

# 11<sup>th</sup> Annual Report and Financial Statements

of the HSP Research Foundation Inc.

2015/'16



**HSP Research  
Foundation**

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

# 11<sup>th</sup> ANNUAL REPORT 2015/'16

## to members of the HSP Research Foundation Inc.

September 2016

### **Mission and strategic direction**

The Foundation was created in 2005 to facilitate and fund research to find a cure for Hereditary Spastic Paraplegia (HSP) and also to serve the interests and needs of those with HSP as the hub of the HSP community, creating awareness and providing support, information and education.

Medical researchers tend to be discipline-based and work on a number of diseases simultaneously. Therefore it is only our support and advocacy groups whose primary mission is serving the interests of people with HSP, and the onus for ensuring that the interests of people with HSP are being well served rests squarely with support groups such as this Foundation.

The Foundation has an important role in helping set research priorities; in providing funding for research; in facilitating ongoing dialogue and mutual collaboration between researchers, and in the avoidance of duplication; in advocacy, public awareness, community development and social action, especially in concert with support groups for other conditions who share similar goals.

Your Foundation Committee is determined to maintain the progress with the research program to establish an effective treatment for HSP and to continue to grow, foster and support the HSP community. While there is never a guarantee on research outcomes, we encourage our members to remain positive and continue or commence to engage in the HSP community by making contributions, including donations, fundraising activities and events, comments on the website, e-mail and Facebook so that news, achievements, issues and concerns can be shared. We are only as strong as our community, and if it is to be, it is up to us.

This report describes the extent to which we achieved our mission over the 2015/'16 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 two drug validation studies commenced in late 2014 that are nearing completion:

- A drug validation study by Dr. Gautam Wali on human corticospinal neurons derived from induced pluripotent HSP stem cells has been conducted in Prof. Carolyn Sue's lab at the Sydney University Kolling Institute, Royal North Shore Hospital, in Sydney.
- A drug validation study by Dr. Yongjun Fan on HSP mice has been conducted at the Eskitis Institute for Drug Discovery at Griffith University in Brisbane.

The purpose of these studies is twofold:

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

The Foundation funded the HSP research program in the amount of \$140,000 in total for the 2015/'16 financial year. A similar amount of funding for the program came from the SP

Foundation (USA) whose continuing collaboration and partnership is both important and highly valued.

We also value highly the partnership and collaboration with the research team as they continue to build a strong case for clinical trials with our full support and confidence.

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

<http://www.hspersunite.org.au/hsp-research-update-september-2015/>

<http://www.hspersunite.org.au/hsp-research-update-december-2015/>

<http://www.hspersunite.org.au/research-update-march-2016/>

<http://www.hspersunite.org.au/research-update-june-2016/>

### **HSP Genetics**

There are now 77 forms of HSP described, an increase in 3 over the past 12 months.

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

Next generation genetic testing and screening is available in 4 locations in Australia, two in Sydney, one in Melbourne and one in Perth <http://www.hspersunite.org.au/genes-hsp/gene-testing-service/> while some Australian health services use overseas testing and screening facilities. Affordability of advanced genetic testing is getting better worldwide as it becomes the standard, and further reductions in price are expected over time. Current testing methods are now confirming clinical HSP diagnosis in over 40% of cases, a major advancement over limited range, traditional genetic testing. A new facility has recently been established at the Garvan Institute in Sydney using whole genome sequencing that significantly increases detection rates and only moderately higher costs compared with exome sequencing technology.

### **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 over the past year cover spasticity management, exercise, mobility issues and devices, getting diagnosed, chronic pain, assistive devices, footwear, surgery... and many more.

### **Awareness, Education & Support - Developing the HSP Community**

#### *Information, Education & Support*

The National Disability Insurance Scheme (NDIS) has the potential to provide tangible support for all Australians living with disability and has now been launched nationwide with all States and Territories participating. There are regular updates on the Foundation website about this and

other government services, as well as political issues and decisions relevant to the HSP community.

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.

Information and education media include articles on the Foundation website, information about third-party events, conferences, workshops and webinars, and personal responses to e-mail 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. 84 written responses to inquiries were provided over the course of the 2015/'16 year to people from 10 countries spread over 5 continents.

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 2015/'16 year of:

- 529 active users – almost identical to last year
- having 758 separate sessions – again, almost identical to last year
- with a total of 3,668 website page views – a 47% increase over last year
- viewing 5 website pages per session – a 20% increase over last year
- for over 7 min per session – a 55% increase over last year

Other website statistics:

- 37% of website users are from Australia, 28% from the USA, 9% from the UK, just under 4% each from Germany and France, just over 3% from Canada, and 2% each from the Netherlands, Spain, Italy and India, making up the top 10. These figures are almost identical to the previous 12 months.
- In all, active users from 89 countries viewed 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)
- 60% of website users do so with desktop or laptop computers, while 25% use their mobile, and 15% use a tablet device, almost identical to last year.

For those without computers, a way 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. Family members, including extended family, are another way to access the website.

### *Awareness*

Coming out of the recently established international network of national HSP support groups, there is now a single logo as the universal symbol for HSP and HSPers everywhere. This 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.

Also coming out of the global network is recognition of the potential for *Potato Pants* to become a lay descriptor for HSP, as well as a marketing and promotional tool related to events and fundraising. *Potato Pants* initiatives have been held in the UK, Europe and the USA to date.

