



Minutes of the Annual General Meeting of the Australian NPC Disease Foundation Inc

Date: 16th February 2025 Time: 1.00pm – 3.30pm Location: Zoom virtual meeting

Attendees:	Deanna Carpino, Ellen Van Velsen, Amanda (Mandy) Whitechurch, Felicity Munro, Andrew (Drew) Woolfe, Dirk Van Beekhuizen, Nathalia Rios, Anna-Maria (Mary) Calcagno, Amy Leddick, Andrew Carpino, Philippa (Pip) Johnston, Marian Shoebridge, Milva Carpino, Vince Demarte, Carly Heath, Omar Ebaih, Natalie Heriot, Harington Chen, Seema Patil, Ashley Bush, Ya Hui Hung, Brendon Boot, Sharmila Kiss, Jov Moratalla, Annamol (Anna) Johny, Riddhi Gopinath
Apologies:	Caroline Hastings, Tina Soulis, Ali Malone
Proxies:	

Minutes:

Item	Description		
1	Welcome and introductions		
2	Apologies		
3	Review of actions from previous annual general meeting (none)		
4	Acceptance of minutes of previous annual general meeting		
	Proposed resolution	Moved by/ Seconded by:	Passed/ Not Passed
	That the minutes of the 2024 annual general meeting be accepted.	1. Mandy Whitechurch 2. Mary Calcagno	Passed
5	President/Chair's report		
6	Treasurer's report		
7	Questions to directors		
8	Committee reports, proposed resolutions:		
	Proposed resolution	Moved by/ Seconded by:	Passed/ Not Passed

	That the President's report tabled at the annual general meeting be accepted.	1. Andrew Carpino 2. Vince Demarte	Passed
	That the Treasurer's report tabled at the annual general meeting be accepted.	1. Mandy Whitechurch 2. Carly Heath	Passed
9	Acceptance of Scientific Advisory Board (SAB) report		
	Proposed resolution	Moved by/ Seconded by:	Passed/ Not Passed
	That the Scientific Advisory Board (SAB) report tabled at the annual general meeting be accepted.	1. Milva Carpino 2. Felicity Munro	Passed
10	Patient Liaison reports		
	Proposed resolution	Moved by/ Seconded by:	Passed/ Not Passed
	That the Adult Patient Liaison report tabled at the annual general meeting be accepted.	1. Andrew Carpino 2. Amy Leddick	Passed
	That the Paediatric Patient Liaison report tabled at the annual general meeting be accepted.	1. Mandy Whitechurch 2. Mary Calcagno	Passed
11	Appointment of an auditor		
	Proposed resolution	Moved by/ Seconded by:	Passed/ Not Passed
	That CSM Advisors be appointed as the ANPDF's auditor for the next reporting period.	1. Mandy Whitechurch 2. Andrew Carpino	Passed
12	Results of the Executive Committee election: Board Members stepping down: Mary Calcagno (Treasurer), Amy Leddick (Secretary), Andrew Carpino (Public Officer), Sarah Mercuri (Assistant Treasurer, General Committee)		
	Position	Person	Nominated by
	President & Adult Patient Liaison	Mandy Whitechurch	Andrew Carpino
	Vice President	Felicity Munro	Mandy Whitechurch
	Treasurer	Andrew Woolfe	Mandy Whitechurch
	Secretary	Dirk Van Beekhuizen	Mandy Whitechurch
13	Results of the General Committee election:		
	Position	Person	Nominated by
	Assistant Treasurer	Nathalia Alejandra Rios Castro	Mandy Whitechurch

Paediatric Patient Liaison	Pip Johnston	Mandy Whitechurch	Amy Leddick
Corporate Liaison	Andrew Carpino	Mandy Whitechurch	Amy Leddick
General Committee Member	Ali Malone Amy Leddick Anna Maria Calcagno Annamol Johny Carly Heath Heng Peng Harington Chen Jov Derrick Moratalla Marian Shoebridge Milva Carpino Natalie Rose Heriot Omar Ebaih Riddhi Gopinath Seema Pralhadraro Patil Vince Demarte	Accepted	
Congratulations to all new and returning members.			
Deanna Carpino to coordinate Treasurer and Secretary handovers between new and previous members.			

