

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

of the HSP Research Foundation Inc.

2012/'13



**HSP Research  
Foundation**

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

**8<sup>th</sup> ANNUAL REPORT 2012/'13**  
**to members of the HSP Research Foundation Inc.**  
**and the HSP community.**

September 2013

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 2012/'13 financial year.

***Towards a Cure Research Program - Stem Cell Research Project***

The stem cell research project *Identifying Therapeutic Drug Candidates for treating HSP* that began in January 2011 was successfully completed at the end of 2012. Co-Principal Investigator and Director of the National Centre for Adult Stem Cell Research, Professor Alan Mackay-Sim, provided a [final report](#) in February 2013. The results are detailed in a research paper [A patient-derived stem cell model of hereditary spastic paraplegia with SPAST mutations](#) published in the Journal *Disease Models & Mechanisms* in January 2013.

Prof. Mackay-Sim gave an [informative interview](#) in June 2013 on the next phase of research that was initiated in January 2013 - [Testing & Selecting Therapeutic Drug Candidates for treating HSP](#) – outlining the opportunities and challenges ahead in the next year.

Results are promising and there is cause for cautious optimism. Potential drug candidates for treating HSP, and already approved for other conditions, have been found to compensate for impairments in stem cells from people with HSP. Further validation and testing is now required, and this is the focus of the research for the year ahead. Testing may be carried out on induced pluripotent (iPS) HSP stem cells and possibly also on laboratory animals to establish the suitability of one or more of the candidate drugs to enter into clinical trials. This Foundation supported the HSP stem cell research this financial year in the amount of \$50,000.

**Gene Testing**

All Australians at risk of HSP can avail themselves of testing and screening services for SPG4, SPG3A and SPG31 located in both New South Wales and Western Australia. For those who test negative to the three gene tests offered, but who have clinical symptoms of HSP and would like to know their genetic mutation for purposes such as family planning, next generation gene testing pilot studies are underway at 2 locations in New South Wales and one in Western Australia. A world leading commercially available next-generation service has now been established in Germany, and it is hoped that a similar service is available in Australia within 12 months. HSPers thinking of getting tested should talk with their GP or neurologist for referral to a genetic counsellor.

**Management & Treatment**

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 experience 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 and indefinitely. Our website now represents a significant

resource regarding [management and treatment](#) with specific interests serviced by the excellent Search function available at the top of every page of the website.

There is a slowly increasing amount of research globally into the management and treatment of HSP, and we are fortunate in Australia to have 2 HSP gait studies, one for adults in progress and one for children that is now completed and awaiting publication, both located in Victoria. The adult study is a retrospective one, involving an analysis of HSP gait patterns of around 40 adults who have had a gait assessment through the Southern Health Clinical Gait Analysis Service. The gait study of children with HSP is the focus of a Ph.D. study at the University of Melbourne by physiotherapist Brooke Adair. The Foundation supported these studies in a total amount of around \$13,000.

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

#### *Education & Support*

Mobility maintenance and management is a major concern for HSPers. Relevant issues and medical professionals concerned 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.

The website is a significant resource and library/archive. Web statistics continue to consistently show that a monthly average of around 800 people from 70 countries view about 4,000 pages on the site. About 50% of the site traffic is international, mainly from the US (20%), the UK and Germany (8% each). A listing of community recommended medical practitioners is on the website with the ability to be added to at any time.

There is a steady stream of inquiries to the Foundation (including from medical practitioners) seeking information mostly related to gene testing, family planning, mobility management, finding a suitable neurologist or physiotherapist, and spasticity management. Each and every inquiry, whether from Australia or overseas receives a timely, personal response.

#### *Awareness*

We advocated community participation through petition signing and attendance at nationwide gatherings in support of the National Disability Insurance Scheme, which became a reality on 1 July 2012 through the establishment of [DisabilityCare Australia](#) pilot regions in different locations across the country. We will continue to keep the community informed of developments and decisions regarding the scheme and how it may potentially benefit people with HSP.

#### *Growing & Developing the Community*

At the end of the financial year, the HSP community listed on our database numbered 541, an increase of 63 or 13% over the previous year. Given the issues with HSP diagnosis, and the limitations of current gene testing, the best estimate is that about half of community members have HSP, with the remainder comprising family, friends and supporters. So we have roughly 270 of the estimated 1,700 HSPers in Australia who have joined the HSP community. 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 most importantly to have sufficient HSPers for clinical drug trials in the future.

### *Connecting with each other*

There is an ongoing need for more connection between community members. 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.

71 people from Australia are now shown on the HSP/PLS global database <<http://freyerse.org>> up from 54 a year ago, a 31% increase. The visual interface is a global map on the website, and this can be magnified to local level 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 just 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 lines of ongoing 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 can play an important role in helping set research priorities; in providing funding for research; in facilitating ongoing dialogue between researchers in the interests of leverage and synergy, 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.

