

10th Annual Report and Financial Statements

of the HSP Research Foundation Inc.

2014/15



**HSP Research
Foundation**

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

10th ANNUAL REPORT 2014/15

to members of the HSP Research Foundation Inc.

October 2015

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 and education.

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 2014/15 financial year.

Towards a Cure HSP Research Program

With the nasal stem cell investigations by Dr. Yongjun Fan continuing, the research program underwent a significant expansion under the guidance of Principal Investigator Prof. Alan Mackay-Sim, with 2 new studies getting underway in late 2014:

- A drug validation study by postgraduate researcher Gautam Wali on human corticospinal neurons derived from induced pluripotent HSP stem cells commenced in September 2014 in Prof. Carolyn Sue's lab at the Killing Institute in Sydney.
- A drug validation study on HSP mice was initiated early in 2014 but significantly delayed until early 2015 due to regulatory, quarantining and export/import issues. This study is being conducted by Dr. Yongjun Fan at the Eskitis Institute for Drug Discovery at Griffith University in Queensland.

The central purpose of these drug validation studies is to establish a compelling case for approval for human clinical trials with the regulatory Therapeutic Goods Administration (TGA). Application to the TGA for approval for human clinical trials is planned for 2016, subject to successful outcomes of the current drug validation studies.

The Foundation continued to support the HSP research program described in the amount of \$120,000 in total for the 2014/15 financial year. We value highly the partnership and collaboration with the research team as they continue towards clinical trials with our full support and confidence.

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

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

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

<http://www.hspersunite.org.au/hsp-research-update-december-2014/>

<http://www.hspersunite.org.au/stem-cell-research-update-september-2014/>

HSP Genetics

There are now 74 forms of HSP described, an increase in 2 over the past 12 months
<http://neuromuscular.wustl.edu/spinal/fsp.html>

Next generation genetic testing and screening is available in 3 locations in Australia, two in Sydney 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.

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 weight control 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 should be done regularly as prescribed.

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 devices, getting diagnosed, chronic pain, assistive devices, footwear, surgery... and many more.

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

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 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. Over 80 written responses to enquiries were provided over the course of the 2014/15 year.

The website is an ever-expanding HSP library/archive. Web statistics show a monthly average over the financial year of:

- 525 active users
- having 760 separate sessions
- with a total of 2,500 page views.

These numbers are not comparable with previously reported statistics, as more refined analytics allow us to identify and eliminate brief transient visits and visitors.

Other website statistics:

- 36% of visitors to the website are from Australia, 29% from the USA, 10% from the UK, 3% each from Germany and Canada, 2% each from India and France, with Norway, Brazil and the Netherlands all between 1–2%.
- In all, visitors from 133 countries viewed the website.
- 61% of website users are under 35, with a further 28% aged 35–54
- gender breakdown is 54% male, 46% female
- 58% of website users do so with desktop or laptop computers, while 26% use their mobile, and 16% use a tablet device.

For those without computers, a way to access our website regularly is through the local library, where assistance is often available for those who require it.

Awareness

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 necessarily limited due to the rareness of the condition (perceived irrelevance to the bulk of the population), 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.

In June this year, the first-ever meeting of the leaders of support groups worldwide was held in Madrid, Spain where the desirability of increasing public awareness and recognition led to the establishment of a working group to come up with a universal identifier or symbol for HSP. The outcomes of this will be implemented in the current financial year.

There has been significant progress in the rollout of the National Disability Insurance Scheme (NDIS) as Victoria and New South Wales have now signed agreements to implement the scheme across those States, while Queensland has announced some acceleration and expansion of its rollout plans.

Growing & Developing the Community

As of 30 June 2015, the HSP community numbered 628 members, an increase of 50 or 9% over the previous year (Note: these numbers are not comparable to previous years as the criteria for calculation have been adjusted to more accurately reflect the definition of 'community member'). This rate of increase is significantly less than previous years, with such a slowdown inevitable after many consecutive years of more than 20% annual growth.