1. **General Business: Niemann-Pick Landscape**

presented by Mandy Whitechurch

1.1. Key Stakeholder Groups

Mandy presented today's landscape of Niemann-Pick Disease (NPD), highlighting the key groups and their roles and relationships with relevant stakeholders. The ANPDF is recognised as a key player, collaborating closely with these groups to advocate for patient needs, drive research, and ensure treatment access remains a priority.

Overview of Key Groups and Their Roles:

- Global Patient Organisations:
 - INPDA: Serves as a central hub for national patient groups, facilitating resource sharing and advocacy.
- National Patient Organisations:
 - Including, NNPDP (USA association), NPUK, FNPE, etc. Particularly close liaison with Tony Mathieson from NPUK.
 - These organizations provide family support, advocacy, fundraising, and research funding at their respective national level.
- Research Networks and Registries:
 - INPDR: An INPDA data/ patient register that focuses on data collection, supporting clinical trials, and enhancing disease understanding. This register includes ASMD (formerly NPA, NPB). Mandy is the Australian Ambassador for the INPDA. Royal Melbourne Hospital collects confidential patient information for the INPDR.
- Pharmaceutical Companies:
 - Including, Zevra, Mandos, IntraBio, Cyclo.
 - Responsible for drug development, conducting clinical trials, and engaging with regulatory bodies.
 - ANPDF has a close relationship with these international companies with our patients on existing trials.
- Advocacy and Policy Groups:
 - Examples: EURORDIS, RVA, Global Genes, Childhood Dementia Initiative.
 - These groups work on rare disease policies, patient rights, and ensuring access to treatment.
 - Mandy
- Medical and Scientific Experts:
 - Integral to clinical research, providing treatment guidance, and delivering patient care.
 - ANPDF works closely with SAB members Brendan Boot, Ya Hui, Sharma Kiss, etc. Sadly, Mark Walterfang has now retired. Mark Patterson (world leader for NPC, previous Mayo Clinic, now working with IntraBio) and Pip Johnston close connection.

1.2. Current Therapies on the Drug Discovery Pathway for Niemann-Pick Disease

Mandy presented an overview of the Clinical Trials and Therapies for Niemann-Pick C. It can take up to at least 10 years and anywhere up to \$3 million for a drug to reach human trials, a timeline that can shock families affected by Niemann-Pick Disease.

Cyclo Therapeutics now offers some patients home infusions, significantly trial advancement and improvement for patient life quality, in reducing time flying interstate for treatment. Miglustat remains the primary treatment to slow progression, but it is not TGA-approved and is very expensive. Not all Australian patients are able to access Miglustat.

Key Drug Trial Stages (some not all)

- Azafaros – Nizubaglustat (Miglustat equivalent – no gastrointestinal side effects)
Phase 2 trial complete,
Phase 3 in planning – actively looking for enrolments.
- Cyclo Therapeutics – Trappsol® Cyclo™
Phase 3 Active Clinical Trial,
fully enrolled
- Zevra Therapeutics – Miplyffa™
Trial Completed, approved by FDA
- IntraBio – AQNEURSA™
Trial Completed, approved by FDA
- The Florey Institute
mRNA Gene Therapy

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2. General Business - Investment and Project Updates

2.1. The Florey Institute - mRNA Gene Therapy Research Update

presented by Dr. Ya Hui Hung (Lead Researcher)

Ya Hui presented a summary overview of mRNA-based gene therapy for NP-C research. Ya Hui also presented an overview of her team projected research activities for 2025:

- Continuing with testing new NPC1 mRNA therapeutic designs in vitro in NP-C1 patient cell lines.
- Continuing with optimisation of NPC1 mRNA loading into extracellular vesicles.
- Proof of concept pilot study of NPC1 mRNA-LNP treatment in Npc1 mice.
- Investigation of different LNP formulations with potential to cross the blood-brain barrier against a benchmark LNP formulation (not capable of crossing the blood-brain barrier).
- Investigation of mRNA-LNP delivery directly to brain cells by intracerebroventricular injection.
- Determine dosing regimen of NPC1 mRNA-LNP.
- Commence chronic treatment toxicity study and outcomes to assess NPC1 mRNA. therapeutic efficacy.

