

9th Annual Report and Financial Statements

of the HSP Research Foundation Inc.

2013/'14



**HSP Research
Foundation**

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

9th ANNUAL REPORT 2013/'14 to members of the HSP Research Foundation Inc.

September 2014

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. This report describes the extent to which we achieved our mission over the 2013/'14 financial year.

Towards a Cure Research Program

Two promising drug candidates for treating HSP were the focus of a [scientific paper](#) published in May 2014 by the team at the Eskitis Institute for Drug Discovery that receives support funding from this Foundation. The research program has shifted from identifying potential drugs, through a testing & selection phase and now, on to a validation phase of work. A central purpose of validation studies is to establish a compelling case for approval for human clinical trials with the regulatory Therapeutic Goods Administration (TGA). There are 3 validation studies being conducted in parallel:

- continuing investigation and exploration at the Eskitis Institute for Drug Discovery of structural and trafficking defects in stem cells derived from nasal tissue of people with HSP. There have been new and important findings recently regarding organelle transport, microtubule initiation and microtubule proliferation. The 2 candidate drugs under consideration continue to successfully return all functions studied to normal levels.
- a drug testing study on human corticospinal neurons derived from induced pluripotent HSP stem cells commenced in September 2014 at the Kolling Institute in Sydney.
- a drug testing study on HSP mice was initiated early in 2014 but has not yet progressed due to regulatory, quarantining and export/import issues, which it is hoped are all overcome by the end of 2014. There are 2 parts to this study - one to be conducted at the Eskitis Institute for Drug Discovery at Griffith University in Queensland, and the other at the University of Sheffield in the UK.

Application to the TGA for approval for human clinical trials is planned for early 2016. The Foundation continued to support the HSP research program of the Eskitis Institute for Drug Discovery at Griffith University in Queensland, in the amount of \$50,000 in the 2013/'14 financial year. We value highly the partnership and collaboration with the research team at Griffith University as they continue towards clinical trials with our full support and confidence.

Genetic Testing

A major research finding recently identified 18 new autosomal recessive HSP-causing genes, over half of which had never before been implicated in human disease of any sort, almost doubling the number of known HSP genes. There are now 72 forms of HSP described.

Advanced genetic testing and screening by whole exome sequencing is now available in 3 locations in Australia, although they are not what could be yet described as readily available or affordable services to the HSP community. Despite recent advances, a global review of the literature has found that the number of families without genetic diagnosis after systematic

testing ranged from 45–67% for autosomal dominant HSP and from 71–82% for autosomal recessive HSP. These numbers suggest that there is a long way to go before a negative gene test can be reliably taken to mean the absence of HSP.

Management & Treatment

Although no major advances in managing or treating HSP have emerged over the past year, there is much that HSPers can do to mitigate and alleviate symptoms. Physical fitness, especially strength and flexibility, 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. The [management and treatment](#) section of our website is a significant resource with specific interests served by the excellent Search function available at the top of every page of the website.

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 such as incontinence. Other topics covered include genetics, family planning and mental health. Information and education media include the Foundation website, e-mail and phone inquiries.

There are regular enquiries 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 100 written responses to enquiries were provided over the course of the 2013/'14 year.

The website is an ever-expanding HSP library/archive. Web statistics show quite an increase in usage over the past year with a monthly average now of 1,000 users from 70 countries having almost 1,200 separate sessions with a total of 7,000 page views (this excludes visitors who 'bounce' from the site almost as soon as they arrive). This compares with the average from a year ago of 800 people from 70 countries viewing about 4,000 pages on the site.

Other website statistics:

- 40% of visitors to the website are from Australia, 23% from the US, 8% from the UK, 3% from Germany, with Canada, Norway, India, Spain, France and Italy being the other countries in the top 10 for numbers of visitors to the site
- 60% of website users are under 35
- gender breakdown is 54% male, 46% female
- 60% of website users do so with desktop or laptop computers, while 40% use a tablet or mobile device. Amongst US and UK users, the split between computers and mobile devices is close to 50:50. This is a big shift in recent times in how people access the website. The website has now been optimised for tablet and mobile devices.

Awareness

With the prospect of the National Disability Insurance Scheme (NDIS) being established nationwide, we regularly update the HSP community on developments with the NDIS, including the political perspective, the agency perspective, and that of people with disability and their advocates. Pilot studies/trial sites have been established in a handful of locations around the country, but it is a long way yet from a scheme that broadly benefits everyone with significant disability, including members of the HSP community.

Plans are currently underway for leveraging the excellent results from the stem cell research program to establish some public awareness of HSP in the community by creating publicity and broadcast media opportunities, most likely in the first half of 2015. As an extension of this, we also hope to attract many more HSPers to the community and signing up for potential participation in clinical trials.

Growing & Developing the Community

As of 30 June 2014, the HSP community numbered 658 members, an increase of 117 or 22% 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, to provide a source of volunteer support for the work of the Foundation, and to have sufficient HSPers for clinical drug trials in the future.

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 will be held online. This means that members of the HSP community, no matter where they live, will have the opportunity to participate in the meeting and be involved in the running of the Foundation. We are proud of this major advancement towards equitable participation for everyone in the running of the Foundation and hope that it encourages broader participation of community members.

Connecting with each other

Community members regularly express the need for more connection with others in the community. The bulk of communications will necessarily remain electronic with the website and e-mail 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 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 a handful of support groups such as this Foundation in existence, there is a compelling need to open and continually develop communication and dialogue with our international colleagues in the mutual best interests of everyone with HSP everywhere. Medical researchers tend to be discipline-based and work on a number of diseases simultaneously. Therefore 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.

