



# 2011 Rare Diseases *symposium*

**AWAKENING AUSTRALIA TO RARE DISEASES:**  
Global perspectives on establishing a coordinated approach to a national plan

Esplanade Hotel, Fremantle Western Australia 17 - 20 April 2011

## INVITATION TO REGISTER

On behalf of the committee, We would like to invite you to join us for the Awakening Australia to Rare Diseases Symposium to be held in Fremantle, Western Australia from 17-20 April 2011.

The symposium aims to:

- Combine international, national and local expertise and experiences;
- Present a range of perspectives on major policy issues such as patient empowerment, research, diagnosis, development of and access to treatments and integrated healthcare, disability and social support services;
- Provide opportunities for delegates to participate in discussions that will contribute to the development of a National Plan for Rare Diseases in Australia.

The symposium builds on the work of the the Australian Paediatric Surveillance Unit which led the development of a Draft National Plan for Rare Diseases.

Places are limited, so we encourage you to return the enclosed Registration Form by email, mail or fax as soon as possible.

We look forward to welcoming you in April.

Kind regards








**Hugh Dawkins**, Symposium Chair  
**Elizabeth Elliott**, Deputy Chair  
National Organising Committee

## SYMPOSIUM OBJECTIVES

Using the Europlan and other international rare disease plans as a framework, international and national scientists, policy-makers, patient advocates, patients and carers will give plenary presentations on selected rare disease issues. The presentations will guide symposium participants in collaborative workshop discussions to apply the issues presented to the further development of a national plan for Australia.

## CONFIRMED SPEAKERS include:

### INTERNATIONAL SPEAKERS

-  Domenica Taruscio, National Centre for Rare Diseases
-  Stephen Groft, NIH
-  Sharon Terry, Genetic Alliance
-  Segolene Ayme, Orphanet (video presentation)
-  Christophe Beroud, INSERM
-  Hanns Lochmuller, TREAT-NMD
-  Peter L Saltonstall, NORD

### NATIONAL SPEAKERS

Elizabeth Elliott, Australian Paediatric Surveillance Unit  
Susan Peden, Disability Services Commission  
Jack Goldblatt, Genetic Services WA  
Monique Ryan, The Royal Children's Hospital Melbourne  
Yvonne Zurynski, Australian Paediatric Surveillance Unit  
Kathryn North, Australasian Neuromuscular Network  
Rhonda Galbally, National People with Disabilities and Carer Council

### Collaborating Organisations

Office of Population Health Genomics,  
Public Health Division,  
Department of Health WA (OPHG)  
Australian Paediatric Surveillance Unit (APSU)  
Disability Services Commission (DSC)

## MAIN ISSUES TO BE COVERED

- Development of national plans for rare diseases;
- Patient empowerment;
- Patient care, support and management;
- Research and translation;
- International and national networks;
- Networks, partnerships and collaboration.

## IMPORTANT DATES

Please Register

EARLY

Book Accommodation

by Friday 18 March 2011

Conference Program

Sunday 17 - Wednesday 20 April 2011



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## ABOUT THE SYMPOSIUM

Organized by a national committee with a commitment to improve the welfare and wellbeing of all Australian people affected by rare diseases and their families, through better knowledge, research, treatment, care, information, education and awareness of rare diseases.

The number of patients with each rare disease is very small, but collectively rare diseases affect between 6 and 8% of the Australian population. Similarly, rare diseases do not know country boundaries and consequently, they are best studied through global collaborations. Patient support and advocacy groups are effectively driving policy development in many countries, changing the way we view rare diseases and understand their impact on our community.

## OFFICIAL LAUNCH OF THE AUSTRALASIAN NEUROMUSCULAR NETWORK -20 APRIL 2011

The Australasian Neuromuscular Network (ANN) is committed to establishing a cohesive, integrated network that enables clinicians and researchers to work together across Australia and New Zealand for the wellbeing of patients with muscle and nerve disorders such as muscular dystrophy, and peripheral neuropathy. The ANN will provide a forum to advance and disseminate information, be a single voice to advocate for patients, guide best practice in diagnosis, care and treatment and drive improved and equitable access to services. The ANN has also joined the European neuromuscular network as a partner of TREAT-NMD, and is closely affiliated with US consortia.

The ANN will:

- Provide ready access to Standards of Care;
- Develop a unified approach to diagnosis and clinical trials;
- Improve communication;
- Develop and support integrated training programs for clinicians and researchers;
- Assist the set up multidisciplinary services; and
- Advertise opportunities to participate in registries, research studies and clinical trials.

