affected individual is self-funded, has a respite package, etc.
If you think you will need a support worker, please register as soon as possible to give plenty of time for the respite organisations on the Sunshine Coast to plan for a support worker.
There are a number of private childcare and babysitting agencies available on the Sunshine Coast. Listed below are some of the agencies operating on the Sunshine Coast. Contact them directly for quotes and enquiries. Discuss with them your child/children's requirements, costs, cancellation polices, whether or not they are experienced in handling special needs children etc. Some agencies will minimise your costs by allowing children from one or more families to be cared for, for a set fee. You may want to search the web for other agencies in the area.

Equity Works is a Sunshine Coast based disability service organisation. They are the main respite provider for our conference. You are welcome to contact them for additional fee for service staffing hours on +61.7. 5441 2122. www.equityworks.org
Kidz Cove at Novotel Twin Waters Resort - kidzcovenovotel@bigpond.com +61.7.5450-9545
Angelcare – info@angelcare.net.au +61.7.5450-6222, +61.449-663-586
Super Nannies – info@supernannies.com.au, www.supernannies.com.au +61.406-448-572
Bo Peeps Babysitting Service – bopeeps@bigpond.net.au, www.bo-peepsbabysitting.com +61.439-791-240

Children's Room
Children are welcome in the main conference room. However, we do ask that you consider all attendees and presenters if your child becomes upset or noisy as sound and movement are a distraction for both speakers and attendees. A separate room, the Maroochy Room, will be available for our chromosome 18 children, their family members and carers to utilise. Engaging the services of a support worker and utilising the childcare room may help alleviate some of the pressures and distractions of minding your child, allowing you to gain most benefit from the presentations and networking opportunities.

The Maroochy Room is situated a short distance across the foyer from the Mudjimba Room where the conference is being held. Please ensure your children are fully supervised at all times. A DVD player will be provided. Please feel free to bring your own DVD's, and any other toys that may keep your child entertained. Colouring pencils, books and craft material will be available. Depending on child numbers we may organise some additional entertainment.

In-House babysitting Service
In House babysitting and childcare is available via Kidzcove at the Resort. Bookings are required. Call +61.7.5450 9545 if you require this service.

Pre-Conference Reading
Professor Cody will not be addressing Basic Genetics in her presentation. Therefore, it is important that all Attendees should go to The Chromosome 18 Registry Home Page www.chromosome18.org then to "About Ch18 Conditions – Genetic Basis" and acquaint or reacquaint themselves with basic genetics.

Merchandise
We will have Chromosome 18 Australasia t-shirts and caps available for purchase at the conference. We are not able to accept pre-orders at this time.

Volunteers
We can always do with a few extra hands. If you family or friends can give a few hours to help, please have them contact us.

Phone Contact numbers for use from 18 – 23 April 2017

Marlene: 0400-809-366	Scott: 0400-808-366
Veronica: 0433-433-204	Belinda: 0401-768-040
Tracey: 0407-030-733	Serena: 0423-920-941
Heidi: 0404-473-072	Nichola: 0455-462-333

Cancellations
Cancellation of registration must be advised in writing. Each cancellation made before Friday 2nd April 2013 will incur a penalty fee of $20 per person. Refunds of fees after this time may be considered. No refunds after Friday 9th April2013. Substitute Attendee will be accepted and details must be provided in writing. Please note that cancellation refunds may not be processed until after the conference concludes.

Disclaimer
Information and costs in the Registration Pack are correct at the time of writing, but maybe subject to change. In the event of industrial disruption or other unforeseen circumstances, the Organisers accept no responsibility for loss of monies incurred by attendees.

Conference enquiries
Contact us if you have any further questions at admin@chromosome18.org.au or +61.2.9580-5707 or +61.400-809-366. Enquiries after 10th April should be directed to admin@chromosome18.org.au or +61.400-809-366 or +61.404-473-072 or 0401-768-040
We look forward to seeing you in April!

Organising Committee
Scott and Marlene Brightwell
Nichola Chappell
Mary Steenson
Belinda McAuliffe
Tracey Healy
Heidi Hulspas
Veronica Wain
Serena Whelan
Cinzia Travaglini
Allycia Staples
Tim Steenson