

6th Annual Report and Financial Statements

of the HSP Research Foundation Inc.

2010/'11



**HSP Research
Foundation**

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

6th ANNUAL REPORT 2010/'11 to the Members of the HSP Research Foundation Inc.

September 2011

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 community hub, creating awareness and providing support and education. This report evaluates the level of achievement of our mission over the preceding financial year.

Towards a Cure for HSP Research Program

Stem Cell Research Project

The stem cell research project *Identifying Therapeutic Drug Candidates for treating HSP* began in January 2011, building on the discoveries of the pilot study, and is progressing well. Principal researcher and Director of the National Centre for Adult Stem Cell Research, Professor Alan Mackay-Sim, provided a progress report in May 2011, saying that the project has advanced according to schedule, with the first four aims achieved and the fifth currently progressing. The progress report and details of the Research Program are available on the website at: <http://www.hspersunite.org.au/stem-cells-hsp/>.

Final validation of the results of the stem cell Pilot Study was completed in late 2010. The researchers expect to publish their groundbreaking findings in an eminent journal in the near future. We are both pleased and proud that Prof. Mackay-Sim was awarded Australia's most prestigious science prize, the People's Choice Eureka Prize for excellence in scientific research and innovation in September 2011.

Drug Discovery & Development

With a view to the future, we are also thinking about future phases in the program. Drug discovery and development is the process that bridges the gap between a potential drug cure being discovered and a drug treatment being commercially available to treat people. This is where the safety and efficacy of a potential cure is established. It is a long and costly process, with no guarantee of a product at the end. We are currently developing a position paper on this process as the basis for fostering partnerships and collaboration both in Australia and globally to optimise the potential for sustainable long-term success in developing cures for HSP.

Gene Testing

All Australians at risk of HSP can avail themselves of the testing and screening service for SPG4, SPG3A and SPG31. Information is available on the website at: <http://www.hspersunite.org.au/genes-hsp/gene-testing-service/>. For those who test negative to the three gene tests offered, but who almost certainly have HSP and would like to know for purposes such as family planning, there is no easy answer at this point. Scientific and technical advances in gene testing still continue at a hectic pace. In the not too distant future, indications are that affordable mapping of an individual's whole genome will be available, and will be the preferred gene testing option.

HSPers thinking of getting tested are strongly encouraged to see a genetic counsellor first. One of the issues you can explore with your counsellor is the feasibility of getting tested as an outpatient

in a public hospital. In some cases, this may significantly reduce or even eliminate out of pocket expenditure. Health card holders pay nothing.

Awareness, Support & Education... Developing the Australian HSP Community

Information and Education

Mobility maintenance and management is a primary focus for HSPers. Issues that we cover in this regard include neurology, orthopaedics, spasticity and pain management and treatment, specialised therapies including physiotherapy, neurophysiotherapy, podiatry / orthotics and occupational therapy. We also cover fitness, self-managed exercise programs, assistive technologies, lifestyle and quality of life issues. Other topics covered include genetics, family planning and mental health. Information and education media include the Foundation website, e-mail and phone inquiries, and workshops.

The website is a significant resource and library/archive. Web statistics 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 now available on the website with the ability to be added to at any time. While it is small at present, it is hoped that people will continue providing the names and details of medical professionals that they would recommend to other HSPers.

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, the US, Dubai, Indonesia or Turkey, receives a personal response.

An HSP Workshop was held in Brisbane in November 2010, and was judged a worthwhile effort, both in educational and in social terms, by all concerned - participants, presenters and organisers. It was held at the stem cell research centre, a tour of which was a highlight. This year the Foundation will hold a Workshop in Adelaide in November for the South Australian HSP community, however anyone from anywhere is most welcome to attend. The feasibility of conducting future workshops as Web seminars (webinars) will be considered before any decisions are made regarding workshops for 2012 and beyond.