## SOCIAL PROGRAM

**SUNDAY 17 APRIL 2011**

**WELCOME RECEPTION, Esplanade Hotel, Fremantle  
1730 - 1830**

Please join us for a special opportunity to renew old acquaintances or make new friends in this unique environment.

Cost included for full delegates.

Additional tickets: \$44 inc GST per person

**TUESDAY 19 APRIL 2011**

**SYMPOSIUM DINNER, Esplanade Hotel, Fremantle  
1900 - 2400**

The dinner is a highlight of every symposium and this one will be no exception. Experience the fine dining, fun and entertainment.

Cost included for full delegates.

Additional tickets: \$110 inc GST per person

## WHO WILL ATTEND

The symposium will bring international experts on rare diseases together with stakeholders nationally. We envisage national stakeholders will include: patients and carers, health, disability and social service providers, patient support organisations, patient advocates, researchers, biotechnology and pharmaceutical industry representatives and government.

## WHY YOU SHOULD ATTEND

Let your voice be heard in the development of a national plan for rare diseases in Australia. Attend this symposium for the opportunity to join discussions of the local and global needs of the rare disease community.

You will meet key members of the national and international community involved in policies, research, diagnosis, treatment and care of patients with rare diseases.





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2011

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## PROVISIONAL PROGRAM

### REGISTRATION DAY: SUNDAY 17 APRIL 2011

1630 - 1830 Registration commences from 1630 followed by the **WELCOME RECEPTION** from 1730

### DAY ONE: MONDAY 18 APRIL 2011

0800 Registration

0900 - 1030 **Plenary Session 1: Developing Strategies and National Plans**  
Chair: Dr Elizabeth Elliott, Convenor, National Task Force for Rare Diseases

#### PLENARY SESSION 1

**Welcome to Country by Indigenous Traditional Owners**  
Mr Noel Nannup, Noongar Elder

**Welcome Address**  
Mr Kim Snowball, Director-General, WA Health

**Developing A Rare Diseases National Plan for Australia**  
Dr Elizabeth Elliott, Professor of Paediatrics & Child Health, The University of Sydney, Children's Hospital at Westmead and Director, Australian Paediatric Surveillance Unit (Australia)

**Perspective of a Person Living with a Rare Disease on Developing a Rare Diseases National Plan for Australia**  
Mr Bruce Langoulant, Disability Services Commission Board, Confederation of Meningitis Organisations

**Effective Collaborative Efforts Among Regional Governments and the Development of EUROPLAN**  
Dr Domenica Taruscio, Director, National Centre for Rare Diseases, National Health Institute (Italy)

**Introduction to Workshop Discussions**  
Ms Caron Molster, Manager, Community & Policy, Office Population Health Genomics, Department of Health WA

1030 - 1100 Morning Tea

1100 - 1230 **Workshop 1: Strategic Planning for Rare Diseases in Australia**  
Experiences within the Australian health, disability and social services system. Challenges for rare diseases within this system. Why do we need a national plan?

**Room 1**  
**Breakout Groups A**  
Medical and health/clinicians  
Allied health  
Social services

**Room 2**  
**Breakout Groups B**  
Patients/Family members/Carers  
Patient support/advocacy groups  
Alliances

**Breakout Groups C**  
Scientists/Industry  
Researchers  
Policy-makers/regulators

1230 - 1330 LUNCH BREAK

1330 - 1500 **Plenary Session 2: Patient Empowerment**  
Chair: Mr John Forman, Executive Director, New Zealand Organisation for Rare Disorders (NZORD)

#### PLENARY SESSION 2

**Perspective of a Person Living with a Rare Disease on Patient Empowerment**  
Ms Megan Fookes, President Fabry Support Group Australia Inc. (FSGA), Director Fabry International Network (FIN), Committee Member The Association of Genetic Support of Australasia (AGSA)

**Patient Groups and Umbrella Organisations: The Power of Collaboration**  
Mr Peter L Saltonstall, President and CEO, National Organization for Rare Diseases (NORD) (USA)

**Raising the Voice of all Australians Living with a Rare Disease Through Advocacy**  
Dr Rhonda Galbally AO, Director of Galbally Associates, Chair of the National People with Disabilities and Carer Council and interim CEO of the Australian National Preventive Health Agency



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## DAY ONE: MONDAY 18 APRIL 2011