## **Foundation Operations**

### *Communications*

Electronic communications: 87% of the community have provided us with an e-mail address, 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. 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*

The ongoing challenge of every small non-profit, us included, is how to be effective and businesslike so that scant resources can be well 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 the fundraising campaigns and donation processing and receipting.

We continue to have way 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 Isaac Nakhla (website), Ryan Keating (IT) and Jay Seneviratne (bookkeeper). Also thanks to community member Margaret Flood for her management of the Contacts Management System and administrative support. Finally, my thanks to fellow committee members of 2012/13 – Robin Bligh (Vice President), Chris Hall (Secretary/Treasurer), Ken Price (Community Development), and Tim Xiros (Fundraising) for their continued efforts in the interests of the Foundation.

## **Fundraising**

### *'Give Generously' Campaigns*

The Christmas campaign in 2012 yielded just under \$19,000, more than double the 2011 figure of \$9,000. The June campaign this year amounted to \$27,685, down from \$43,626 last year, a decline of almost \$16,000 or 36%. A sincere *'thank you'* to all who gave, however the overall result was very disappointing. Event and other fundraising produced under \$2,000 total compared to just over \$10,000 last year. As expected, no philanthropic grants were received.

### Who Gives?

One of the larger challenges we face is expanding the base of contributors to the Foundation. There are two main sources of contributors:

1. 'Inner Circle' – this is how we describe people in the HSP community. 20% of this inner circle of community members contributed over the financial year. However the reality is that fully 80% give nothing. The significant challenge to engage this 80% 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.
2. 'Outer Circle' – this is how we describe people who are supporters or potential supporters but are not part 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 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*

We continue to be proud that over 95% of all money raised goes to fund research, and also proud that this can happen only because we are a 100% volunteer organisation. Last calendar year we raised a total of \$115,382. This year's target is \$75,000 with only just over \$29,000 raised so far. This is an enormous shortfall and only time will tell how much of that we can make up with this

year's Christmas campaign. We may be facing challenging times ahead in the quest to facilitate and fund research to find a cure for HSP.

### **Financial Statements**

A Summary of the Audited Financial Report of the Foundation for the 2012/13 financial year follows on the next two pages. 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).

Yours Sincerely,

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

Frank McKeown  
President

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

**SUMMARY OF AUDITED FINANCIAL REPORT 2013**

**PROFIT AND LOSS STATEMENT FOR THE YEAR ENDED 30 JUNE 2013**

	2013	2012
	\$	\$
<b>INCOME</b>		
Gross Loss Trading	-	-
Membership Fees Received	-	-
HSP – DGR Donations Received	67,480	130,383
Interest Received	7,157	5,929
Other Income	-	-
ATO Refunds	186	211
<b>TOTAL INCOME</b>	74,823	136,523
<b>EXPENSES</b>		
Accountancy	600	623
Auditors Remuneration – Fees	1,050	1,060
Dues	460	396
Other Expenses	47	323
Subscriptions	-	-
Research Expenditure	59,449	110,000
Subscriptions	-	-
Sponsorship	-	600
Web Site Development Amortised	-	800
<b>TOTAL EXPENSES</b>	61,606	113,802
<b>OPERATING PROFIT</b>	13,217	22,721
Retained Profits at July 1	142,479	119,758
<b>PROFIT AVAILABLE FOR APPROPRIATION</b>	155,696	142,479
<b>RETAINED PROFITS</b>	155,696	142,479

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

**BALANCE SHEET AS AT 30 JUNE 2013**

	2013	2012
	\$	\$
<b>CURRENT ASSETS</b>		
Cash Assets	155,696	142,479
Receivables	-	-
<b>TOTAL CURRENT ASSETS</b>	<u>155,696</u>	<u>142,479</u>
<b>NON-CURRENT ASSETS</b>		
Intangible Assets	-	-
<b>TOTAL NON-CURRENT ASSETS</b>	<u>-</u>	<u>-</u>
<b>TOTAL ASSETS</b>	<u>155,696</u>	<u>142,479</u>
<b>TOTAL LIABILITIES</b>	<u>-</u>	<u>-</u>
<b>NET ASSETS</b>	<u>155,696</u>	<u>142,479</u>
<b>EQUITY</b>		
Retained Profits	155,696	142,479
<b>TOTAL EQUITY</b>	<u>155,696</u>	<u>142,479</u>

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A full copy of the Audited Financial Report 2013 is available to members on request by emailing [admin@hspersunite.org.au](mailto:admin@hspersunite.org.au) (2.3MB PDF file; 12 pages) or by writing to:

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