

Fabry Australia National Fabry Patient Meeting *‘Exploring the Fabry Future’*

Saturday 9th September 2017
Novotel Melbourne, St Kilda
16 The Esplanade St Kilda, Victoria, 3182 ☎(03) 9525 5522

Welcome

Fabry Australia is pleased to invite the Fabry patient community to this year’s Fabry Australia National Fabry Patient Meeting – **‘Exploring the Fabry Future’** being held on **9th September 2017** at the Novotel Hotel in St Kilda Victoria.

This year’s conference is shaping up to be a fabulous program. We are fortunate to have excellent speakers presenting on a range of topics including; the latest clinical Fabry Disease research, findings from the Australian Experience of living with Fabry Disease, Management of Fabry Disease in the clinical setting, Fabry Disease and Genetics / inheritance, Fabry patient support programs, Carers Support Programs / NDIS, Fabry Disease Testing Programs, the isolation of living with Fabry Disease in New Zealand and some Fabry Disease patient testimonies. Fabry Australia has invited a facilitator to help with a workshop on Fundraising – putting the ‘Fun’ back into fundraising.

All attendees will receive conference materials, program, access to speakers, opportunity to contribute to panel Q & A sessions, morning and afternoon tea, hot & cold lunch and dinner at the Hotel restaurant. To ensure you don’t miss out, please register your attendance by **18th August 2017**. Further details are on the Fabry Australia website. Please complete your [Registration Online](#).

We look forward to catching up with the Australian Fabry Community very soon!

The Novotel St Kilda is a 4-star hotel beachfront hotel overlooks Melbourne's Port Phillip bay. Ideally positioned facing St Kilda beach and surrounded by some of the city's finest attractions. It is a 10-minute walk from the beach, 1.8 km from Balaclava Station and 6km from the National Gallery of Victoria. It is a short stroll to Luna Park, Acland Street cafés, a tram stop outside the hotel. The hotel rooms offer satellite TV, Wi-Fi, whirlpool baths and spas and tea and coffee making facilities. There is relaxed restaurant with a terrace and a bar. Attendees staying at the hotel will receive complimentary buffet breakfast served in the restaurant overlooking the beach. Other amenities include a fitness centre, an outdoor pool, business centre and an airport shuttle (fee).



Full Program

Friday 8th September

Fabry Australia Committee ONLY

| Schedule | Program | Participants |
|-----------------|--|--|
| 10.00-13.00 | Fabry Australia Committee Strategy Meeting | Fabry Australia Committee Facilitator |
| 14.00 | Fabry Australia Committee Meeting | Fabry Australia Committee |
| 15.00-16.00 | Industry & Fabry Australia Committee Meeting | Fabry Australia Committee and Pharmaceutical Company representatives |
| 18.30 | Dinner – Fabry Australia Committee Only | Fabry Australia Committee |

Fabry Australia National Fabry Patient Meeting

Saturday 9th September
Novotel St Kilda

| Schedule | Program | Speaker/s |
|-------------|---|---|
| 9.00-9.25 | Registration open | |
| 9.30-9.40 | Welcome and introductions | Sheridan Campbell <i>Fabry Australia</i> |
| 9.40-10.00 | What's new in clinical management of Fabry Disease | Assoc Prof Kathy Nicholls <i>Royal Melbourne Hospital</i> |
| 10.00-10.20 | Genetics and Fabry Disease | Prof Ingrid Winship <i>Research for Melbourne Health and the Chair of Adult Clinical Genetics at The University of Melbourne</i> |
| 10.20-10.40 | The Australian Experience of Living with Fabry Disease – Fabry Australia Survey | Megan Fookes <i>Fabry Australia</i> |
| 10.40-11.00 | Fabry Patients in Melbourne – Research | Dr Andrew Talbot <i>Royal Melbourne Hospital</i> |
| 11.00-11.15 | QUESTION TIME | |
| 11.15-11.30 | MORNING TEA BREAK | |
| 11.30-11.50 | Qld fabRy Epidemiology Study | Dr Andrew Mallett QLD Renal Genetics Service |
| 11.50-12.10 | Caring for Fabry Children in Victoria | Carla Rogers <i>Royal Children's Hospital, VIC</i> |
| 12.10-12.25 | Fabry Genetic Support Service Program (Sanofi Genzyme Initiative) | Ms Vicki Petrou <i>Genetic Counsellor MyDNA</i> |
| 12.25-12.40 | atYOURside service (Shire Australia Patient Program) | Ms Natalie Fraser <i>atYOURside service</i> |
| 12.40-12.55 | QUESTION TIME | |
| 13.00-14.00 | LUNCH – Novotel Hotel at 'The Esplanade Diner' | |

