



Australian Pompe Association & New Zealand Pompe Network Family Support Forum 2023

20th -22nd October 2023

Location:

**Pullman Hotel
Adelaide**

Accommodation:

Pullman Hotel
16 Hindmarsh Square
Adelaide, SA 5000

Objectives of the meeting

- To bring members together.
- Provide some advice on Pompe Disease, Genetics of Pompe, Vaccines, Anaesthetics, Newborn Screening, Pre Conception testing, Advocacy for change, New Treatments, advances for Pompe
- Provide an opportunity for members to talk with and learn from other members and build a supporting group.

Agenda

Time	Topic	Speaker
Friday 20th		
17.00 – 19.00	Reception and Registration	
Saturday 21st		
6:30 – 8:00	Breakfast	
8:15 – 8:45	Registration	



8.45 – 8.55	Acknowledgement to Country & Housekeeping, Introduction of Committee	Tarryn Holland Raymond Renee Steven Maddy Jemma Peter Scott Jeff Catherine Bev Allyson. Welcome to new members.
8:55 – 9:00	Welcome and opening	Maddy
Time	Topic	Speaker
9:00 – 9:15	Patients Story	Shelley
9:15 – 09:45	When to treat for Pompe	Dr Priya Kishnani Duke University Via Zoom
09:45 – 9:50	Questions	
09:50 – 10:15:	New Physio testing measuring results of Pompe treatments.	Meredith James UK live Via Zoom
10:15 – 10:40	Break	
10:40 – 11:10	What is Gene Therapy and Substrate reduction Therapy.	Dr Drago Bratkovic
11:10 – 11:20	Preconception Testing -the patient experience	Maddy
11:20 – 11:40	Progress with Newborn screening	Raymond and Felicity McNeil
11:40 – 12:00	Advocacy for change	Felicity McNeil PSM
12:00 – 13:00	Lunch	
13:00 – 13:30	Pain and pain management	Prof Lorimer Moseley AO to be confirmed
13:30 – 14:05	Anaesthetics and Pompe disease	Dr Julia Cox specialist anaesthetist
14:05 – 14:30	Exercises for Pompe Patients	Josie Lock exercise physiologist
14:30 – 15:00	Break	
15:00 – 15:15	Patient Story	Lauren Money
15:15 – 15:40	Home Infusions the patient experience	Renee Brown
15:40 – 16:00	Pompe nursing support	Care for Rare nursing service
19:00 – 22:00	Dinner at Hotel	



Time	Topic	Speaker
Sunday 22nd		
08:30 – 09:00	Australian Pompe Association Annual General Meeting election of new Committee	All Aust Pompe Members who wish to attend.
6:30 – 8:45	Breakfast	
09:00 – 09:10	New Zealand Patient Story	Sam
09:10 – 09:50	How to encourage drug trials in Australia and New Zealand	Dr Drago Bratkovic Aust and Dr Richard Roxburgh NZ
9:50 – 10:00	Long road to Diagnosis The cost of a diagnostic odyssey	Renee Video
10:00 – 10:10	Reggie's Gift	Chris- Reggie's Dad
10:10 – 10:20	Patient Story Catherines exercise journey	Catherine Video
10:20 – 10:45	Break	
10:45 – 11:15	NDIS My Aged Care and discussion on applications	Carly
11:15 – 11:30	Fundraising -how to help	Tarryn
11:30 – 12:00	Virtual Reality to enrich the lives of Pompe Patients -Mental Health-Anxiety-Pain-management	Iain Chalmers and Joshua Lawson from Mobiddiction Video and Live
12:00 – 15:30	Afternoon tea and departure	

This agenda and speakers listed are subject to change at any time.

The information provided at this patient forum is intended to provide general information in regard to the matter covered. It is provided as a public service by the Australian Pompe's Association. Medicine is constantly changing and humane error and changes in practice make it impossible to certify the accuracy of such complex material. Confirmation of this information from your doctor or medical practitioner is required.



We would like to thank everyone who have helped raise funds for this forum including our generous sponsors.



The Australian Pompe Association and New Zealand Pompe Network Family Support Forum 2023 has been partially funded by Amicus Therapeutics UK Limited, who have had no input into the content.

