



Minutes of the Annual General Meeting of the Australian NP-C Disease Foundation Inc

Date:	18th February 2024
Time:	1.00pm – 3.00pm
Location:	Zoom virtual meeting
Attendees:	Amy Leddick, Andrew Carpino, Carly Heath, Deanna Carpino, Felicity Munro, Mandy Whitechurch, Marian Shoebridge, Pip Johnston, Sarah Mercuri, Ya Hui Hung
Apologies:	Ellie Van Velsen, Vince Demarte, Graham Kirk, Mary Calcagno
Proxies:	

Minutes:

Item	Description			
1	Welcome and introductions			
2	Apologies			
3	Review of actions from previous annual general meeting			
4	Acceptance of minutes of previous annual general meeting <i>Proposed resolution: That the minutes of the 2023 annual general meeting be accepted.</i>			
	Moved: Milva Carpino	Passed	Seconded: Mandy Whitechurch	Passed

5	President/Chair's report		
6	Treasurer's report		
7	Questions to directors		
8	Proposed resolutions		
	Proposed resolution	Moved by	Passed/ Not Passed
	That the President's report tabled at the annual general meeting be accepted.	Andrew Carpino Carly Heath	Passed
	That the Treasurer's report tabled at the annual general meeting be accepted.	Mandy Whitechurch Milva Carpino	Passed
9	Acceptance of Scientific Advisory Board (SAB) report		
	Note, addition to report: • Dr Joy Lee has resigned. • There were 2 new members in 2023 to the Scientific Advisory Board – 1) Dr Brendon Boot 2) Dr Sharmila Kiss		
	Proposed resolution	Moved by	Passed/ Not Passed
	That the Scientific Advisory Board (SAB) report tabled at the annual general meeting be accepted.	Andrew Carpino Milva Carpino	Passed
10	Patient Liaison reports		
	Proposed resolution	Moved by	Passed/ Not Passed
	That the Adult Patient Liaison report tabled at the annual general meeting be accepted.	Andrew Carpino Milva Carpino	Passed
	That the Paediatric Patient Liaison report tabled at the annual general meeting be accepted.	Andrew Carpino Milva Carpino	Passed

11	Results of the Executive Committee election: Board Members stepping down: Deanna Carpino (Board Secretary), Pip Johnston (Vice President)			
	Position	Person	Nominated by	Seconded by
	President	Mandy Whitechurch	Deanna Carpino	Amy Leddick
	Vice President	TBC		
	Treasurer	Mary Calcagno	Mandy Whitechurch	Amy Leddick
	Assistant Treasurer	Sarah Mercuri	Mandy Whitechurch	Milva Carpino
	Secretary	Amy Leddick	Deanna Carpino	Mandy Whitechurch
	Public Officer	Andrew Carpino	Mandy Whitechurch	Deanna Carpino
12	Results of the General Committee election:			
	Position	Person	Nominated by	Seconded by
	Paediatric Patient Liaison	Pip Johnston	Deanna Carpino	Amy Leddick
	Adult Patient Liaison	Mandy Whitechurch	Deanna Carpino	Amy Leddick
	Corporate Liaison	Andrew Carpino	Deanna Carpino	Mandy Whitechurch
	Merchandise Manager	Sarah Mercuri	Deanna Carpino	Mandy Whitechurch
	General Committee	Sarah Mercuri Pip Johnston Marian Shoebridge Milva Carpino Vince Demarte Carly Heath Marlena Lyras-Hull Norman Hull	Accepted	
13	Grants & Therapies – presented by Mandy Whitechurch			
	Therapies: - Arimoclomol - due to finish in due to June 2024 – seems to be good data but more is needed. Not currently in Australia. Oral drug that appears to be safe with minimal side effects. More feedback required from the US. - Adrabetadex – no feedback on this drug yet, it is due to be presented to the FDA. - Trappsol Cyclo Phase 3– 4 paed in Adelaide, 2 adults + 1 paed in Melbourne. We will learn more about the trial and its findings at the conference in June 2024. Dr Carolyn Hastings will be attending the conference again to provide updates.			

	• IB1001 Phase 3 – 4 adults in Melbourne. Completed the 24 week (12 weeks placebo and 12 weeks actual drug) now all patients of the actual drug. Appears to be positive data from IntroBio but we will learn more about this at the conference. • Rainbow Phase 2 – Azafaros are keen to bring this to Australia. This is proposed alternative drug to Miglustat without the gastrointestinal side effects. Patients are reluctant to give up miglustat without strong evidence of its efficacy. Non miglustat taking patients would be the most suitable candidates. However, there is a stringent age criterion for this trial that could restrict some of our patients. Note, Miglustat is on a 12 month by 12-month review for Royal Melbourne patients. Thanks to the efforts of Dr Mark Walterfang and Pip Johnston, they were able to halt its cancellation all together and get it extended however for how long, is uncertain. It is very doubtful that any new patients will be approved Miglustat. Grants: • National Disability Conference initiative 2022 to 2024 grant was approved again thanks to the effort of Dr Ya Hui Hung and team. • mRNA Victoria Research Acceleration Fund grant was also approved again thanks to the effort of Dr Ya Hui Hung and team.
14	Florey Research Updates presented by Dr. Ya Hui Hung • mRNA-based gene therapy for NP-C research activities summarised. Preclinical stage begun. • Details of the results of this research are to remain confidential and not to be shared outside of foundation members. • Publications listed. • Update on grants – successful, pending and 2 unsuccessful. • Presented the names, photos, and positions of this year's Florey NP-C Research team for 2024 who will be working with Dr Ya Hui Hung. • Future research direction shared and will be covered again in more detail at the 2024 conference.
15	Project Updates – presented by Deana Carpino • <u>NP-C Care and Guidelines</u> – A project manager is needed to oversee the consolidation of NP-C Care and Guidelines, efficiently utilising the limited time available from medical experts. This 'paid' project manager role is currently being scoped for this project task. There will be further discussion about palliative care information will be covered on the website. CDI will be engaged to learn how they have covered this. • <u>Website to be Updated</u> – new FAQ page, useful links page, including NDIS page and content update for 'What is NPC?' This action is 70% complete and once final will be sent to the board for final approval.

