

14th Annual Report and Financial Statements
of the HSP Research Foundation Inc.

2018/19



**HSP Research
Foundation**

*A better deal for HSPers, their
children and their grandchildren*



HEREDITARY SPASTIC PARAPLEGIA



Taking Steps Toward a Cure

14th ANNUAL REPORT 2018/19

to members of the HSP Research Foundation Inc.

September 2019

Summary

- \$100,000 of Foundation funding has been invested in pre-clinical investigations as part of the *Towards a Cure* HSP Research Program in 2018/19.
- Three biomarker studies are in progress, while a drug dose range finding study was completed, unfortunately with inconclusive results. This has delayed the move to initiate a clinical trial.
- In the 2018 calendar year, over \$130,000 came in through fundraising, exceeding the \$120,000 annual target by \$10,000.
- Over the financial year, \$127,000 was given by 330 people, the highest number of contributors ever.
- Community member numbers have grown to 743, a significant net increase of 62 (11%) over the year, with new members largely from Australia, but with additions from India, Pakistan, the UK and the USA.
- Various areas of Foundation activity have been identified for review, including communications, community development, fundraising, business model and organisation design.

Foundation Purpose

Mission: To serve the interests and needs of people with Hereditary Spastic Paraplegia (HSP) by facilitating & funding research to find an effective treatment and by being the hub of the HSP community, creating awareness and providing support, information and education.

Vision: to have treatments for the HSPs that are:

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

Values:

- the dignity, respect for and privacy of people in the HSP community that we serve are of the utmost importance
- opportunity and equality in participation for all community members
- to maximise the funding that goes towards establishing effective treatments for the HSPs
- to be globally collaborative and facilitative with other HSP support groups, foundations, researchers and their organisations, clinicians and other medical professionals to maximise learning, understanding and positive impact
- to be businesslike and professional in everything we do.

Distinctive competency: effectiveness interfacing with and amongst the HSP community, medical researchers and clinicians, other support groups and other stakeholders, to mutual benefit.

Foundation Focus

The focus on finding an effective treatment for HSP continues with preclinical studies ahead of a clinical trial to test the effectiveness of a drug treatment. We also continue to grow, foster and support the HSP community. The research and clinical trials can only happen with the financial support of the HSP community. We are only as strong as our community and our Foundation. *If it is to be, it is up to us!*

This report describes the extent to which progress was made towards fulfilling our purpose over the 2018/19 financial year.

Towards a Cure HSP Research Program

The Foundation funds and facilitates an HSP Research Program aimed at establishing an effective treatment for HSP. Currently this comprises preclinical studies as the initial phase of the clinical trials process to test the effectiveness of a candidate drug for treating SPG4 HSP, by far and away the most prevalent form of the disease, which is associated with mutations in the SPAST gene.

Calculating drug dose

The question “how much of the candidate drug is needed to be taken orally to achieve the target concentration in the brain?” remains unanswered despite three studies spanning 22 months at a cost of \$186,000 to the Foundation. The results of the dose range finding study in mice that was completed in March 2019 were inconclusive.

By any measure in medical research terms, the progress we have made with the HSP research program on a shoestring budget in a short space of time is nothing short of astounding. Just six years into the program, the research team had already identified potential drug candidates to treat SPG4 HSP, the main form of the condition. These inconclusive results have slowed us down considerably, but are not a roadblock. A new, small study is being designed and planned to shed more light on this important precursor to gaining regulatory approval for a clinical trial.

Biomarker studies

A major challenge is how to measure HSP treatment effectiveness in a clinical trial. For example, how would you know if a drug stopped disease progression given that HSP is only slowly progressive and the rate of progression can vary a lot? What about improvements in mobility, balance, walking speed and so on? Anyone with HSP can tell you that the severity of symptoms can change from day to day, depending on how well you slept, what the temperature is, how much stress you are experiencing, time of day, how regular you have been with exercise, and so on.

Valid, scientific measures of HSP status and changes in status need to be developed to allow the measurement of treatment effectiveness in a clinical trial. Such measures of sufficient sensitivity do not currently exist. The regulatory authorities, as well as good science, demand high confidence in measures and measurement before granting approval to conduct a clinical trial.

Three biomarker studies were in progress during the year. The most advanced of these is a blood biomarker study being carried out in Germany. A second blood biomarker study being undertaken in Sydney is also showing promise and progressing well. A smart phone app is in testing and development to quantify and characterise individual mobility with the potential for

being able to measure changes that might occur with treatment. Over the year, there were two further rounds of data collection providing a valuable database covering 18 months.