	<b>PLENARY SESSION 2 continues</b> <b>The Power of Information (video presentation)</b> Dr Segolene Ayme, Director of Research, French Medical Research Council and Head, Rare Diseases Taskforce of the European Commission (INSERM) (France)	
1500 - 1530	Afternoon Tea	
1530 - 1700	<b>Workshop 2: Patient Empowerment</b> What improvements can be made in Australia regarding patient/family empowerment? Does Australia need a rare diseases umbrella organisation? If so, to do what? What should a National Plan focus on for patient empowerment?	
	<b>Room 1</b> <b>Breakout Groups A</b> Medical and health/clinicians Allied health Social services	<b>Room 2</b> <b>Breakout Groups B</b> Patients/Family members/Carers Patient support/advocacy groups Alliances
		<b>Breakout Groups C</b> Scientists/Industry Researchers Policy-makers/regulators
1700	Close of Sessions Day One	

## DAY TWO: TUESDAY 19 APRIL 2011

0800	Registration	
0900 - 1030	<b>Plenary Session 3: Patient Care, Support and Management in Australia</b> Chair: Dr Gareth Baynam, Clinical Geneticist, Genetic Services WA (Australia)	
	<b>PLENARY SESSION 3</b> <b>Tristan and Tiarna's Journey - Perspectives on Care, Support and Management</b> Maria Heaton, Mother of two children with Bilateral Perisylvian Polymicrogyria and Clinical Nurse Consultant Palliative Care, Board Member NSW CID	
	<b>A Comprehensive Approach to the Management of Rare Diseases in Primary Care: The Role of GPs</b> Dr Chris Fox, General Practitioner	
	<b>Integrated Approach to Health Care</b> Dr Elizabeth Elliott, Professor of Paediatrics & Child Health, Westmead Children's Hospital and Director, Australian Paediatric Surveillance Unit (Australia)	
	<b>The Clinical Management of Rare Diseases such as Inherited Disorders of Metabolism</b> Dr Jack Goldblatt, Director, Genetic Services & Familial Cancer Program of WA (Australia)	
	<b>Inclusive Approaches to Social Supports and Disability Services - Count Me In</b> Ms Susan Peden, Disability Services Commission (Australia)	
1030 - 1100	Morning Tea	
1100 - 1230	<b>Workshop 3: Patient Care, Support and Management in Australia</b> What improvements can be made in Australia to better identify and meet medical, health and social needs across the lifespan for patients with rare diseases? What should a National Plan focus on in this area?	
	<b>Mixed Breakout Groups</b>	<b>Mixed Breakout Groups</b>
1230 - 1330	LUNCH BREAK	



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## DAY TWO: TUESDAY 19 APRIL 2011

1330 - 1500	<b>Plenary Session 4: Research and Translation</b> Chair: Dr Christophe Beroud, Assistant Professor, Laboratory of Molecular Genetics, National Health and Medical Research Institute (INSERM) (France)	
	<b>PLENARY SESSION 4</b> <b>Perspective of a Person Living with a Rare Disease on Research and Translation</b> Ms Diane Dale, Member Australian Pompe Association	
	<b>Clinical Research Opportunities and the Importance of Global Patient Registries</b> Dr Stephen J Groft, Director, Office of Rare Diseases, National Institutes of Health (USA)	
	<b>Clinical Trials and Translation in the Australian context</b> Dr Monique Ryan, Paediatric Neurologist, Neurosciences Department, Royal Children's Hospital Melbourne (Australia)	
	<b>PLENARY SESSION 4 continues</b> <b>Research Gaps and Needs in the Australian Context</b> Dr Yvonne Zurynski, Associate Professor, Paediatrics & Child Health, The University of Sydney and Assistant Director, Australian Paediatric Surveillance Unit (Australia)	
1500 - 1530	Afternoon Tea	
1530 - 1700	<b>Workshop 4: Research and Translation</b> What improvements can be made in Australia regarding research and translation? What should a National Plan focus on in this area?	
	Mixed Breakout Groups	Mixed Breakout Groups
1700	Close of Sessions Day Two	
1900 - 2400	<b>SYMPOSIUM DINNER</b>	

## DAY THREE: WEDNESDAY 20 APRIL 2011

0800	Registration	
0900 - 1100	<b>Plenary Session 5: Networks, Partnerships, Collaborations</b> Chair: Dr Hugh Dawkins, Manager, Office of Population Health Genomics, Department of Health WA	
	<b>PLENARY SESSION 5</b> <b>Perspective of a Person Living with a Rare Disease on Networks, Partnerships, Collaborations</b> Ms Lesley Murphy, Muscular Dystrophy Western Australia	
	<b>Effective Strategies for Ensuring Patients are Equal Partners in Research and Clinical Care</b> Ms Sharon Terry, President and CEO, Genetic Alliance	
	<b>Creating Clinical Research and Infrastructure Networks in Europe</b> Dr Hanns Lochmuller, Professor of Experimental Myology, Institute of Human Genetics, Newcastle University	
	<b>Australasian Neuromuscular Network - Official Launch of a Collaborative Approach to Rare Disease</b> Dr Kathryn North, Douglas Burrows Professor and Associate Dean, CHW Clinical School, Faculty of Medicine, University of Sydney and Head, Institute for Neuroscience and Muscle Research, The Children's Hospital at Westmead (Australia)	
1100 - 1130	Morning Tea	
1130 - 1300	<b>Workshop 5: Networks, Partnerships, Collaboration</b> What improvements can be made in Australia to build better networks, partnerships and collaborations? What should a National Plan focus on in this area?	
	Mixed Breakout Groups	Mixed Breakout Groups
1300 - 1400	LUNCH BREAK	