We are grateful for the good relationships we have with our international colleagues, which includes collaboration with the SP Foundation in the USA and the HSP Support Group in the UK.

Foundation Operations

Communications

Electronic communications: 91% of the community have provided us with an e-mail address, up 4% 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. Another way is to access our website regularly at the local library, where assistance is often available for those who require it.

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 many more jobs and projects than people to do them professionally. This human resource shortage is far and away the critical limitation regarding what the Foundation can be and can achieve.

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 thanks to fellow committee members for 2013/'14 – Robin Bligh (Vice-President), Chris Hall (Secretary), Ken Price (Community Development) and Tim Xiros (Fundraising) for their continued efforts in the interests of the Foundation. Special mention and thanks to Treasurer, Margaret Flood who manages the Contacts Management System, the lifeblood of the Foundation, and also manages the central e-mail function... both are important and time-consuming jobs on top of the demanding Treasurer role.

Governance

At this year's Annual General Meeting in late October, a revised Constitution will be proposed to members for adoption by special resolution. This is an attempt to align our Constitution 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. Community members are encouraged to review the proposed Constitution that they will be able to access on the Foundation website as per the notice of the AGM that they will receive in early October.

The Foundation's Privacy Policy has also been revised to reflect best practice in information security 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 not being required to do so.

Fundraising

'Give Generously' Campaigns

The Christmas campaign in 2013 brought in a staggering \$35,000, almost double the \$19,000 raised in the 2012 Christmas campaign, which itself doubled the 2011 figure of \$9,000. So there has been a 300% increase in Christmas campaign fundraising in 2 years. This has been a pleasing and tremendous effort by community members and it would be wonderful if the trend continues. The June campaign this year raised \$35,000, following totals of \$28,000 last year and \$44,000 in 2011. A sincere *'Thank You!'* to all who contributed so generously over 2013/'14.

Other sources of funds

Event fundraising dwindled, and this significant source of funds over the years, averaging around 10% of our total raised each year, is missed. No applications for philanthropic grants were made during the year, however the Foundation contributed to, and tangibly supported an application from the research team to our US friends, the SP Foundation, for matching funding for the 2 new drug validation projects. The outcome of this application is unknown at this time.

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'

This is how we describe members of the HSP community. Around 16% of community members contributed over the financial year... down 4% on last year. This means that 84% of community members gave nothing in the 2013/'14 financial 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 \$750 on average, while those community members who gave mostly by credit card through GiveNow gave \$375 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.

In the 2013/'14 financial year, donations from the 'outer circle' amounted to around \$14,000 with 142 people contributing just under \$100 each on average.

Summary

We continue to be proud that well over 95% of all money raised goes directly to fund research, and also proud that this can happen only because we are a 100% volunteer organisation that is committed to professionalism in all that we do. Last calendar year 2013 we raised a total of just over \$64,000... \$11,000 short of target. The 2014 calendar year target is the same as last year at \$75,000 with just over \$48,000 raised as at the time of this report (late September 2014). This makes the target for the 2014 Christmas campaign \$27,000, which, based on last year's fundraising for the Christmas campaign, is within our collective capability to achieve.

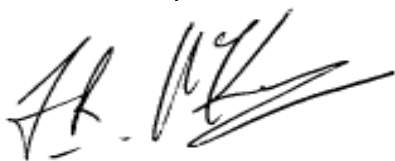
Financial Statements

A Summary of the Financial Report of the Foundation for the 2013/'14 financial year follows on the next two pages. The Foundation Committee has made a change this year in that the Financial Report is prepared by an independent accountant rather than an auditor. This saves almost \$2,000 annually and the Committee is confident that the process, and this year's Report, are both of at least equal quality and reliability in every respect compared with previous years. 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.

Yours Sincerely,



Frank McKeown
President

HSP RESEARCH FOUNDATION INCORPORATED
ABN 46 648 875 912

SUMMARY OF FINANCIAL REPORT 2014

PROFIT AND LOSS STATEMENT FOR THE YEAR ENDED 30 JUNE 2014

	2014	2013
INCOME		
HSP Donations received	84,267	67,480
Interest received	3,826	7,157
ATO refunds	191	186
Total Income	<u>88,284</u>	<u>74,823</u>
EXPENSES		
Accountancy	1,650	1,650
Other expenses	535	507
Research Expenditure	50,000	59,449
Total Expenses	<u>52,185</u>	<u>61,606</u>
Operating Profit/Loss	<u>36,099</u>	<u>13,217</u>
Operating profit before income tax	36,099	13,217
Retained profits at July	155,696	142,479
Profit available for appropriation	191,794	155,696
RETAINED PROFITS	<u>191,794</u>	<u>155,696</u>

HSP RESEARCH FOUNDATION INCORPORATED
ABN 46 648 875 912

BALANCE SHEET AS AT 30 JUNE 2014

	2014	2013
CURRENT ASSETS		
Cash Assets	191,794	155,696
Total Current Assets	<u>191,794</u>	<u>155,696</u>
TOTAL ASSETS	<u>191,794</u>	<u>155,696</u>
EQUITY		
Retained profits	191,794	155,696
TOTAL EQUITY	<u>191,794</u>	<u>155,696</u>

A full copy of the Financial Report 2014 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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