

12th Annual Report and Financial Statements

of the HSP Research Foundation Inc.

2016/'17



**HSP Research
Foundation**

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



HEREDITARY SPASTIC PARAPLEGIA



Taking Steps Toward a Cure

12th ANNUAL REPORT 2016/'17

to members of the HSP Research Foundation Inc.

September 2017

Foundation Purpose

Mission: to facilitate and fund research to find an effective treatment for Hereditary Spastic Paraplegia (HSP) and also, as the hub of the HSP community, to serve the interests and needs of people with HSP, creating awareness and providing support, information and education.

Vision: to have effective 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 between the HSP community, medical researchers and clinicians, other support groups and other stakeholders to mutual benefit.

Foundation Focus

Your Foundation Committee is determined to continue support for the implementation of clinical trials underway aimed at establishing an effective treatment for HSP and to 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 as our Foundation. *If it is to be, it is up to us!*

This report describes the extent to which we achieved our purpose over the 2016/'17 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 start of the clinical trials process to test the effectiveness of a candidate drug for treating SPG4 HSP, caused by mutations in the SPAST gene.

The first half of the financial year (July – December 2016) saw the completion of drug validation studies with a twofold purpose:

- testing the effectiveness of potential drug candidates in other HSP models and comparing results with those obtained with HSP nasal stem cells
- building a strong case for approval for clinical trials with the regulatory Therapeutic Goods Administration (TGA).

Whilst the results of the studies with HSP mice were inconclusive, those with the human corticospinal neurons differentiated from HSP stem cells were very positive. Principal investigator Prof Alan Mackay-Sim expressed the view that these results confirm the drug's effectiveness and make a strong case for regulatory approval for clinical trials.

Prof Alan Mackay-Sim, Australian of the Year 2017

It is worthy of note that Prof Mackay-Sim was awarded the honour of Australian of the Year in January 2017 for his groundbreaking work on olfactory stem cells in the development of an effective treatment for spinal cord injury. This Foundation applauds and honours Prof Mackay-Sim and believes that we are fortunate to have such a long, successful and continuing association with him as the Principal Investigator of the HSP research program.

The focus since January 2017 has been on clinical trials with the following being achieved:

- a clinical trials team of seven has been recruited and formed, including three long-standing members of the HSP research team
- a clinical trials consultant has been identified and retained
- scoping and planning has been carried out and is ongoing, identifying the main challenges to be addressed and how to go about that
- support work for clinical trial implementation in the form of legal, logistical, regulatory, financial and managerial activities has begun and is ongoing.

Progress reports were made each quarter over the 12-month period and can be accessed here:

<https://hspersunite.org.au/hsp-research-program-update-september-2016/>

<https://hspersunite.org.au/hsp-research-program-update-december-2016/>

<https://hspersunite.org.au/hsp-research-program-update-march-2017/>

<https://hspersunite.org.au/hsp-research-program-update-june-2017/>

HSP Genetics

There are now 79 forms of HSP described, an increase in 2 over the past 12 months.

<http://neuromuscular.wustl.edu/spinal/fsp.html>

Living with HSP - Management & Treatment

There is a lot that HSPers can do to mitigate and alleviate symptoms, and the range of symptoms experienced by HSPers is vast. 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 HSPers 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 a 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 every imaginable aspect of living with HSP.

Awareness, Education & Support - Developing the HSP Community

Information, Education & Support

The National Disability Insurance Scheme (NDIS) continues to roll out nationwide with mixed results. The scheme has the potential to provide tangible support for all Australians living with disability, including significant proportion of HSPers. There are regular updates on the Foundation website about the scheme.

Mobility maintenance and management is a major concern for HSPers. Relevant issues and medical specialties include neurology, rehabilitation, orthopaedics, spasticity and pain management and treatment, 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.

Education, information and social media include the Foundation website, Facebook page, information about third-party events such as conferences, workshops and webinars, and personal responses by email and phone to inquiries, to support 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.

There are regular inquiries to the Foundation seeking information mostly related to diagnosis and treatment, including gene testing, family planning, mobility management, finding a suitable neurologist or physiotherapist, spasticity management, clinical diagnosis/symptoms, and bladder and bowel issues. Each and every inquiry, whether from Australia or overseas receives a timely, personal response. 145 written responses to inquiries were provided over the course of the 2016/'17 year to community members, with a similar number of personal phone call responses over the period.

