



Minutes of the 2024 HSPRF Annual General Meeting, 29 October 2024, 8-9PM AEDT

Meeting held online via Zoom. Opened 8 PM AEDT. Chair: Kenneth Price (President)

Attendance by registered members of the Foundation (28)

Ken Price	Scott Price	Laurie and Maree Roebuck
Karen Johnson	Norma Pruitt	Stephen Acton
Lori Linton	Frank McKeown	Philip Woolsey
Christine McCorkell	Jackie Wellman	Anne Thompson
Jim Gorrington	Nancy Shaidnagle	Ted O'Hare
Annette John	Dina Landphair	Jill Barclay
Chris Faeshe	Tim Xiros	Chez Hey
Andrew Whitehead	Stuart Arms	Colleen Hickey
Kishore Kumar	Sharon Newport	Judith Harris
Supervisor 24		

Agenda

1. Opening Welcome
2. Acknowledgement of Traditional Owners
3. Apologies
4. Confirmation of Minutes from 2023 AGM
5. Annual Report 2023/24
6. Election of Office Bearers & Committee Members
7. General Business: Feedback from attendees on Gathered Here proposal
8. Guest Presentation – Spasticity Management

Apologies

Greg Emery, Nev Austin, Brendon Flood, Margaret Flood and David McKerihan

PO Box 4064, Warrimoo NSW 2774 Australia
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Documentation

The following documents relating to the AGM were available to members in the 4 weeks prior to the meeting and advised in the initial notice of meeting:

- Annual Report 2023/24
- Minutes of the 2023 AGM.

Welcome

In the spirit of reconciliation, the Foundation acknowledges the Traditional Custodians of country throughout Australia and their connections to land, sea and community. We pay our respect to their Elders past and present, and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

Confirmation of Minutes 2023 AGM

A resolution was put:

That the minutes of the 2023 AGM, certified by the President and Secretary as a true and correct record of the meeting, and with a quorum in attendance, be accepted.

Proposed: Ken Price Seconded: Stephen Acton Carried unanimously

Annual Report including the Financial Report

The President highlighted the following:

- Foundation Focus
 - o Still a two part mission in finding effective treatments for the HSPs and providing education and support to the HSP community
- Research Activities
 - o No major research activities currently underway, mainly due to the current state of flux in the area of HSP research
 - o There is a continuing increase in the quantum of HSP research on the global basis
 - o A pause in our research program is considered prudent on our part while we review some of the developments and consider how we can most effectively contribute to this
- Scientific Advisory Board
 - o Announced the establishment of the board last year for the Foundation
 - o Their guidance will allow us to pinpoint the highest value research initiatives that will lead to a breakthrough in the shortest time frame.
 - o When the initiatives are discovered we will then proactively approach the most appropriate people and researchers to implement the strategy
- Spastic Paraplegia Centre of Excellence Research Network (SP-CERN)
 - o Foundation has accepted an invitation to support and participate in a global HSP initiative designed to ensure efficiency in the development, dissemination and application of new knowledge obtained by SP-CERN, based in the US.
 - o The collaboration includes a number of US foundations, including the SP Foundation and other foundations based in Canada, UK, European Union, Germany and Australia
 - o It is early stages and the Foundation is looking forward to what can be achieved

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- The HSP Community - website, communication, gatherings
 - the new website has had a lot of design work done to it, however one of the biggest challenges is transferring the material from our current website to the new one
 - Due to this the foundation does not have an implementation date set as yet. Currently working with the designer to work through this, and will keep everyone informed of the progress.
 - Current website is still functioning and available
 - Communication will still be through social media (Facebook), and emails, as well as highlighting dates and times of community gatherings
- Fundraising
 - Left the donor base alone over the Christmas period, however raised \$26,000 in our June campaign
 - The foundation received over \$70,000 in donations over the full year
- Volunteers
 - Special thank you to Ryan Keating who has been with us for many years. He supports our contacts management system, which is an important database for the foundation
 - Thank you to the committee members, Scott Price (Secretary/Treasurer), Frank McKeown (Manager-Research), and our committee members, Christine McCorkall, Greg Emery, Stuart Arms and Ted O'Hare
 - Special thank you to Margaret Flood, who is our public officer, and provides support in terms of helping with our financial management
- Governance, security, confidentiality and privacy remain key focus areas
 - The Foundation has a focus on compliance
 - There has been an increase in spending on cyber security, in order to protect the Foundation and of course the privacy of our members
 - We are registered with the Australian Charities and non-for profits Commission, which is the national regulator for charities
 - The Foundation benefits from the support provided from them, as well as a basis for our continued improvement in compliance obligations.
- Financial Statement
 - Proud that we are still keeping a low expense amount, thanks in large to having a 100% volunteer base.
 - Donations were down this financial year, however we did have an increase in bank interest earned, due to the increase in interest rates on term deposits.
 - Currently just over \$1.5 million available to put towards research activities that may come to our attention

A resolution was put:

That the 19th Annual Report and the Financial Report be received and accepted by the meeting as a fair and accurate picture of the Foundation's activities, achievements and challenges over the 2023/24 year.

Proposed: Ken Price Seconded: Stephen Acton Carried unanimously

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Election of Office Bearers & Committee Members

All positions were declared open. As there were no other nominations, the nominated candidates were deemed elected as per the Constitution, with one position declared vacant.

Office Bearers and Committee Members for 2024/25:

President: Ken Price

Vice President: Vacant

Treasurer: Scott Price

Secretary: Scott Price

Committee Members

Greg Emery

Frank McKeown

Stuart Arms

Christine McCorkell

Ted O'Hare

General Business

- Gathered Here
 - o The Foundation has approached Gathered Here
 - o They provide free online wills for life, and arrange pledging for charities
 - o Committee member Stuart Arms has had lengthy discussions with them
 - o The Foundation believes that we should pursue an arrangement or partnership with Gathered Here
 - o Tens of thousands of Australians write their will on their online platform every year, with over 200 charities currently linked to Gathered Here.
 - o Would allow our community members to use the online platform and make pledges if they wish to do so
 - o There is no cost to the foundation as we will not have any reporting requirements
 - o Some of their partner organisations are The Salvation Army, Beyond Blue, MS Australia and Black Dog.

Members were invited to comment on the proposal - something we should pursue or not.
Response indicates we should progress.

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Guest Presentation

- Dr Kishore Kumar presented a session on Managing Spasticity and Frank McKeown facilitated the presentation
 - Spasticity is a disruption in muscle movement patterns, causing certain muscles to contract all at once
 - Common medications for spasticity include, Baclofen, Tizanidine, Dantrolene sodium, Diazepam, Clonazepam and Gabpentin
 - Presentation covered certain positive and negatives for each medication option
 - Methods on how medication is administered
 - Balance and spasticity was also discussed, in regards to whether or not balance could be improved without working to reduce your spasticity.
 - Attendees were welcome to ask questions to finish the presentation with a Q and A between Dr Kumar and the attendees.

Ken thanked Dr Kumar for his presentation and for his support of the Foundation.

Close and meeting evaluation

Meeting closed at 9.15PM AEDT after completion of an evaluation. Supporting documentation for the meeting held on file includes these minutes, a list of attendees, a summary of the messages posted during the meeting and a video of the meeting.

Declaration

We, the undersigned, certify the above to be a true and correct record of the 2024 Annual General Meeting of the HSP Research Foundation Inc. and that the Annual General Meeting was held with a quorum in attendance and in accordance with the HSP Research Foundation Inc. Constitution.



Ken Price, President

Date: 10/11/2024



Scott Price, Secretary

Date: 10/11/2024

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