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|--------------|--|---|
| 14.00-14.15 | 'About us' & NDIS - Carers Victoria | Kate Outhred <i>Carers Victoria</i> |
| 14.15-14.50 | Patient Stories/ Testimonials | Liz Hunt Monica Hunter Ian Emmerich |
| 14.50-15.00 | AFTERNOON TEA BREAK | |
| 15.00 -15.40 | Fundraising for Fabry Australia Workshop | Mary Lalor Megan Fookes |
| 15.40-16.00 | Fabry Australia Annual General Meeting (AGM) | Fabry Australia Members ONLY |
| 16.00 | BREAK | |
| 18.30 | DINNER – Novotel Hotel at 'The Esplanade Diner' | |

Please Note : Program is subject to change without notice

Sunday 10th September

Novotel St Kilda

Sunday will be free time to catch up with old and new Fabry friends. Or if you need to get back home you won't need to stay around.

There will be various activities arranged that you may like to join in, or feel free to wander around St Kilda and explore the St Kilda Market which is right across the road from the hotel.



Fabry Australia National Fabry Patient Meeting Registration Details

Registration

Fabry Australia are pleased you are coming to the **National Fabry Patient Meeting Saturday 9th September 2017**. Please note, **registrations close 18th August 2017**. All registrations must be completed online via the Fabry Australia website. Please [PRESS HERE](#) to complete your registration. When registering please indicate any dietary and/or mobility requirements. The cost to register is **FREE** to Fabry Australia Members and \$150 for non-members. Registration includes; Conference entrance, conference materials/papers/presentations, morning & afternoon tea, cold/hot lunch and dinner in the Novotel Hotel restaurant.

Travel and Transfers

Travelling to and from the conference is the responsibility of attendees. The **Novotel St Kilda**, 16 The Esplanade 3182 St Kilda, Melbourne is 30kms from Melbourne Tullamarine Airport.

Transfer options:

- SkyBus – approximately \$19 each way (booking recommended)
<https://www.skybus.com.au/st-kilda-express/>
- Taxi/uber – 30kms
- Public Transport – Bus to Spencer Street Station, Train to Flinders, Tram to St Kilda.
[https://www.accorhotels.com/gb/hotel-1506-novotel-melbourne-st-kilda/index.shtml#/#!](https://www.accorhotels.com/gb/hotel-1506-novotel-melbourne-st-kilda/index.shtml#/)

If travelling by car to the conference, parking onsite at the hotel is available at a discounted rate of \$10/day but must be prior-booked. Please advise Fabry Australia via email at secretary@fabry.com.au if you intend to drive and park as spaces are limited.

There is some limited offstreet parking and metered parking around St Kilda streets.

Accommodation

Fabry Australia has an agreed conference rate of \$175.00 – including standard room, one full-buffet breakfast and Wi-Fi access only (*excludes additional items such as Mini bar purchases, phone calls from hotel room, inroom dining service and inroom entertainment movie purchases which are separate and at your own expense*). Bookings are essential, directly through the Novotel Hotel reception on (0)3 9525 5522.

The Novotel does accommodate for Accessibility for people with reduced mobility. Please indicate if required when booking.

Check-in: 14:00

Check-out: up to 11:00

Meals

Conference registration includes the following meals - morning tea, lunch, afternoon tea and dinner on Saturday 9th September. When completing registration please indicate if you have any dietary requirements and indicate if you are coming to the dinner.

Travel Scholarships

Fabry Australia offers limited places for Travel Scholarships. Applications are subject to Fabry Australia Committee approval. To obtain a form please contact secretary@fabry.com.au.

Acknowledgements

Fabry Australia would like to thank and acknowledge the speakers and the following companies for contributing educational grants to Fabry Australia to host this event.