\$100,000 of Foundation funding has been invested in these studies in the HSP Research Program in 2018/19.

Progress reports were made each quarter over 2018/19 and can be accessed here:

<https://hspersunite.org.au/hsp-clinical-trial-program-update-september-2018/>

<https://hspersunite.org.au/hsp-clinical-trial-program-update-december-2018/>

<https://hspersunite.org.au/hsp-clinical-trial-program-update-march-2019/>

<https://hspersunite.org.au/hsp-clinical-trial-program-update-june-2019/>

Living with HSP - Management & Treatment

It is hoped that clinical management guidelines will soon be available to guide physiotherapists and other allied health professionals in the management and treatment of HSP symptoms.

Mobility maintenance and management is a major concern for people with HSP as are other manifestations of HSP that can significantly impact quality of life. Relevant issues and medical specialties include neurology, urology, rehabilitation, orthopaedics, spasticity and pain management, specialised therapies including physiotherapy, neurophysiotherapy, podiatry / orthotics and occupational therapy.

The Foundation provides regular, ongoing information on fitness, self-managed exercise programs, assistive technologies, lifestyle and quality-of-life issues in managing symptoms. Other topics covered include genetics, family planning and mental health.

There is a lot that people with HSP can do to mitigate and alleviate the broad range of symptoms experienced. Physical fitness, especially strength and flexibility, and maintaining correct body weight can make a significant difference in the quality-of-life experienced with HSP. One of the best investments that people with HSP can make is to see a neurophysiotherapist, or a physiotherapist whose practice focuses on neurological conditions and their rehabilitation, for assessment, treatment and the development of a custom-designed, self-managed exercise program that when done regularly as prescribed, has the potential to maximise the quality-of-life achievable at any given stage of HSP progression.

Articles on multiple aspects of HSP management and treatment can be found in the [Living with HSP](#) section of the website. This is a significant resource with specific interests served by the excellent Search function available at the top of every page of the website. Articles in this section cover numerous aspects of living with HSP.

Communicating effectively with members of the HSP community on Living with HSP could be significantly enhanced. The Foundation has never had people with professional competence in this area and is a topic for review.

Developing the HSP Community

Information, Education & Support

Information, education and support for the HSP community takes on multiple forms and formats:

- The website is updated every quarter with highlights of the most important recent research studies concerning both the quest for effective treatments for HSP and for the management and treatment of the symptoms of HSP, aimed at enhancing quality of life.
- The website also contains up-to-date information on government policy and funding decisions with 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 library/archive. Statistics for the 2018/19 year:
 - 7,700 active users
 - conducted 20,300 sessions (2.65 sessions/average active user over the year)
 - of 3 min 45 sec average duration per session
 - viewing 61,000 pages (8 different pages viewed/active user/year)
 - from 162 countries, with:
 - 35% of all users in the USA
 - 24% Australia
 - 9% UK
 - 5% Canada
 - 3% India
 - 2% Germany
 - with France, Netherlands, Denmark and Russia filling out the top 10 and each under 1.5%.
- Email communications from members arrive in a steady stream, mostly with questions about diagnosis, symptoms, treatments, genetic testing, medical and allied health resources in the member's locality, requests for intervention with doctors, hospitals or healthcare systems, the NDIS and questions about participation in the clinical trial. Every email is responded to personally, either by return email or phone call or both, as most appropriate. Sometimes a dialogue is necessary involving multiple communications over an extended period. This supports community members 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 their HSP.
- The Foundation's Facebook page remains popular and active, with a total of 814 'Likes', an annual increase of 18%. There were 28 Foundation posts to the page over the year with a total viewing audience of around 17,500 people, a 65% increase year-on-year. The Foundation's Facebook friends are:
 - 72% female, 28% male (unchanged)
 - 40% from Australia; 33% USA; 8% UK; 3% Canada; 2% India, with the remainder from countries in Europe, Asia and South America (almost the same as last year)
 - 71% are in the 25–54 age range and 28% in the >55 age group.

For those who may have relatives or friends in the HSP community without computers, offering them the opportunity to browse or search the website and read Foundation emails represents valuable and tangible support. Alternatively or additionally, a way for them to access the website regularly is through the local library, where assistance is often available for those who require it, or through over 50's clubs and groups.