Growing the Community

There are roughly 400 people in the Australian HSP community listed in our Contacts Management System, up from 280 this time last year... an increase of 45%... and double number from two years ago. Given the issues with HSP diagnosis, and the limitations of gene testing currently, the best estimate is that about 200, or half the community, have HSP, with the other half comprising family, friends and supporters. Based on the estimate that there are around 1,500 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 volunteers, and to have sufficient HSPers for clinical drug trials in the future.

Connecting with each other

There is a significant, ongoing demand for more connection between community members. The bulk of communications will necessarily remain electronic with the website and e-mail being the main methods. Recently the Foundation launched its own Facebook page, and this has already proven quite popular. Given that HSP is a rare disease in a big country, is a huge challenge to create opportunities for personal interaction.

The Community Contact Initiative was launched in June, with the aim of making personal contact by phone with all community members for whom we have a phone number. This is to give them the opportunity to talk and hear about issues of interest to HSPers. It also helps keep the Foundation in touch with the community and aware of relevant issues. With the support of a number of volunteer callers, we have reached a high percentage of the community this year. Final statistics and an evaluation of the initiative are not available at the time of this report.

42 people from Australia are now shown on the global database <<http://freyerse.org>> for those with HSP and similar diseases. 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.

Running the Foundation

Communications

Electronic communications: over 80% of the community have provided us with an e-mail address. We utilise e-mail communications with community members where possible, with postal mail being a backup for those without e-mail. However postal mail recipients do not receive quarterly updates and certain other communications that are only transmitted electronically due to the time, manpower required and expense. 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.

Being Businesslike

The challenge of every small non-profit, us included, is how to be effective and businesslike so that scant resources can be well employed when we are run totally by volunteers. In 2010 we made a significant investment of time and expertise in developing processes, systems and technologies to make us more effective and businesslike. That has continued in 2011 with continuous improvement to the website, continuing development of the Contacts Management System, and improvements to the handling and processing of community membership inquiries, general inquiries, correspondence, initiatives such as the fundraising campaigns and donation processing and receipting.

Developing our Capability & Capacity

We have way more jobs and projects than capable people who are available to do them. At the start of the year we undertook a drive to find capable, available people to take on projects and roles for the Foundation. We are enormously grateful to those who responded, and we're happy

to report some success with the initiative. While there are still roles that are not filled, we are pleased with the ones that are now getting attention.

Our heartfelt thanks to Isaac Nakhla, our dedicated Web designer and technician, for his attention to, and improvement of the website; also to Ryan Keating who continues to support the development of the Contacts Management System. Both Ryan and Isaac have no connection with HSP, but a keen sense of contributing to society and selflessly doing good. Both also volunteer their valuable time, knowledge and expertise for other charities.

Volunteers this year from within the HSP community who are playing a valuable role worthy of special mention are Margaret Flood, Chris Hall, Stuart Arms, Brendon Flood, Jill Barclay, Tim Xiros and Stephanie De Vere... Thanks to you all!

Fundraising

'Give Generously' Campaigns

The Christmas campaign conducted in December 2010 was our first at that time of year and realised \$8,000. The June campaign this year amounted to \$39,000, down from \$50,000 in 2010. This campaign is designed to coincide with the end of the tax year so that people can claim immediate deductions for their charitable contributions to the Foundation.

Events

Event fundraising through sponsorships continues to be a significant source of Foundation income, with Sydney's City 2 Surf, Sydney Half Marathon and the Gold Coast Marathon attracting HSPers and their supporters in 2011. In total, event fundraising amounted to \$14,000, a significant part of our annual minimum financial commitment of \$100,000 to research funding. Events are also important as we see HSPers doing extraordinary things, and this is good for us all. Sponsorships come largely from outside the community via participants' families and relatives, friends, colleagues and community. Events provide a rare chance to get some publicity and raise awareness of HSP and HSPers.

Philanthropic Grants

Many high-quality applications to carefully chosen philanthropic organisations and grant makers were submitted over the past year, and fortunately, this is reflected in our results. Our largest success was with an application for \$30,000 per year for two years that was granted by the Ronald Geoffrey Arnott Foundation, managed by Perpetual. We have recently been advised that our application to the Flack Trust was again successful this year with another award of \$10,000.