Communications with the HSP community and other stakeholders such as other national support groups, researchers and medical professionals, mostly through the Foundation website and mass e-mail communications, constitute the basis for creating awareness of topics related to HSP. Such topics cover research progress, management and treatment, as well as social, legal, financial and political occurrences that have relevance to 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 2016, the Foundation's HSP community numbered 629 members, with 38 new members joining, an increase of 6% over the previous year.

The best estimate is that about half of community members have HSP, with the remainder comprising family, friends and supporters. Based on the estimate that there are around 1,700 HSPers in Australia, we still have a long way to go to reach out and support everyone who can benefit from joining the HSP community. 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.

It has been a challenge from the outset for the Foundation to provide ways for community members to connect, interact, and have their say in the Foundation. Opportunity and equality in participation have been difficult to achieve despite that being a priority. The Annual General Meeting is now held online, giving members no matter where they live the opportunity to participate and have a say in the running of the Foundation.

### *Connecting with each other*

The bulk of communications are 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 can offer support to help make that happen. Anyone who is interested just needs to let us know by e-mail and we can circulate their contact information to community members near them with a view to forming a local social group.

There is also the HSP/PLS global database <http://freyerse.org> that shows a global map, which can be magnified to local level, or the location search function can be used so that people can see who in the community lives near them and make contact. It also allows information to be shared and friendships to develop at a distance.

### *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.

Since the first international meeting of national HSP support group leaders in June 2015, an expanded dialogue has been established with regular interactions taking place. As well as initiatives and achievements mentioned in other sections of this report, two important communications regarding HSP research matters have been jointly signed by almost all national support group leaders.

## **Foundation Operations**

### *Communications*

Electronic communications: 89% of the community have provided us with at least one e-mail address for themselves or their families, the same as 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.

### *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. Sincere thanks to our long-term volunteers Isaac Nakhla (website), Ryan Keating (IT) and Jay Seneviratne (independent accountant) and to committee members for 2015/'16 – Margaret Flood (Secretary/Treasurer) who puts in week after week across a range of functions; Ken Price (Community Development) and Stuart Arms (part year Committee Member) for their efforts in the interests of the Foundation and its members.

## *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 just 1.5% of total funds raised. 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 is currently an area at 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 2015 and June 2016 fundraising campaigns raised \$22,000 and \$66,000 respectively, with the calendar year target of \$80,000 achieved. The financial year accounting total raised in 2015/'16 was \$109,378, a new record for a financial year.

There were fewer planned fundraising initiatives in the 12-month period, possibly reflecting the lack of a fundraising manager to stimulate community members to create, plan and implement initiatives.

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

### *Who gives... 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 around 150 individual contributors in total over the financial year.

### *'Inner Circle'*

This is how we describe members of the HSP community. Our sincere thanks to the roughly 20 % of community members who contributed over the financial year, repeating the pattern of previous years. This means that more than 80% of community members gave nothing over the year. 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 encourage community members to fundraise on behalf of the Foundation. Whether it is a barbecue or a birthday, trivia night or cake bake or something more adventurous – we all need to be thinking about ways to engage the broader community in contributing to the cause. There may also be publicity/awareness opportunities with these sorts of activities as well. The other advantage of the outer circle is that the potential and limits are much greater in terms of who we can reach and the funding we can raise.

### *Summary*

Over 98% of all money raised in the 2015/'16 financial year is directly available to fund HSP research and will be put to that purpose. 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 2015 calendar year, the \$80,000 annual target for fundraising was exceeded by \$675.

### **Financial Statements**

A Summary of the Financial Report of the Foundation for the 2015/'16 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](mailto:frank@hspersunite.org.au).



Frank McKeown  
President



HSP RESEARCH FOUNDATION INCORPORATED  
ABN 46 648 875 912

SUMMARY OF FINANCIAL REPORT 2015/'16

PROFIT AND LOSS STATEMENT FOR THE YEAR ENDED 30 JUNE 2016

	2016	2015
<b>INCOME</b>		
HSP Donations received	109,378	91,647
Interest received	4,381	5,289
ATO refunds	96	148
Other income	726	363
<b>Total Income</b>	<u>114,581</u>	<u>97,447</u>
<b>EXPENSES</b>		
Other expenses	1,586	1,319
Research Expenditure	140,000	120,000
<b>Total Expenses</b>	<u>141,586</u>	<u>121,319</u>
<b>Operating Profit/Loss</b>	<u>(27,005)</u>	<u>(23,872)</u>
Operating profit before income tax	(27,005)	(23,872)
Retained profits at July	167,922	191,794
Profit available for appropriation	140,917	167,922
<b>RETAINED PROFITS</b>	<u>140,917</u>	<u>167,922</u>

**HSP RESEARCH FOUNDATION INCORPORATED**  
**ABN 46 648 875 912**

**BALANCE SHEET FOR THE YEAR ENDED 30 JUNE 2016**

	2016	2015
<b>CURRENT ASSETS</b>		
Cash Assets	140,917	168,740
<b>Total Current Assets</b>	<u>140,917</u>	<u>168,740</u>
<b>CURRENT LIABILITIES</b>		
Creditors	0	818
<b>TOTAL NET ASSETS</b>	<u>140,917</u>	<u>167,922</u>
<b>EQUITY</b>		
Retained profits	140,917	167,922
<b>TOTAL EQUITY</b>	<u>140,917</u>	<u>167,922</u>

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A full copy of the Financial Report 2016 is available to members on request by emailing [admin@hspersunite.org.au](mailto:admin@hspersunite.org.au) (270KB PDF file; 9 pages) or by writing to:

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