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## DAY THREE: WEDNESDAY 20 APRIL 2011

1400 - 1500 **Workshop 6: Staying Awake to Rare Diseases**  
How to maintain the momentum for a national plan on rare diseases

	<b>Room 1</b> <b>Breakout Groups A</b> Medical and health/clinicians Allied health Social services	<b>Room 2</b> <b>Breakout Groups B</b> Patients/Family members/Carers Patient support/advocacy groups Alliances
		<b>Breakout Groups C</b> Scientists/Industry Researchers Policy-makers/regulators

1500 - 1530 Afternoon Tea

1530 - 1615 **Plenary Session 6: Staying Awake to Rare Diseases In Australia**  
Chair: Dr Peter O'Leary, Director, Office of Population Health Genomics, Department of Health WA

### PLENARY SESSION 6

Mini-talks (5 mins each) by four presenters drawn from the Plenary Speakers:

Summary of symposium highlights and key outcomes. How to maintain the momentum for a national plan on rare diseases?

Patients, carers, patient groups

Policy-makers

Researchers, Industry

Clinical, disability and social services

OPEN FORUM DISCUSSION

1615 - 1630 **CLOSING ADDRESS**  
Dr Peter O'Leary, Director, Office of Population Health Genomics, Department of Health WA

1630 Close of Symposium





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## HOW TO REGISTER

Delegates can register by email, mail or fax. Full symposium details and a downloadable pdf registration form are also available at:

[www.raredisease.com.au](http://www.raredisease.com.au)

All delegates (including speakers) must complete a registration form for administrative purposes.

**Full 3-Day Registration** includes:

- attendance at all symposium sessions;
- morning/afternoon teas and lunches;
- program;
- welcome reception;
- symposium dinner.

## METHOD OF PAYMENT

Payment must accompany the registration form and should include (as appropriate): registration fees, hotel deposit (one night's tariff) and extra tickets to the social functions.

Payment can be made by EFT, credit card, cheque or for international delegates, by bank draft in Australian dollars. Personal or company cheques will not be accepted from international delegates. Please note that all payments made by credit card will be subject to a 3% bank fee on the total amount.

## ACKNOWLEDGEMENT

Registrations received prior to Friday 1 April 2011 will be acknowledged in writing. Delegates are asked to check their confirmation letter and advise the organisers immediately, if changes/amendments are required. For registrations made after Friday 1 April 2011, please telephone or email the secretariat to confirm receipt of your registration.

## REGISTRATION DESK

The registration desk, located in the Southern Cross Foyer of the Fremantle Esplanade Hotel will open from 1630 - 1830 on Sunday 17 April 2011 and also each day of the symposium from 0800 - 1600 for the collection of delegate kits and general assistance.

## DIETARY REQUIREMENTS

Delegates with special dietary needs must advise Promaco Conventions via the registration form or in writing to ensure they are suitably catered for.

## REGISTRATION FEES (all fees are inclusive of GST)

	STANDARD	CONCESSION <sup>1</sup>	PATIENTS/CARERS
Full 3-Day Rate	\$660	\$484	\$308
Day Rate <sup>2</sup>	\$330	\$242	\$154
Session Rate <sup>3</sup>	N/A	N/A	\$66
Symposium Dinner <sup>4</sup>	\$110	\$110	\$110

1. Concession Full 3-Day rate applies for paid employees of patient groups and fulltime students. Fulltime student registrations must supply proof of fulltime student status from their institution.
2. Day rate includes morning/afternoon teas and lunch on the selected day.
3. Session rate includes morning or afternoon tea as applicable to the selected session. It does not include lunch.
4. The dinner is included in the full 3-day registration. It is not included in the day or session rates.

**IMPORTANT NOTE:** Payment in FULL must be received by the symposium secretariat to enable delegates to collect their information and attend the symposium sessions. Please ensure that your organisation/institution has finalised all necessary payments prior to registration day - Sunday 17 April 2011.

## VENUE AND LOCATION

The symposium will be held in Fremantle at the Esplanade Hotel on the corner of Marine Terrace and Essex Street.