Ya Hui also summarised the following points:

- Confirmed publications listed.
- Update on intentions for grant submissions in 2025.
- Presented an overview of the changes to this year's Florey NP-C Research team for 2025 and who will be working with Ya Hui.
- Future research direction shared and will be covered again in more detail at the 2025 conference.

Ya Hui has only had a team working with her in the past 12-18 months, prior to this working on her own, demonstrating growth for the foundation.

2.2. NPC Consensus Guidelines Project

presented by Ellie Van Velson (Project Coordinator)

Ellie provided an overview of the project objective which is to create and publish Australian Diagnosis and Disease Management Consensus Guidelines for Niemann-Pick Type C Disease. The project contributors include a medical advisory group (30 members), a community advisory group (6 members), and a lead team. It is funded by ANPDF, covering the project coordinator and medical writer. Currently, the projected costs are under budget, which is a positive outcome.

2.2.1. See Appendix 1, Annual General Meeting Presentation Slides

2.3. 2025 Events hosted by the ANPDF

presented by Deanna Carpino (ANPDF General Manager)

2.3.1. 2025 Annual Australian Niemann-Pick Conference

- Key information, dates, registration were shared with the committee. Confirmed members of the Conference Sub-Committee: Mandy Whitechurch, Felicity Munro, Dr. Ya Hui Hung.
- Current Stage: Final stages of agenda setting. All but one speaker is confirmed.
- Next Steps:
 - Finalise Agenda
 - Finalise Sponsorship Packages
 - Finalise accommodation
 - Invitation to register to families
 - Invitation to rsvp to all attendees
- The successful grant submission by Dr Ya Hui Hung of \$10K greatly assists in bringing families to the conference (covering meals, accommodation and flights).