The website is a valued resource by HSPers, researchers and health professionals alike from around the world, with an ever-expanding library/archive. Statistics of people actively using the website show a monthly average over the 2016/'17 year of:

- 543 active users – almost 3% more than last year
- having 696 separate sessions – an 8% decrease from last year
- with a total of 5,443 website page views – a 48% increase over last year
- viewing 2 website pages per session – a 60% decrease over last year
- for over 2 mins per session – a 55% decrease over last year

Other website statistics:

- 32% of website users are from the USA, 30% from Australia, 10% from the UK, 3% each from 3% from Canada, Italy and India, 2% each from Germany, France and the Netherlands. These figures represent an appreciable change from the previous 12 months.
- In all, people from 135 countries used the website.
- 61% of website users are under 35, with a further 28% aged 35–54 (same as last year)
- gender breakdown is 54% male, 46% female (same as last year)
- 50% of website users did so with desktop or laptop computers (down from 60% last year), while 37% use their mobile (up from 25% last year), and 13% use a tablet device.

The Foundation's Facebook page has 640 'Likes', an annual increase of 12%. There were 24 Foundation posts to the page with a total viewing audience of around 14,280 people (increases over last year of around 30% and 50% respectively). The Foundation's Facebook friends are:

- 73% female, 26% male (almost the same as last year)
- 42% from Australia; 33% USA; 10% UK; 3% Canada; 2% India, with the remainder from 37 countries in Europe, Asia and South America (almost the same as last year)
- 72% are in the 25–54 age range, with 29% aged 35–44. 14% are in the 55-64 age group.

For those who may have relatives or friends in the HSP community without computers, a way for them to access the website regularly is through the local library, where assistance is often available for those who require it. Another way is through over 50's clubs and groups.

Awareness

The universal symbol for HSP and HSPers everywhere is used on all official Foundation letterhead or banner in all forms of communication. It appears together with the Foundation logo wherever it is used, such as on the Foundation website banner <http://www.hspersunite.org.au>. This has the potential to increase public awareness through increased recognition that is possible with the same logo being used worldwide, however wholesale uptake by other HSP support groups has been inconsistent to date.

The potential for *Potato Pants* to become a lay descriptor for HSP in raising public awareness, as well as a marketing and promotional tool related to events and fundraising, is as yet unrealised in Australia. *Potato Pants* initiatives have been held in the UK, Europe and the USA, with the UK and Austria leading the way in terms of scale, exposure and impact.

Communications with the HSP community, researchers and medical professionals occurs mostly through the Foundation website and mass e-mail communications, creating awareness of topics related to HSP. Such topics cover research progress, management and treatment, as well as social, legal, financial and political news with relevance for the HSP community.

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 number of rare diseases (6,000), the lack of differentiation and distinctiveness from other conditions, the lack of newsworthy information, and the strategic choice to channel the limited resources available towards research to find an effective treatment.

Growing & Developing the Community

As of 30 June 2017, the Foundation's HSP community numbered 670 members, a net increase of 7% over the year, with 50 new members joining - 31 from Australia and 19 from the UK, USA, Canada, Chile, France, India, Italy, the Netherlands and Turkey. 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 around 1,700 HSPers in Australia with perhaps 25% of this number being community members recorded on our database. 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 provide a source of volunteer support for the work of the Foundation.

Connecting with each other

It is a continuing challenge for the Foundation to facilitate community members connecting, interacting, and having their say in the Foundation. Communications are almost exclusively electronic with the website, e-mail and Facebook being the main methods.

Given that HSP is a rare disease and Australia is a big country, it is a huge challenge to create opportunities for personal interaction. We encourage people to initiate social contact with community members who may live near them, and we offer support to help make that happen.

An Australian HSP Facebook support group that is independent of the Foundation has initiated and convened several social get-togethers in Brisbane, Sydney and Melbourne over the year. The Foundation encourages and has gladly supported these initiatives with email communications to potential attendees in the target area. The Foundation also reports on these activities in website updates.

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 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 clinical trials studies. We highly value this relationship and continue to seek opportunities to leverage impact through joint effort.

Foundation Operations

Communications

Electronic communications: 91% of the community have provided us with at least one e-mail address for themselves or their families, an increase of 2% over the 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.

Developing our Capability & Capacity

Apart from the limitations associated with the level of funding we attract, by far and away 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.

The 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 all those with whom we interact and communicate to maximise the effectiveness of our contacts management; to service the handling and processing of general inquiries, requests for medical and technical information on HSP; for correspondence and for initiatives such as fundraising campaigns, donation processing and receipting.

