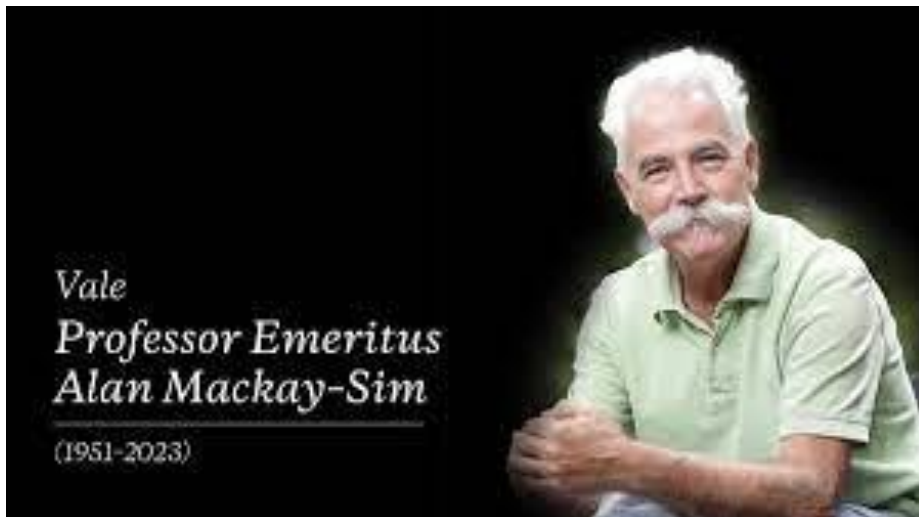


18th Annual Report and Financial Statements
of the HSP Research Foundation Inc.
2022/23



18th ANNUAL REPORT 2022/23
to members of the HSP Research Foundation Inc.

September 2023



It was with great sadness that we learned of the passing of Professor Emeritus Alan Mackay-Sim AM in early January. He was the principal researcher in the Foundation's HSP research program from the very start and contributed significantly to the enormous progress made to the understanding of the HSPs globally over the past 15 years. He is sorely missed by all who knew him. Our deepest sympathies are extended to his family. [Read more.](#)

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 reputable-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 2022/23 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.

There has been some progress in the research program with continuing biomarker development in one study and gait analysis of HSP in another, both funded by the Foundation. No major research initiatives are currently underway due to 3 things, firstly, the passing of our Principal Researcher, Prof Alan Mackay-Sim, who guided our research program since inception; secondly, the transition to establishing a Scientific Advisory Board to which all significant proposals and undertakings of a technical nature by the Foundation will be referred; and thirdly, the current state of flux in HSP research reflecting a continuing steady increase in the quantum of HSP research being done globally and the ongoing emergence and development of promising genetics technologies. This time for relative pause in the Foundation's HSP Research Program is considered prudent while we continue to reviewed developments and strategise on how we can most effectively contribute to having HSP treatments available given our size, resources and capabilities.

Information and educational opportunities on various aspects of living with HSP continued apace over the year. The Foundation also played a role in the welcome return to the calendar of social events for community members, with the abatement of the global COVID pandemic.

The research program can only happen with the financial support of the HSP community. Fundraising activities brought in over \$145,000 in the financial year, making it amongst the best ever.

Developing the HSP Community

Information, Education & Support

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

Website

The website is updated quarterly with an average of 25 brand-new articles in each edition, covering the most important recently published research on HSP; management and treatment of the symptoms of HSP; and a news section that contains up-to-date information on government policy and funding decisions of relevance to the HSP community, notably the National Disability Insurance Scheme (NDIS). There are also stories of social and human interest to community members.

The website is a resource valued by the HSP community, researchers and health professionals alike from around the world, with an ever-expanding searchable library/archive. Annual statistics for website usage over the year are not available due to changes in Google Analytics and the migration to the new system.

Facebook

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

- there were 33 posts to the page, reaching 14,822 people
- most popular post was 'June fundraising campaign' reaching 2,389
- the page received 1,234 likes
- 12% of followers are in the 18-34 age bracket, 53% aged 35-54 and 35% over the age of 55
- our Facebook followers are 72% female and 28% male, the same as last year
- 40% live in Australia, 34% in the USA, 9% in the UK, 3% in Canada and 1.4% 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 2023, the Foundation's HSP community numbered 823 members, a net increase of 28 members or 3.5% year-on-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 1,900 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

The Foundation facilitates community members connecting, interacting and having their say. Communications are almost exclusively electronic with the website, e-mail and Facebook being

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

Global Collaboration

With over half a million people globally estimated to have HSP and only about a dozen national support groups known to exist, continual development of communication and dialogue with our international colleagues is in the mutual best interests of everyone with HSP. The Foundation continues to communicate with our global colleagues every quarter, sharing news and updates, as well as whenever a need or opportunity is identified.

We have developed and maintained good communications and working relationships globally with the leading clinicians, researchers and institutes concerned with HSP. We directly and indirectly encourage, facilitate and nurture opportunities for collaboration on both a planned and ad hoc basis. We are firmly of the belief that for low profile, rare diseases especially, that collaboration leading to aligned action significantly increases the likelihood of effective treatments being established and brought to market.