	2.3.2. (Bi-)Annual Fundraiser: Dreams in Motion 2026 • Dreams in Motion, is a cocktail fundraiser for the Australian NPC Disease Foundation. • Date will be in June 2026, occurring on the first Saturday post the 2026 ANPDF Conference. • Purpose of the event is to raise minimum \$50,000 (projected \$80,000) towards research conducted at The Florey for a better treatment of NP-C and to help cover the costs of the annual conference. • Location is planned to be at Big Plans Melbourne - 109 Munster Terrace, North Melbourne, Victoria 3051. Key Benefits of this chosen location: 400pax state-of-the-art audio-visual equipment, incl wall and floor projection features. • Tickets will be \$200pp. Won't have a floor plan space for VIP booths. • Deanna provided a highlight video presentation of the 2024 Minds in Motion event and images of the location for the 2026 event. • Theme of "Dreams in Motion", creates a natural and powerful link to "Minds in Motion," emphasising continuity and progress in our mission. It reflects the transition from thought and awareness (minds) to aspirations and action (dreams). • Goal is to inspire hope and action for families impacted by Niemann-Pick disease. • Key objectives will be to raise a minimum of \$50,000 in funds, increase disease awareness, increase community and stakeholder engagement and to create a memorable and impactful experience. • Target audience will be corporate sponsors and partners, medical and research professionals, families affected by childhood dementia or rare diseases, philanthropists and advocates and general supporters of ANPDF's mission. 2.3.2.1. See Appendix 1, Annual General Meeting Presentation Slides 17 to 28				
16	3. <u>General Business - Governance and Future Planning</u> <i>Presented by Deanna Carpino</i> 3.1. List of Certificates of Appreciation presented in previous period: <table> <tr> <td> • 2024 ANPDF Committee Members (National Volunteer Week) • Mark Walterfang • Goat Club </td><td> • Tullamarine Swim School • Kando Martial Arts • Nunawading U3A Cooking Class </td></tr> </table> 3.2. Acceptance of Policy and Procedures: <table> <tr> <td> • Constitution • Code of Conduct • Fundraising Policy • Complaints Handling Policy </td><td> • Governance Policy • Privacy Policy • Safeguarding Policy </td></tr> </table> 3.2.1. See Appendix 2, List of Policies 2025 3.2.2. Proposed resolution: That the policies and procedures listed be accepted. Moved by: Mandy Whitechurch, Seconded by: Mary Calcagno	• 2024 ANPDF Committee Members (National Volunteer Week) • Mark Walterfang • Goat Club	• Tullamarine Swim School • Kando Martial Arts • Nunawading U3A Cooking Class	• Constitution • Code of Conduct • Fundraising Policy • Complaints Handling Policy	• Governance Policy • Privacy Policy • Safeguarding Policy
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	3.3. Policies to be created in 2025: • Financial Management Policy • Human Resources Policy • Volunteer Management Policy 3.4. Previous Period Cashflow forecast vs actual was discussed and noted that the successful fundraising campaign largely contributed to the results of being above budget in the second half of the year. 3.4.1. See Appendix 1, Annual General Meeting Presentation Slide 31 3.5. 2025 to 2027 Strategic Plan document was introduced, highlighting the need to clarify the organisation's strategic goals and deliverables within an achievable framework. 3.5.1. Deanna Carpino to organise follow-up committee meeting to finalise the strategic plan document. 3.6. The current 2025/2026 Cash Flow Forecast was presented to give basis for future fundraising goals and activities. 3.6.1. Deanna Carpino to share document with Drew Woolfe to finalise the report, and seek final approval by executive committee. 3.6.2. See Appendix 1, Annual General Meeting Presentation Slide 32
17	4. <u>General Business - Fundraising</u> <i>presented by Deanna Carpino</i> 4.1. Grants and Partnerships • Grant Applications: 6 applications made, 0 were successful • Grant Gifts: \$4,000 gifted to Fran Platt's Lab, Funding for research wage at The Florey recommitted. • University of Melbourne Community Placement confirmed for 2025. • 7 Community Partners: Printing (EPG), Accounting (CSM), Law (Domantay Legal), Fundraising (Goat Club, Derrimut Gyms, Glenarthon), and Communications (Access Ability Australia). To be confirmed: InLife • Advocacy Partners: International Niemann-Pick Disease Alliance & Registry (INPDA & INPDR), Rare Voices Australia (RVA), and Childhood Dementia Initiative (CDI) 4.2. List of currently known fundraising initiatives for the calendar year of 2025, total estimated amount raised is \$35,000 • Merchandise via online shop: \$200 - \$500 • Chocolate Drive (Mandy): \$2,000 • Marathon (Tash): \$2,000 • Shopping Tour (Mary): \$650 - \$1,500 • Poker Tournament (Mandy): • Golf Tournament (ANPDF): \$2,000 • Round-Up programs (Andrew): \$1,000 - \$2,000 • Awareness Month (ANPDF): \$2,000 - \$5,000 4.3. Committee members were encouraged to reach out with any new ideas or thoughts for fundraising in 2025.

18	5. New Business Discussions 5.1. Me and NP-C by Sue Van Velsen – Deanna Carpino to send request for feedback to all committee members 5.2. NDIS Pathway Project - Carly Heath discussed need for improvements in this area and a sub-committee was formed. • Sub-committee members: Carly Heath (Lead), Mandy Whitechurch, Felecity Munro, Amy Leddick, Marianne Shoebridge, Vince Demarte, Jov Moratalla. • Potential alliance with organisations. Rare Voices Australia was suggested. • Amy Leddick to contact NDIS Senior Managers she met at the 2024 RVA Summit. • Deanna to organise committee set-up and initial teams meeting.
15	Meeting close at 3:05pm

Minute taker:	Amy Leddick
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Signed:	
Name:	Mandy Whitechurch
Position:	President & Founder
Date:	05/03/2025