Growing & Developing the Community

As of 30 June 2019, the Foundation's HSP community numbered 743 members, a net increase of 62 new members or 9%. 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 1,865 people with HSP in Australia with perhaps 20% of this number being community members recorded on our database, down from 25% of the projected population. Given our small size, it is important to continue the focus on growing the community with the aim of achieving critical mass and sustainability, thus ensuring 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 in the Foundation to a modest extent. Communications are almost exclusively electronic with the website, e-mail and Facebook being the main methods.

Opportunities for face-to-face social interaction continue to increase thanks to the independent Australian HSP Facebook support group that initiates and convenes several get-togethers in multiple locations around the country, including two in Melbourne, two in Brisbane and one each in Perth, Canberra, Sydney, NSW Central Coast and Newcastle in 2018/19. We lend support with communications about the events to community members in the various locations. The social events are reported in articles that are amongst the most popular on the website.

Global Collaboration

With 560,000 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 everywhere. The Foundation continues to communicate with our global colleagues every quarter, sharing news and updates.

We continue to collaborate closely with the SP Foundation in the USA, including seeking opportunities to jointly fund research studies. We highly value this relationship and continue to seek opportunities to leverage impact through joint effort. Foundation President Frank McKeown [presented at the Annual Conference](#) of the SP Foundation in Texas in late June.

Raising Awareness

Opportunities for increasing public awareness of HSP are limited due to the rareness of the condition, perceived irrelevance to the bulk of the population, the large number of rare diseases (over 6,000) the lack of differentiation and distinctiveness from other conditions, the lack of regular newsworthy information, and the strategic choice to channel the limited resources available towards research to find an effective treatment.

However some support organisations for other rare diseases have been successful in establishing a significant profile, recognition, public awareness and fundraising, mostly through creative and well resourced initiatives, such as the Mitochondrial Foundation's "Bloody Long Walk" <https://www.bloodylongwalk.com.au/> that is now an annual event in nine locations around the country and has raised over \$2 million. This is an enviable achievement and demonstrates what is possible.

Review

With the changing nature of communications and their role in community development, these various aspects of Foundation activity under the umbrella of community development now especially warrant review.

Finance

Fundraising

The December 2018 and June 2019 fundraising campaigns raised \$30,000 and \$32,000 respectively, representing around 50% of the \$127,000 financial year total.

This highlights both the importance of these two annual campaigns and also of non-fundraising campaign related income, such as through regular giving and individually inspired and undertaken initiatives to raise funds for HSP research, including sporting/physical challenges; selling goods specifically designed for charitable fundraising; and asking for donations in lieu of gifts for birthdays or other notable personal events.

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). There were 330 contributors who made 470 individual donations over the financial year, a very significant increase over previous years. The average amount given per contributor was \$385 over the year, although this did not convert to a significant increase in the total amount raised for the year (a similar amount was raised 2 years ago with 245 contributors giving higher amounts). Giving occurs through a number of channels – mainly by direct electronic funds transfer, PayPal, Good 2 Give (regular workplace giving), Everyday Hero and Give Now.

A major impediment to fundraising overall is the lack of a fundraising strategy and people with the requisite skills to implement it. This is also an area of Foundation activity for review.

Summary

With an expenses ratio of just 0.7% in 2018/19, over 99% of all incoming funds in the financial year is directly available to fund HSP research. We are proud of the fact that this can happen only because we are a 100% volunteer organisation that is committed to professionalism in all that we do. In the 2018/19 year, the \$120,000 annual target for fundraising was exceeded by \$7,000 (6%).

Foundation Operations

Communications

Electronic communications: 91% of the community have provided us with an e-mail address for themselves and/or their families, an increase of 1% compared to last year. We utilise e-mail communications with community members where possible. Everyone is encouraged to provide us with an e-mail address, and for those community members for whom e-mail is not feasible, we encourage them to explore the possibility of receiving e-mails via family, friends or carers. 9% of community members not receiving emails, the main form of Foundation communications with the community, is a worryingly high number.

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 promotion, and in communications. Another shortage is in potential committee members with significant experience from business or the non-profit sector and who can add significant value in the deliberation, decision and development of Foundation strategy. As these limitations are both serious and chronic, an exploration of alternative business models and organisation design is called for.

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 systems and processes:

- 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 general inquiries and requests for information on HSP
- for correspondence and for initiatives such as fundraising campaigns and financial transaction processing.

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 thanks to our long-term volunteers Isaac Nakhla (website) and Ryan Keating (IT) and to committee members for 2018/19, Ken Price (Secretary/Treasurer), Chris Faehse and Margaret Flood, for their efforts in the interests of the Foundation and its members.