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 7,000) 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. Increased media coverage of elite sporting events for people with disability is one area where mainstream society is getting exposed to both better-known and rare diseases, such as from parallel coverage of able-bodied and disability world championships in several sports. Several sports are now integrating world championships for both able-bodied people and those with disability into the same program, giving a huge boost of exposure through mass media. People with disability are also being seen more in high profile roles as well. Multi-gold medal winning Paralympian Kurt Fearnley was appointed as the chair of the National Disability Insurance Agency that administers the NDIS in September 2022. These are promising developments regarding increasing societal awareness of disability, rare diseases and even HSP to some extent.

Finance

Fundraising

Over the financial year \$146,000 was donated (last year \$127,00). One long-term community member made the magnificent contribution of \$50,000 during the year for which we are enormously grateful. Aside from that single outstanding contribution, all forms of fundraising were very much in line with the previous year, with around 20% of families in the HSP community contributing. Special thanks to members who make regular donations and also to those who did birthday fundraisers on Facebook. Community members contributed \$26,000 in

the December 2022 fundraising campaign and \$35,000 in the June 2023 campaign. A sincere thank you to all who gave during the year.

Diversity of fundraising streams is desirable as each contributes significantly to the total. Fundraising is publicised to the community on a calendar year basis in two campaigns – end of financial year in June and an end of year campaign in December. In the 2022 calendar year \$110,000 was raised.

Who gives, how, and how much?

One of the larger challenges we face is expanding the base of contributors to the Foundation. Contributors are categorised in two groups - inner circle (members of the HSP community) and outer circle (supporters or potential supporters outside the HSP community). Donations to the Foundation are made through a number of direct and indirect channels – electronic funds transfer to the bank account, PayPal, Good 2 Give (regular workplace giving), Everyday Hero and Go Fundraise (events) and Give Now (credit card), whilst community members collect money for their own initiatives (26% of the total) through channels of their choosing, mostly birthday fundraisers on Facebook.

Summary

With an expense to income ratio of 1.3% in 2022/23 (0.4% last year) 98.7% of all incoming funds in the financial year is directly available to fund HSP research. We are spending more on cyber security than previously in line with increased risk globally in all forms of digital communications using the Internet. We are proud of the fact that such 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

Email: We have a current, working email address with consent to use for 98% of the community, who receive regular email communications for themselves and their families. 28% of community members prefer not to receive email, a significant increase over previous years reflecting the understandable caution in society about the risk of personal digital information being compromised.

We utilise e-mail with community members as our most important communications channel. For those community members who don't use email, we encourage them to get e-mail communications via family, friends or carers. An initiative to update email addresses for community members is warranted, as is a reflection on the increasing trend not to receive email, and the place of social media and website communications as alternative channels.

Website: An initiative to remodel the website is underway, aimed at making it visually more appealing, easier to use and with more convenient access to desired information.

The focus is on email, website and Facebook 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 2022/23 - Ken Price (Secretary/Treasurer), Margaret Flood, Christine McCorkell and Greg Emery, as well as to Anthony McInnes (part year) and Stuart Arms (part year) 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.

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, amounting to 1.3 % of total income. 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 2022/23 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.

Two handwritten signatures in black ink. The signature on the left is for Frank McKeown, and the signature on the right is for Ken Price.

Frank McKeown
President

Ken Price
Secretary & Treasurer

HSP RESEARCH FOUNDATION INCORPORATED
ABN 46 648 875 912

PROFIT AND LOSS STATEMENT
FOR THE YEAR ENDED 30 JUNE 2023

	30/06/2023	30/06/2022
	\$	\$
INCOME		
HSP Donations received	145,710	126,679
Bank Interest received	15,153	4,269
ATO refunds (GST)	114	1,754
Total Income	<u>160,977</u>	<u>132,702</u>
EXPENSES		
Other expenses	1,273	584
Research Expenditure	825	3,382
Total Expenses	<u>2,098</u>	<u>3,966</u>
Operating Profit/Loss	<u>158,879</u>	<u>128,736</u>
Operating profit before income tax	158,879	128,736
Retained profits	1,290,541	1,161,805
Profit available for appropriation	1,449,420	1,290,541
RETAINED PROFITS	<u>1,449,420</u>	<u>1,290,541</u>

HSP RESEARCH FOUNDATION INCORPORATED
ABN 46 648 875 912

BALANCE SHEET
AS AT 30 JUNE 2023

	30/06/2023	30/6/2022
	\$	\$
CURRENT ASSETS		
Cash Assets	1,449,420	1,290,541
Total Current Assets	<u>1,449,420</u>	<u>1,290,541</u>
TOTAL NET ASSETS	<u>1,449,420</u>	<u>1,290,541</u>
EQUITY		
Retained profits	1,449,420	1,290,541
TOTAL EQUITY	<u>1,449,420</u>	<u>1,290,541</u>