



20th Annual Report and Financial Statements

of the HSP Research Foundation Inc.

20th ANNUAL REPORT 2024/25
to members of the HSP Research Foundation Inc.

September 2025

Foundation Strategy

Mission/Purpose (what business are we in?)

To serve the interests and needs of people with Hereditary Spastic Paraplegias (HSPs) by:

- facilitating and funding research to find an effective treatment for the HSPs
- being the hub of the HSP community, creating awareness and providing information, education and support.

Vision (where do we want to be?)

To have effective treatments for the HSPs that are:

- highly effective
- widely available (globally) and
- readily affordable.

Values (what do we stand for?)

- preserve and enhance the dignity, respect for and privacy of people in the HSP community that we serve
- create and maintain opportunity and equality in participation for all community members
- be guided by evidence-based, peer-reviewed and reputably published science
- be globally collaborative, facilitative and constructive with other HSP support groups, foundations, researchers and their organisations, clinicians and other medical professionals to maximise learning, understanding and positive impact
- maximise the funding that goes towards establishing effective treatments for the HSPs
- be businesslike and professional in everything we do.

Distinctive competency (what do we need to be distinctively good at?)

Skilled and effective in community, relationship and strategy development, interfacing with and between the HSP community, medical researchers and clinicians, other support groups and other stakeholders to mutual benefit in implementing our mission and achieving our vision.

This report describes the extent to which progress was made towards implementing our strategy and fulfilling our mission over the 2024/25 financial year.

Foundation Focus

Reflecting the two-part mission, the focus of strategy implementation remains on finding effective treatments for the HSPs and providing information, education and support to the HSP community.

Our HSP research program has been underway since 2008. Research expenditure in recent years has been minimal but with the guidance of the Foundation's Scientific Advisory Board, the Foundation has identified a project to be funded over the next 2 years up to an amount of \$230,690 with a focus on exploring the potential for a drug treatment for SPG 7. Principal researchers from Neuroscience Research Australia (NeuRA) are Dr Gautam Wali (our guest for this year's AGM) and Prof Carolyn Sue. The first tranche of \$50,000 has been funded.

We have long supported the contention that globally coordinated efforts are necessary to accelerate progress and achieve breakthrough in developing disease-modifying treatments for the HSPs and we have looked to maintain close contact with the other global bodies.

Developing the HSP Community

Information, Education & Support

Information, education and support activities for the HSP community are implemented in multiple forms and formats.

Launch of the new website has been delayed due to internal resourcing required and we will be aiming to progress this in the 2025/26 financial year. The focus will be on 'Living with HSP' for our community members, with reduced emphasis on technical research aimed mainly at clinicians and researchers. The new website will only be updated every so often as the capacity to maintain and update the website as previously is limited. Our Facebook page will continue to be used more for disseminating news and information. As an all-volunteer organisation, our resources, capacity and capability change regularly.

The current website is still a valuable resource for the HSP community, researchers and health professionals alike from around the world, with searchable library/archive.

Facebook

The Foundation's Facebook page had the following activity over the year:

- there were 50 posts to the page with close to 50,000 views.
- most popular posts have related to members sharing their experience on the Living with HSP theme.
- the page has 1,400 followers
- 10% of followers are in the 18-34 age bracket, 52% aged 35-54 and 38% over the age of 55
- our Facebook followers are 73% female and 27% male
- 40.5% live in Australia, 33.5% in the USA, 9% in the UK, 2.4% in Canada, 1.2% in Italy and 1.2% in India.

Email

Email communications from members, non-members, clinicians (predominantly allied health professionals) and researchers mostly include questions about diagnosis, symptoms, treatments, genetic testing, the research program, medical and allied health resources in the member's locality, requests for intervention with doctors, hospitals or healthcare systems, the NDIS, family planning and questions about participation in the clinical trials. Every email is responded to personally, either by return email or phone call or video call or

some combination, as most appropriate. Sometimes a dialogue is necessary involving multiple communications over an extended period. This supports community members and others in getting the information and understanding required to maximise the quality of the numerous aspects of their lives that are, or have the potential to be, impacted by HSP.

For those who may have relatives or friends in the HSP community who do not use the internet, valuable support can be provided by helping them receive Foundation emails at your address on your laptop, tablet or phone. Another way for them to access the Foundation website or Facebook page regularly is through the local library or other council facilities such as community centres, where assistance is often available, or through clubs and groups for seniors.

Growing the Community

As of 30 June 2025, the Foundation's HSP community numbered 876 members, with 22 new members joining during the year. The best estimate is that about half of community members have HSP, with the remainder comprising family, friends and supporters.

It is estimated that there are currently around 2,000 people with HSP in Australia with around 20% of this number likely being community members recorded on our database. This is in line with percentages of the overall HSP population who join HSP support groups in other countries. Given our small size, continuing to grow the community is important for sustainability and to ensure continuing support, funding, the ability to take on initiatives, and to reflect HSP community confidence in the direction and work of the Foundation.

Connecting with each other

We are happy to support social events organised by others, communicating about them with our members.

Raising Awareness

Opportunities for increasing public awareness of HSP are difficult to create due to the rareness of the condition, perceived irrelevance to the bulk of the population, the large number of rare diseases (over 8,000) the lack of differentiation and distinctiveness from other conditions, the lack of regular newsworthy information, and the strategic choices to channel our limited resources elsewhere. Social media has helped increase awareness of HSP related topics, most often focused on individuals being recognised for their achievements and in some cases on children with HSP and their families who have raised funds to develop treatments, however the exposure is limited to niche audiences.

More broadly, there is increasing recognition and coverage of rare diseases in general as advocacy groups are becoming more effective at creating social and political impact.