	• <u>Blog: NP-C Corner</u> - Ellie Van Velsen has been creating and publishing the monthly blog each month which has received positive response. NPUK were also impressed with the blog have chosen to share in on their webpages and communication forums. A big thank you and job well done to Ellie for her incredible work, especially as she was busy studying for her Masters at the same time. • <u>Infographics</u> – SAB approved visual representations to be visually displayed on website to facilitate the understanding of Nieman Pick Disease. Ellie is working with Dr Hung and the SAB on this project task.
16	Annual Events – presented by Deana Carpino • 2024 NPC Conference will be held on 20-21 June 2024 at the Florey Institute. (meals will be provided) • The intention to combine the conference and the cocktail event this year was to hopefully increase attendance and of course have a celebratory night at the end of 2 information packed conference days. • For Thursday and Friday, dinner and accommodation expenses will be covered. Regarding Saturday night accommodation, coverage will depend on the outcome of sponsorships received. Accommodation will be at the Pegasus again. • Registration forms have been drafted, completed and ready to be communicated this week to our families, potential attendees, and speakers. • The conference structure for this year will follow a similar format to last year's conference, taking place in the same room. • MC for the 2-day conference will be Felicity Munro again, thank you. • Minds in Motion Charity Cocktail event will be held on 22 June 2024 at The Timber Yard. Unlike previous charity galas, this event will feature a different format, with canapés and drinks instead of a sit-down dinner. It aims to be an interactive, immersive, and educational experience focused on raising awareness about NP-C (Niemann-Pick disease type C). Attendees can expect exciting activities such as VR experiences and magic performances. The venue has a capacity of 1500 people, so our goal is to promote the event extensively and sell as many tickets as possible. (Tickets are \$200 pp, reduced for groups of 5 - \$180 pp, VIP booth available for minimum of 5 includes a bottle of Moët) All information is on the website. Tickets have been on sale since early Feb 2024. • Minds in Motion Charity Cocktail – Sponsorship is confirmed for \$50K (8 sponsors). Deanna also shared that several partners, including a MC, DJ, catering services, and an artwork donation, have committed to the event.

17	Fundraising - presented by Deana Carpino • 2023 review of activities. Beanies were successful merchandise. Keen to rerun prior to winter. • Yearly comparison of incomes and expenses to identify challenges. • 2024 forecast of fundraising activities. Minimum target is 25K per quarter. Cashflow spikes in June but drops in second half of the year. Need to look at other fundraising opportunities for that time of year. Could consider Christmas raffle etc. • Mandy is going to run a poker night; Carly's local school will be running a gold coin donation for free dress. • Deanna reminded us that we can contact her if we need any marketing or charity governance documents etc. • 2025 Cash Flow forecast (without gala) - Deanna flagged sponsorship concerns for 2025. Current corporate sponsors need a break from the big charity galas. Will need to look at other opportunities such as small events, e.g. a whisky night, golf day etc. • Andrew Carpino has encouraged everyone to reach out to anyone who could be a potential sponsor and also offered his assistance with corporate liaison activities.
18	New Business Discussion/ Further Actions: • Phillipa Johnston seeks assistance in applying to the PBAC (Pharmaceutical Benefits Advisory Committee) to request funding of compassionate use of Miglustat for NPC patients. Deanna Carpino will arrange time to assist Pip with this application process. • Some members reported that they did not receive all AGM reports – Amy Leddick to resend all reports. • Deanna will circulate promotional materials for the Minds in Motion cocktail event, such as posters and other relevant items. • Sarah Mercuri has been assigned the task of sourcing a beanie manufacturer in time for winter. • Deanna to send Maz NP-C brochures to share with her daughter's service providers as an educational support. • Deanna will send patient passports to the members and review what other materials need to be printed for the conference. • Mandy will ask her boss David Clark about donating another prize for the raffle. • Mandy will talk to Ali Malone about arranging accommodation for carers at Eddie's result. • Mandy is going to run a poker night; Carly's local school will be running a gold coin donation for free dress. • Ya Hui will ask the philanthropy manager about supporting ANPDF events and setting up a merchandise table at the conference. • Mandy will explore partnership opportunities with WeWork and seek Andrew's support with the communication, event planning, corporate liaison activities etc. • Deanna starts her new role on Monday 19th February 2024.

19	Meeting close at 2:31pm
Minute taker:	Amy Leddick

Signed:	
Name:	Mandy Whitechurch
Position:	President & Founder
Date:	24/02/2024