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. For the first time in 2014, the Annual General Meeting was held online and was attended by 20 registered members drawn from NSW, Vic, Qld, SA and one from the USA. This meant that members of the HSP community, no matter where they live, had the opportunity to participate and be involved in the running of the Foundation.

Changes to both the Constitution and the Foundation's Privacy Policy were considered and passed by special resolutions at the meeting. The success of the meeting represents a significant advance towards equitable participation for everyone in the running of the Foundation and it is hoped that it encourages broader participation of community members. Future general meetings are planned to be held online.

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 on the website, and this 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 with them. 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, there is a compelling need to develop communication and dialogue with our international colleagues in the mutual best interests of everyone with HSP everywhere. To this end, the first-ever meeting of the leaders of nine national support groups took place in Madrid, Spain at the beginning of June this year <http://www.hspersunite.org.au/hsp-group-leaders-meet-in-madrid/>. The meeting over one and a half days focused on 3 things:

1. understanding the strategic focus of the different groups and identifying common ground
2. the imperative for establishing a global HSP registry as the basis for future clinical trials, and
3. the desirability of coming up with a global symbol for HSP to reflect the multinational alignment established and to present a unified face to clinicians, researchers, regulators, industry and the public at large.

A joint communiqué produced at the close of the meeting stated:

- the shared commitment to collaboration, and
- the recognition that without multinational collaboration, there will never be sufficient numbers for clinical trials leading to the development of effective treatments.

"We are entering a new era. We must collaborate multi-nationally to get what we all want."

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 the support groups.

Support groups such as this Foundation can play 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.

The Committee of this Foundation is grateful for the good relationships we have with our international colleagues and is heartened by the sentiments expressed and agreements made at the meeting in Spain in June.

Foundation Operations

Communications

Electronic communications: 89% of the community have provided us with at least one e-mail address for themselves or their families, surprisingly down 2% on 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 or friends.

Developing our Capability & Capacity

Our 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 service the handling and processing of general inquiries, requests for medical and technical information on HSP, correspondence, initiatives such as fundraising campaigns and donation processing and receipting.

We continue to have more roles than people to fill them professionally. This human resource shortage is far and away the critical limitation regarding what the Foundation can be and can achieve. The three highest priority areas here are in fundraising and promotion; communications, including social media; and potential committee members with significant relevant experience from business or other non-profit organisations.

Volunteers & Committee

We are enormously grateful for the continuing support of a few key people. Our heartfelt thanks to our long-term volunteers Isaac Nakhla (website), Ryan Keating (IT) and Jay Seneviratne (independent accountant). Also my deep gratitude to fellow committee members for 2014/15 – Margaret Flood (Secretary/Treasurer) who competently shoulders ever-increasing workload and

responsibility and Ken Price (Community Development) for their continuing efforts in the interests of the Foundation and its members.

Governance

A revised Constitution was adopted at last year's AGM, to align with how we operate as a virtual organisation with no physical premises, doing business almost exclusively electronically. Also updated to reflect reality, there are changes to becoming a member of the community and the Foundation. The Mission of the Foundation is included in the Constitution as are the roles and requirements for the Foundation's office bearers.

The Foundation's Privacy Policy has also been revised to reflect best practice and complies with the revised Australian Privacy Principles that came into effect in March 2014. We take very seriously the security, privacy and confidentiality of member information and have chosen to comply with Australian Government guidelines in this regard, despite organisations of our size, scope and nature not being required to do so.

Fundraising

'Give Generously' Campaigns

The Christmas campaign in 2014 brought in a record \$40,000, eclipsing the previous record set in 2013 by \$5,000 and leading to a calendar year total of almost \$89,000, which was above target for the first time ever by a very healthy 18%. This has been a pleasing and tremendous effort by those community members who gave so generously and it would be wonderful if the trend continues. The June campaign this year 2015 brought in just over \$32,000, down about 9% from the previous year, however other donations away from this campaign amounted to a healthy \$9,000.

The year-to-date total is just under \$53,000 with an \$80,000 target by year's end. A sincere *'Thank You!'* to all who contributed so generously over 2014/15.