Fremantle is located at the mouth of the Swan River and is 20 km from central Perth. This relaxed and historic port city has a diverse mix of old and new and the range of activities available for all ages is endless.

Tour the streets or take the Fremantle Aboriginal Heritage Tour. Discover art and craft galleries and the famous Fremantle Markets. Sample boutique beers in one of the nearby brewery pubs or enjoy seeing the sun set over the ocean.

Fremantle is within easy reach of the beaches of the Indian Ocean, Rottnest Island and Western Australia's capital, Perth. The Margaret River wine region is only a few hours away.

**Airport transfers:** Taxi fare to Fremantle is around \$48 from Perth Domestic Airport. Travelling time by car is approximately 45 minutes. Coach transfers to Fremantle operate 24 hours daily to suit flight arrival and departure times. To book a transfer, go to [www.fremantleairportshuttle.com.au](http://www.fremantleairportshuttle.com.au) or call the Fremantle Shuttle on +61 8 9457 7150.

Please note that all symposium registration and accommodation enquiries should be directed to the secretariat: Promaco Conventions on telephone: +61 8 9332 2900, facsimile +61 8 9332 2911 or via email: [promaco@promaco.com.au](mailto:promaco@promaco.com.au).



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symposium website: [www.raredisease.com.au](http://www.raredisease.com.au)

## INTERNATIONAL DELEGATES

Perth is serviced by a range of major airlines, with a choice of routes for international travellers. It has direct international flights to New Zealand and several capitals in Asia and is the only Australian capital city with direct links to Africa. Other international flights are routed to Perth via Sydney, or to Europe and North America via Asia. Domestic carriers are active within Western Australia and provide airlinks to regional centres and some State capital cities.

**Visas/Customs/Immigration:** Anyone who is not an Australian citizen requires a valid Visa/Electronic Travel Authority to enter and spend time in Australia. With the exception of New Zealand citizens travelling on New Zealand passports, all foreign nationals must obtain a Visa/ETA before travelling to Australia. (New Zealand citizens are issued with a Visa upon arrival).

Visas are available from Australian Visa Offices such as Australian Embassies, High Commissions and Consulates. For the location of your nearest Australian Consulate, go to the Department of Foreign Affairs and Trade website at [www.dfat.gov.au/missions/](http://www.dfat.gov.au/missions/). Visas are also available in ETA form from travel agents and airlines in certain countries. There are no visas or border checks required when moving between Australian states. For helpful advice, go to [www.immi.gov.au](http://www.immi.gov.au) and for customs regulations, go to [www.customs.gov.au](http://www.customs.gov.au).

## CANCELLATION AND REFUNDS

**Registration** - cancellation of registration must be advised in writing. Cancellations made before Friday 1 April 2011 incur a penalty fee of \$110. Refunds of fees after this time will only be made in exceptional circumstances. Substitute delegates will be accepted and details must be advised in writing. Please note that all cancellations will be processed after the symposium concludes.

**Accommodation** - cancellation of accommodation must be advised in writing. Each hotel reserves the right to charge delegates for non-arrival on the dates pre-booked and/or for no-shows.

If, for reasons beyond the control of the organisers, the symposium were to be cancelled, fees minus deduction of expenses incurred would be refunded.

Please keep a copy of your registration form and note that by submitting the form, you have agreed to the terms of the cancellation policy.

## DOMESTIC TRAVEL

The longer you wait to book travel - the more you could pay! Do you want to see ALL flight options to the Rare Diseases Symposium 2011 on a single computer screen? You can book up to 9 people in one booking!

To use the latest delegate flight booking technology & book online, please go to: [www.travelctm.com](http://www.travelctm.com) and enter the following details:

Company code: ctmgrps

Login: ctmgroups@travelctm.com

Password: 1234, then click on "make a reservation

Alternatively, please contact Corporate Travel Management (CTM) direct for the best airfare rates on 1800 630 866 or email: [groups@travelctm.com](mailto:groups@travelctm.com). Or if you are travelling from outside of Australia, email your flight request to [groups@travelctm.com](mailto:groups@travelctm.com)

Remember to quote your event code - RARE2011

## GENERAL INFORMATION

**Child Care:** No arrangements have been made for child care during the symposium. Please check with the concierge at your hotel for assistance with babysitting services during your stay.

**Dress and Weather:** Perth weather in April is around 25 degrees celsius. Some warm clothing is recommended, particularly in the evenings.

**Symposium sessions:** Smart casual

**Evening functions:** Smart casual

**Symposium Dinner:** Lounge Suit/Cocktail Dress

**Goods and Services Tax (GST):** A tax refund is not available for goods or services consumed in Australia - and therefore the GST component of conference registration fees, accommodation, etc is not claimable.