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), Ryan Keating (IT) and Jay Seneviratne (independent accountant) and to committee

members for 2016/'17 – Chris Faehse (Secretary/Treasurer) Ken Price and Margaret Flood for their efforts in the interests of the Foundation and its members.

It is with both sadness and gratitude that we note the passing of Foundation founder and inaugural President, Robin Bligh, in November 2016. It was Robin's energy and vision that established the Foundation in 2005 and set us firmly on the path we are now following.

Governance

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 2.7% of total funds raised 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.

Fundraising

'Give Generously' Campaigns

The December 2016 and June 2017 fundraising campaigns raised \$106,670 in total, slightly less than the corresponding amount from the previous year, which was a new record for a financial year. Giving is significantly down thus far in calendar 2017.

There was a lack of community initiated fundraising activities in the 12-month period for the second year running, which is a worrying trend. There is an ongoing need for community members to create, plan and implement independent fundraising initiatives.

No applications for philanthropic grants were made directly by the Foundation during the year.

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 and outer circle. There were 245 individual contributors in total over the financial year, a significantly higher number than the previous year, although the amount given was approximately the same in total. Giving occurs through a number of channels – by direct electronic funds transfer, PayPal, Good 2 Give (regular workplace giving), Everyday Hero and Give Now.

'Inner Circle'

This is how we describe members of the HSP community. Our sincere thanks to the approximately 40% of community member households who contributed over the financial year, a significant increase over previous years. This means that around 60% of community members/households gave nothing over the year, nor have ever given. The significant challenge to engage this majority is necessary, not just because it will mean more funds, but because it will reflect an informed community with a willing spirit, no matter how much they are able to give. We understand that many HSPers do it tough and struggle to make ends meet, however we are confident that a significant percentage of those who currently do not give, have the capacity to do so, even if it is a small amount.

'Outer Circle'

This is how we describe people who are supporters or potential supporters but are not members of the HSP community. This includes people in the extended family, relatives, friends, colleagues, and in the communities in which HSPers live. We have barely scratched the surface with potential fund-raising initiatives instigated by individual community members with this outer circle. The challenge is to inspire and encourage community members to fundraise on behalf of the Foundation.

A major impediment to fundraising overall is the lack of a fundraising strategy and a fundraising manager to implement it.

Summary

Over 97% of all money raised in the 2016/'17 financial year is directly available to fund HSP research and will be put to that purpose. In the 2016 calendar year, the \$120,000 annual target for fundraising was exceeded by almost 20,000. 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.

Financial Statements

A Summary of the Financial Report of the Foundation for the 2016/'17 financial year follows on the next two pages. It has been prepared by an independent 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. I welcome any comments or feedback, thoughts or ideas, or questions that you may wish to ask. E-mail me at frank@hspersunite.org.au.



Frank McKeown
President

HSP RESEARCH FOUNDATION INCORPORATED
ABN 46 648 875 912

SUMMARY OF FINANCIAL REPORT 2016/'17

PROFIT AND LOSS STATEMENT FOR THE YEAR ENDED 30 JUNE 2017

	2017	2016
INCOME		
HSP Donations received	106,670	109,378
Interest received	2,898	4,381
ATO refunds	129	96
Other income	999	726
Total Income	<u>110,696</u>	<u>114,581</u>
EXPENSES		
Other expenses	2,917	1,586
Research Expenditure	56,000	140,000
Total Expenses	<u>58,917</u>	<u>141,586</u>
Operating Profit/Loss	<u>51,779</u>	<u>(27,005)</u>
Operating profit before income tax	51,779	(27,005)
Retained profits at July	140,917	167,922
Profit available for appropriation	192,696	140,917
RETAINED PROFITS	<u>192,696</u>	<u>140,917</u>

HSP RESEARCH FOUNDATION INCORPORATED
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BALANCE SHEET FOR THE YEAR ENDED 30 JUNE 2017

	2017	2016
CURRENT ASSETS		
Cash Assets	192,696	140,917
Total Current Assets	<u>192,696</u>	<u>140,917</u>
TOTAL NET ASSETS	<u>192,696</u>	<u>140,917</u>
EQUITY		
Retained profits	192,696	140,917
TOTAL EQUITY	<u>192,696</u>	<u>140,917</u>

A full copy of the Financial Report 2017 is available to members on request by emailing admin@hspersunite.org.au (240KB PDF file; 8 pages) or by writing to:
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