Finance

Fundraising

Our December 2024 and June 2025 campaigns and other undertakings saw donations of \$62,000 in the 2025 financial year. Our resolve has neither been dented nor diminished. The needs and interests of people in the HSP community are the sole guide for the volunteers who do the work of the Foundation. We hope, your resolve and the resolve of others in the HSP community remains strong.

Summary

We continue to spend in the area of cyber security in line with increased risk globally in all forms of digital communications using the Internet. We are proud of the fact that a low level of expenses can happen only because we are a 100% volunteer organisation that is committed to professionalism in all that we do.

Foundation Operations

Electronic Communications

The initiative to remodel the website is underway but has been delayed due to time issues for the volunteers involved. A determined effort is underway to progress this initiative. We will continue to use Facebook, email and our website for our communications and public presence with the conscious, but not necessarily permanent, choice not to use SMS or other social media platforms

Developing our Capability & Capacity

Apart from the limitations associated with the level of funding we attract, the major impediment to developing our capability and capacity is the lack of skilled volunteers to develop and manage strategic portfolios, notably in fundraising and marketing, and in communications / community development. Even if we had such volunteer support, attracting even more volunteers able to implement these programs appears impossible with volunteering experiencing a steady decline globally across all sectors for more than 10 years now.

An ongoing challenge, like all small non-profit organisations, is how to be effective and businesslike so that minimal resources can be effectively employed, given that we are run totally by volunteers. We are maintaining and continuously improving Foundation systems and processes:

- to strengthen cyber security and increase protection of the private and confidential information of community members
- to maintain an accurate and complete database of community members with whom we interact and communicate to maximise the effectiveness of our contacts management
- to service the handling and processing of inquiries and requests for information on HSP
- for correspondence and for initiatives such as fundraising campaigns and financial transaction processing.

Security & Privacy

Maintenance of the integrity of the Foundation's systems and processes to ensure the security of data and protect the privacy and confidentiality of community member and other information is treated with the highest priority. We have engaged a commercial IT company to support our cybersecurity and provide website support. We regularly review systems and processes, document policies and maintain best-in-class practices to minimise risk and strengthen security.

Volunteers & Committee

Members of the HSP community are indebted to a few key people who are instrumental in the smooth running of the Foundation. Sincere and special thanks to Ryan Keating (Contacts Management System) for his continuing support over many years. Thanks to committee members for 2024/25 - Scott Price (Secretary/Treasurer), Frank McKeown (Manager Research), Christine McCorkell, Greg Emery, Stuart Arms and Ted O'Hare for their diligence and effort in ensuring that the interests and needs of the Foundation and members of the HSP community are being well served. A special thank you to Tim Xiros who has taken on the role of Public Officer following Margaret Flood's resignation; and a sincere thank you to Margaret for her contribution to the Foundation over many years.

Governance

Members of the HSP community can be confident that the Foundation and the business it conducts are being well managed and well done. Financial and other business records are full, accurate and complete. Expenditure outside of research funding is tightly controlled. The Foundation mission/purpose is pursued with singular focus.

The Foundation is registered with the Australian Charities and Not-for-profits Commission (ACNC) set up under the Federal Department of Treasury as the national regulator of charities. They also provide support to charities to assist with their compliance obligations in the form of online tools, of which the Foundation takes full advantage to not only ensure compliance but also to implement enhancements.

Financial Statements

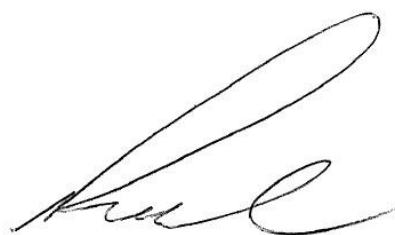
A Summary of the Financial Report of the Foundation for the 2024/25 financial year is included in this report. The Office Bearers of the Foundation are satisfied about the report's quality and reliability in every respect. We have the capacity to meet our current and foreseeable commitments and are confident of our continuing financial good standing into the future.

Comments or Feedback

We submit this Annual Report to you, the members of the HSP community and the Foundation, in good faith and with optimism and confidence that we are currently fulfilling our mission and achieving worthwhile goals and expect to continue that into the future. Comments or feedback, thoughts or ideas, or questions that members may wish to ask are welcome. Email: admin@hspersunite.org.au.



Ken Price
President



Scott Price
Secretary & Treasurer



HSP RESEARCH FOUNDATION INCORPORATED

ABN 46 648 875 912

PROFIT AND LOSS STATEMENT FOR THE YEAR ENDED 30 JUNE 2025

	30/06/2025	30/06/2024
	\$	\$
INCOME		
HSP Donations received	62,037	70,129
Bank Interest received	78,898	45,776
ATO refunds (GST)	146	411
Total Income	<u>141,081</u>	<u>116,316</u>
EXPENSES		
Other expenses	2,479	3,712
Research Expenditure	0	0
Total Expenses	<u>2,479</u>	<u>3,712</u>
Operating Profit/Loss	<u>138,602</u>	<u>112,604</u>
Operating profit before income tax	138,602	112,604
Retained profits	1,562,024	1,449,420
Profit available for appropriation	1,700,626	1,562,024
RETAINED PROFITS	<u>1,700,626</u>	<u>1,562,024</u>

HSP RESEARCH FOUNDATION INCORPORATED

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BALANCE SHEET

AS AT 30 JUNE 2025

	30/06/2025	30/6/2024
	\$	\$
CURRENT ASSETS		
Cash Assets	1,700,626	1,562,024
Total Current Assets	<u>1,700,626</u>	<u>1,562,024</u>
TOTAL NET ASSETS	<u>1,700,626</u>	<u>1,562,024</u>
 EQUITY		
Retained profits	1,700,626	1,562,024
 TOTAL EQUITY	<u>1,700,626</u>	<u>1,562,024</u>