**Insurance Advice:** Registration fees do not include insurance of any kind. It is strongly recommended that at the time you register for the symposium and book your travel, you take out an insurance policy of your choice. The policy should include (1) loss of fees/deposit through cancellation of your participation in the symposium; (2) loss through cancellation of the symposium; (3) loss of international/domestic air fares through cancellation for any reason including force majeure, medical expenses, loss or damage to person or property, additional expenses; and (4) repatriation should travel arrangements have to be altered. The symposium secretariat cannot take any responsibility in the event of industrial disruptions OR for any participant failing to arrange his or her own insurance.

**Shopping Hours:** There are many speciality shops in Perth and Fremantle. Shops are open from 8.30am to 5.30pm, Monday to Friday, (with late night shopping until 9.00pm on Thursday, and in Perth on Friday), 8.30am to 5.00pm on Saturday and from 12.00 noon to 5.00pm on Sunday. These hours may differ slightly from shop to shop.

**Smoking Policy:** No smoking is allowed in restaurants, bars and shopping centres in Perth and Fremantle.



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## ACCOMMODATION

Accommodation is available at special rates at the symposium venue, the Esplanade Hotel and also at the Trade Winds Hotel.

The symposium rates offered can only be obtained by booking through Promaco Conventions. For rooms required before or after the symposium dates, early booking is essential. Breakfast is not included in the rates.

**Deposit:** Bookings require a deposit of one night's tariff and a credit card guarantee. The deposit is non-refundable. One night's room rate will be deducted from the credit card if the reservation is cancelled within 30 days of the date required or, if you do not arrive on the date you have nominated. Delegates are to settle their accounts, including incidentals, upon checking out. Your hotel will provide an accommodation tax invoice/receipt.

**Amendments:** Amendments to accommodation will only be accepted in writing and must be advised to Promaco Conventions in advance. Changes made after Friday 1 April 2011 cannot be guaranteed and will be subject to availability.

**Check-in and Check-out:** Standard check-in time of 1400 and check-out time of 1100 applies to all venues. Requests for late check-out must be made with the venue as you arrive. Please note that early check-in may require the booking of an additional room night prior, to guarantee immediate access to your room.

**Booking deadline:** Hotels impose strict release dates for block accommodation bookings. Unused rooms will be released 30 days prior to the symposium. Please book your accommodation by Friday 18 March.

## HOTELS

Please note: The hotels are responsible for the invoicing of GST. Please ask your hotel for a Tax Invoice upon check-out.

**Fremantle Esplanade** - the venue has 4.5 star facilities including three restaurants, bar, gym, two swimming pools and three spas.

[www.esplanadehotelfremantle.com.au](http://www.esplanadehotelfremantle.com.au)  
Rate: \$199 single/double/twin standard

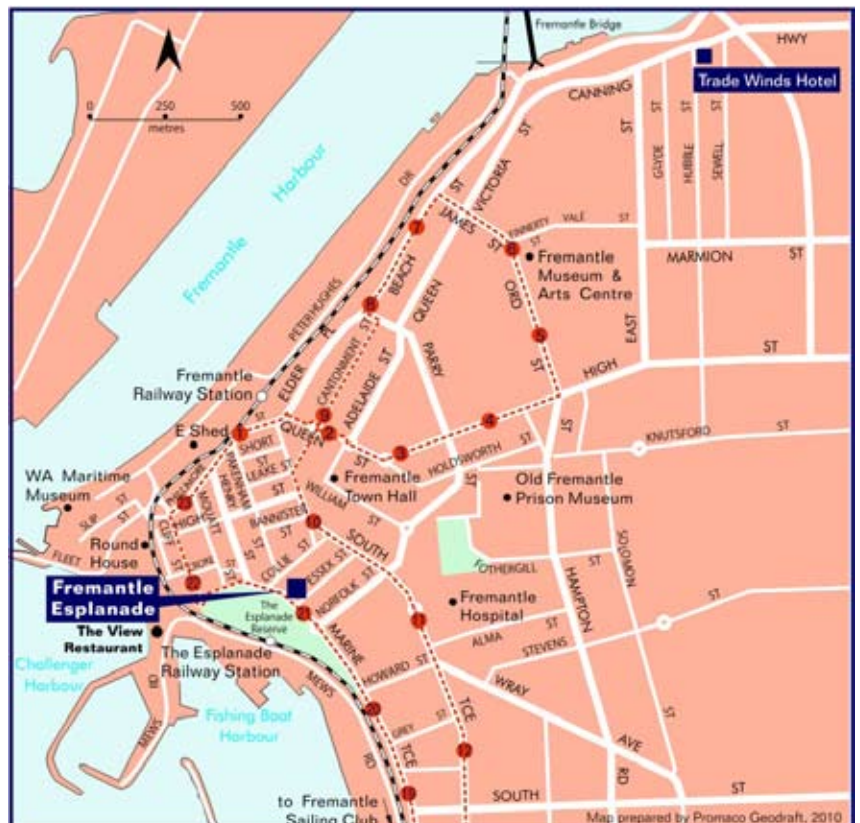
**Trade Winds** - 4 star hotel with river views. Twenty minute walk to venue. Regular bus service and taxis also available.