Other sources of funds – events, donation boxes and Entertainment books

Event fundraising again made a significant contribution to the overall total with 3 events bringing in \$16,000 during the financial year that included Ian Brock's birthday party in Brisbane with donations in lieu of gifts; Therese Bligh's ladies luncheon in the Hunter region; and HSPer Roger Simpson's truly astounding effort of a 20 km open ocean swim in the Perth to Rottnest Island race. Thank you all and well done for your initiative.

Donation boxes in the retail businesses of community members were initiated during the financial year <http://www.hspersunite.org.au/hsp-donation-boxes-on-shop-counters/>. It is hoped that this is successful and expands to become a significant contributor to fundraising. We encourage everyone to think about opportunities for placing donation boxes and signage to advantage and to contact us for details of how to make it happen.

Entertainment books again made a contribution to the yearly total. Community member Chris Whitehead deserves praise for her initiative and fundraising efforts in various ways over the year, including the sale of books. Everyone is encouraged, like Chris, to think about and find ways to raise funds for HSP research.

No applications for philanthropic grants were made directly by the Foundation during the year, however the Foundation contributed to, and tangibly supported a successful application from the

research team to our US friends, the SP Foundation, for \$100,000 USD in matching funding for the 2 drug validation projects currently in progress. Our sincere thanks to our US partners for their vital support for the HSP research program in Australia.

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.

'Inner Circle'

This is how we describe members of the HSP community. Our sincere thanks to the fewer than 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.

Those community members who gave directly to the Foundation, mostly by cheque or EFT, gave around \$400 each on average, while those who gave by credit card through GiveNow gave \$370 each on average.

'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.

Donations from the 'outer circle' amounted to around \$13,000 with 80 people contributing about \$160 each on average.

Summary

Over 98% of all money raised in the 2014/15 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 2014 calendar year, the \$75,000 annual target for fundraising was exceeded by \$14,000 or 18% above target, which is the first time this has happened. The target for the 2015 calendar year has been set at \$80,000 with almost \$53,000 already raised at the time of this report (early October 2015). This makes the target for the 2015 Christmas holidays campaign \$27,000 and we are hopeful of again exceeding the target.

Financial Statements

A Summary of the Financial Report of the Foundation for the 2014/15 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.

A handwritten signature in black ink, appearing to read 'Frank McKeown', with a stylized flourish extending to the right.

Frank McKeown
President

HSP RESEARCH FOUNDATION INCORPORATED
ABN 46 648 875 912

SUMMARY OF FINANCIAL REPORT 2014/15

PROFIT AND LOSS STATEMENT FOR THE YEAR ENDED 30 JUNE 2015

	2015	2014
INCOME		
HSP Donations received	91,647	84,267
Interest received	5,289	3,826
ATO refunds	148	191
Other income	363	0
Total Income	<u>97,447</u>	<u>88,284</u>
EXPENSES		
Accountancy	0	1,650
Other expenses	1,319	535
Research Expenditure	120,000	50,000
Total Expenses	<u>121,319</u>	<u>52,185</u>
Operating Profit/Loss	<u>(23,872)</u>	<u>36,099</u>
Operating profit before income tax	(23,872)	36,099
Retained profits at July	191,794	155,696
Profit available for appropriation	167,922	191,794
RETAINED PROFITS	<u>167,922</u>	<u>191,794</u>

HSP RESEARCH FOUNDATION INCORPORATED
ABN 46 648 875 912

BALANCE SHEET FOR THE YEAR ENDED 30 JUNE 2015

	2015	2014
CURRENT ASSETS		
Cash Assets	168,740	191,794
Total Current Assets	<u>168,740</u>	<u>191,794</u>
TOTAL ASSETS	<u>168,740</u>	<u>191,794</u>
CURRENT LIABILITIES		
Creditors	818	0
EQUITY		
Retained profits	167,922	191,794
TOTAL EQUITY	<u>168,740</u>	<u>191,794</u>

A full copy of the Financial Report 2015 is available to members on request by emailing admin@hspersunite.org.au (635KB PDF file; 9 pages) or by writing to:
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