Governance

Foundation Secretary, Ken Price, undertook a review of governance during the year, based on a formally recognised training course on the topic. Recommendations to strengthen governance have been implemented and opportunities for continuous improvement in governance are sought.

Members of the HSP community can be confident that the Foundation and the business it conducts is being well managed and well done. Financial records are full, accurate and complete. Expenditure outside of research funding is tightly controlled, amounting to less than 1% of total income in the financial year. Security of the member database and confidentiality of its contents are a high priority with both being actively managed to professional standards. The Foundation strategy is pursued with singular focus.

Succession continues to represent an issue of risk. A larger committee with additional competent professionals ensuring diverse perspectives would strengthen and enhance the sustainability of leadership of the Foundation.

Future Strategic Direction

Awareness and fundraising focused outside the HSP community would be good for the sustainability of the Foundation's dual mission – facilitating and funding research to find effective treatments for the HSPs; and providing information, education and support to the HSP community. The challenge is to find people with the skills, motivation, commitment and energy

to make this happen as a major new strategic thrust, possibly involving a different or additional organisational form and structure.

Various areas of Foundation activity have been identified for review, including communications – enhancing accessibility and adoption of technical information on the management and treatment of HSP, and in sophistication of communications channels to enhance community development; fundraising – aimed at increasing net revenue especially from sources outside the HSP community; and the all-volunteer business model and current organisation design – aimed at addressing structural, chronic limitations that have been identified.

Financial Statements

A Summary of the Financial Report of the Foundation for the 2018/19 financial year is included in this report. It has been prepared by the Foundation's Treasurer and a volunteer external accountant. The Committee is 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

I 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. E-mail to: admin@hspersunite.org.au.



Frank McKeown
President

HSP RESEARCH FOUNDATION INCORPORATED
ABN 46 648 875 912

SUMMARY OF FINANCIAL REPORT 2018/19

PROFIT AND LOSS STATEMENT FOR THE YEAR ENDED 30 JUNE 2019

	2019	2018
INCOME		
HSP Donations received	126,766	74,168
Interest received	21,042	18,180
ATO refunds	1,490	540
Joan and John Battisson Legacy	17,158	938,500
Total Income	<u>166,456</u>	<u>1,031,388</u>
EXPENSES		
Other expenses	1,101	2,457
Research Expenditure *	100,202	301,524
Total Expenses	<u>101,303</u>	<u>303,981</u>
Operating Profit/Loss	<u>65,153</u>	<u>727,407</u>
Operating profit before income tax	65,153	727,407
Retained profits	920,103	192,696
Profit available for appropriation	985,256	920,103
RETAINED PROFITS	<u>985,256</u>	<u>920,103</u>

***Note**

Consultancy Fees - preclinical investigations and clinical trial	8,112	10,150
Blood biomarker study - University of Sydney	55,025	24,200
Consultancy Fees - regulatory application (USA)	3,519	0
Mobility (smartphone app) biomarker study	0	5,000
Drug dose range finding study	33,546	149,976
Blood biomarker study - University of Tübingen	0	112,198
Total Research Expenditure	100,202	301,524

HSP RESEARCH FOUNDATION INCORPORATED
ABN 46 648 875 912

BALANCE SHEET FOR THE YEAR ENDED 30 JUNE 2019

	2019	2018
CURRENT ASSETS		
Cash Assets	985,256	920,103
Total Current Assets	<u>985,256</u>	<u>920,103</u>
TOTAL NET ASSETS	<u>985,256</u>	<u>920,103</u>
EQUITY		
Retained profits	985,256	920,103
TOTAL EQUITY	<u>985,256</u>	<u>920,103</u>

A copy of the full Financial Report is available to members on request by emailing:
admin@hspersunite.org.au

or by writing to:
HSP Research Foundation
PO Box 4064
WARRIMOO NSW 2774

3rd August 2019.

Mr Ken Price FCPA,
Treasurer,
HSP Research Foundation Incorporated,

Dear Ken,

Review HSP Research Foundation Accounts 2018/19

My review of the 2018/19 accounts is now completed. In my opinion, the accounts, in all material respects, present a true and fair view using the cash accounting system, of both the Foundation's profit during the year and its financial position at 30th June 2019.

While I did examine accompanying documentation to verify the accounts' accuracy and check the governance procedures, this review should not be considered an audit.

Thank you for asking me to review the Foundation's accounts. Please let me know if I can assist in the future.

Kind regards,

A handwritten signature in black ink, appearing to read 'Sevan', written in a cursive style.

Tim Bevan FCPA