[www.tradewindshotel.com.au](http://www.tradewindshotel.com.au)  
Rate: \$210 single/double/twin standard studio apartments

Other accommodation enquiries can be made to the Fremantle Tourist Centre - [www.fremantlewa.com.au](http://www.fremantlewa.com.au)

**DISCLAIMER** - The information contained in this publication is correct at the time of printing. Promaco Conventions and the Organising Committee reserve the right to alter or delete items from the program or tours. The organisers shall not be responsible for any costs or damages arising from any action based on the information contained in this booklet. E.&.O.E.

Bus Stop Locations (Free CAT Service)	
1 Fremantle Train Station	11 South Terrace Charles Street
2 Queen Street Shopping Precinct	12 South Terrace Wardie Street
3 High Street Kings Square	13 South Terrace Orient Street
4 High Street CBC Fremantle	14 Marine Terrace Douro Road
5 Ord Street Fremantle Park	15 Marine Terrace Fremantle Sailing Club
6 Fremantle Arts & Leisure Centre	16 Marine Terrace Capo D'Orlando Drive
7 Beach Street	17 Marine Terrace Free parking
8 Cheviot Hotel	18 Marine Terrace Free parking
9 Cantonment Street Woolstores Shopping Centre	19 Esplanade Hotel
10 Cappuccino Strip	20 Maritime Museum & Fishing Boat Harbour
11 Fremantle Hospital	21 Phillimore Street
12 South Terrace	22 Victoria Quay





*international*  
**Rare Diseases symposium**  
AUSTRALIA

**TAX INVOICE**  
ABN 88 147 548 141

www.raredisease.com.au

**REGISTRATION FORM**

**DELEGATE INFORMATION**

Mr/Mrs/Ms/Dr/Prof First name: .....

Family name: .....

Position: .....

Organisation: .....

Postal address: .....

..... City: .....

Country: ..... Postcode: .....

Tel (Bus): ..... (Hm): .....

Fax (Bus): ..... Mobile: .....

Email: .....

Special needs (e.g. dietary / wheelchair access, etc) .....

.....

Please tick this box if you DO NOT wish to be included on the published delegate list.

**REGISTRATION FEES** (All fees are inclusive of GST)

	STANDARD	CONCESSION <sup>1</sup>	PATIENTS/CARERS
Full 3-Day Rate	<input type="checkbox"/> \$660	<input type="checkbox"/> \$484	<input type="checkbox"/> \$308
Day Rate <sup>2</sup>	<input type="checkbox"/> \$330	<input type="checkbox"/> \$242	<input type="checkbox"/> \$154
Session Rate <sup>3</sup>	N/A	N/A	<input type="checkbox"/> \$66
Symposium Dinner <sup>4</sup>	See Social Program		

**DAY DELEGATES:** Please select day(s):

Monday     Tuesday     Wednesday

**SESSION DELEGATES:** Please select session(s):

- Session 1: National plans (Monday am)
- Session 2: Patient empowerment (Monday pm)
- Session 3: Patient care, support and management (Tuesday am)
- Session 4: Research and translation (Tuesday pm)
- Session 5: Networks, partnerships, collaborations (Wednesday am)
- Session 6: Staying awake to rare diseases (Wednesday pm)

**INCLUSIONS:**

1. Concession Full 3-Day rate applies for paid employees of patient groups and fulltime students. Fulltime student registrations must supply proof of fulltime student status from their institution.
2. Day rate includes morning/afternoon teas and lunch on the selected day.
3. Session rate includes morning or afternoon tea as applicable to the selected session. It does not include lunch.
4. The dinner is included in the full 3-day registration. It is not included in the day or session rates.

**FULLTIME STUDENTS**

FULL TIME STUDENTS must have the following details completed by their Head of Department or supply proof of fulltime enrolment with their registration.

I hereby certify that ..... is a fulltime student.

Head of Department: .....

Department: ..... Institution: .....

Signed: ..... Date: .....

**SOCIAL PROGRAM**

Please indicate if you will be attending the functions, as only those who have nominated will be catered for.

**Sunday 17 April 2011**

**WELCOME RECEPTION**

Fremantle Esplanade Hotel - 1730

Full 3-Day Registration (included)

Additional tickets @ \$44 ea x \_\_\_\_

**Tuesday 19 April 2011**

**SYMPOSIUM DINNER<sup>4</sup>**

Fremantle Esplanade Hotel - 1900

Full 3-Day Registration (included)

Additional tickets @ \$110 ea x \_\_\_\_

**ACCOMMODATION**

Accommodation bookings should be made as early as possible to avoid disappointment. Please book by Friday 18 March.

Fremantle Esplanade Hotel     \$199    single / twin / double

Trade Winds Hotel     \$210    single / twin / double

Room type:     SMOKING     NON-SMOKING

Check-in date: .....    Check-out date: .....

I will be sharing with: .....

No. of nights: .....    One night deposit: .....

NOTE: One night deposit is required to accept your booking. Hotels are responsible for their own GST. Please ask for a tax invoice at check-out.

**This document will be a tax invoice for GST when you make full payment (in accordance with the ATO) - Please retain a copy**



**TAX INVOICE**  
ABN 88 147 548 141

*international*  
**Rare Diseases** *symposium*  
2011  
AUSTRALIA

**REGISTRATION FORM**

[www.raredisease.com.au](http://www.raredisease.com.au)

**USEFUL WEBSITES TO PLAN YOUR TRIP**

- [www.westernaustralia.com](http://www.westernaustralia.com)
- [www.discoverwest.com.au](http://www.discoverwest.com.au)
- [www.dec.wa.gov.au](http://www.dec.wa.gov.au)
- [www.rotnnest.wa.gov.au](http://www.rotnnest.wa.gov.au)
- [www.indigenouswa.com](http://www.indigenouswa.com)

**RETURN YOUR COMPLETED FORM BY:**

**FAX TO:** +61 8 9332 2911

**EMAIL TO:** [promaco@promaco.com.au](mailto:promaco@promaco.com.au)

**MAIL TO:**  
Promaco Conventions  
PO Box 890, Canning Bridge  
WESTERN AUSTRALIA 6153

**OR TO CONTACT PROMACO CONVENTIONS,  
CALL:** +61 8 9332 2900

NOTE: The registration form is your TAX INVOICE. It is the delegate's responsibility to retain a copy of the tax invoice/form. The receipt of payment will be sent to the person named in the delegate information section. The tax invoice/form together with the receipt, is required by the ATO to reclaim the GST and should be passed to the appropriate person in your organisation. Reprints for tax invoice/forms and or receipts, will be subject to a \$22 administration fee.

**Payment SUMMARY**

Registration Fees [includes GST] .....	.....
Social Program [includes GST] .....	.....
Accommodation [includes GST] .....	.....
<b>TOTAL</b> [will be plus 3% bank fee* if paid by credit card] .....	.....

**CANCELLATIONS POLICY:** Registration cancellations must be made in writing to the Symposium Secretariat, Promaco Conventions. Cancellations received prior to Friday 1 April 2011 will incur a penalty fee of \$110. No refunds will be made for cancellations made after Friday 1 April 2011, however registration may be transferred to another person within your organisation without penalty. Promaco Conventions must be advised of the transfer no later than 48 hours prior to the commencement of the conference.

**IMPORTANT:** In accordance with their terms and conditions, accommodation bookings at the venues offered within this booklet that are cancelled within 30 days of the date booked, will forfeit the deposit paid. Insurance is recommended for reasons beyond your control.

**PAYMENT OPTIONS**

- Cheque - make payable to Promaco Conventions.
- Payment by EFT. Please follow instructions below.
- \* Credit Card - Payment is subject to a 3% bank fee on the total cost.

**PAYMENT BY EFT:**

Account name: Success Events Management  
BSB: 126 568 ACCOUNT NO. 215 683 95  
BANK: Bank of Queensland BRANCH: Fremantle  
SWIFT CODE: BKWAAU6P  
REFERENCE: RARE2011 plus your first name/family name.

Please email: [promaco@promaco.com.au](mailto:promaco@promaco.com.au) or Fax (+61 8 9332 2911)  
confirmation details to Promaco on the day of your EFT transaction.

**PAYMENT BY CREDIT CARD\***

- MASTERCARD
- VISA
- AMEX

Cardholder [please print] .....

Expiry date ..... Signature: .....

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AWAKENING AUSTRALIA TO RARE DISEASES:  
Global perspectives on establishing a coordinated approach to a national plan  
Esplanade Hotel, Fremantle Western Australia 17 - 20 April 2011

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