Who Gives?

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

1. 'Inner Circle' – this is how we describe people in the HSP community / Foundation members. We are very aware that this is a finite resource, however the reality is that only around 15% of our community contribute. We need to find a way to engage the other 85%, 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 outside the HSP community. This includes extended family, relatives, friends, colleagues and the communities in which HSPers live.

As far as the future is concerned, we must find ways to appeal to this group so that they are motivated to contribute. 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.

Research Funding

We are proud that over 95% of all money raised goes to fund research, and also proud of the fact that this can happen only because we are a 100% volunteer organisation. Each year we have a \$100,000 minimum commitment to fund the stem cell research project. Last year we raised around \$85,000, and so have a target of \$115,000 in calendar 2011 to meet our needs. At the time of this report, \$103,000 has been raised, making our Christmas campaign target a minimum of \$12,000.

Looking Ahead

The following are focus areas for the future:

1. 'Living with HSP' including mobility management, lifestyle maintenance, medical and mechanical options, maintaining good mental health, getting and keeping fit, and so on, are vitally important to the quality of life of people in the HSP community. There is little or no direct funding from anyone anywhere to advance knowledge and practice relating to these topics, however there is a vast pool of relevant expertise and resources that can be better organised and accessed. Recently a Melbourne physiotherapist, who is a member of the HSP community, commenced a Ph.D. study on gait in children with HSP.
2. Creating awareness of HSP and HSPers with stakeholder groups such as the most relevant medical and paramedical professionals, funding bodies, and society at large is a challenge. Mass media opportunities are rare and hard to create. Plans are in place to use volunteer professional PR assistance to leverage publicity surrounding the upcoming publication of findings from the stem cell research.
3. Continuing to develop the HSP community by having people more actively engaged with each other. There is potential for the recent community contact initiative, with Foundation support, to develop into self-starting local social groups... realising true grassroots community development.
4. Working toward sustainability in building and developing the capacity and capability required to do all the things we need to do with a 100% volunteer workforce. Continuing efforts to attract and retain talented individuals are a high and ongoing priority.

Financial Statements

A Summary of the Audited Financial Report of the Foundation for the 2010/11 financial year follows on the next two pages. We have the capacity to meet our current and foreseeable commitments including research funding and are confident of our continuing financial good standing into the future.

Foundation Committee

On behalf of every one in the HSP community, I extend my thanks to the committee members of 2010/11 – Robin Bligh, Ken Price and Treasurer Steve Lunn, who generously volunteered their time and talent once again to run the business of the Foundation and pave the way for a brighter 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 have a high expectation of continuing 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,

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 2011

PROFIT AND LOSS STATEMENT FOR THE YEAR ENDED 30 JUNE 2011

	2011	2010
	\$	\$
INCOME		
Gross Loss Trading	-	-
Membership Fees Received	-	195
HSP – DGR Donations Received	95,177	52,192
Interest Received	2,581	1,014
Other Income	240	-
ATO Refunds	9,712	-
TOTAL INCOME	107,710	53,401
EXPENSES		
Accountancy	623	623
Auditors Remuneration – Fees	1,066	1,066
Dues	378	-
Other Expenses	85	195
Postage & Post Box Charges	60	-
Printing & Stationery	180	-
Research Expenditure	50,000	75,000
Subscriptions	726	707
Venue Expenses	-	188
Web Site Maintenance	-	160
Web Site Development Amortised	800	800
TOTAL EXPENSES	53,918	78,739
OPERATING PROFIT	53,792	(25,338)
NON-OPERATING INCOME AND EXPENSES		
Non Operating Expenses		
Less Research Expenditure not yet presented as paid	-	-
OPERATING PROFIT BEFORE INCOME TAX	53,792	(25,338)
OPERATING PROFIT AND EXTRAORDINARY ITEMS	53,972	(25,338)
Retained Profits at July 1	65,966	91,304
PROFIT AVAILABLE FOR APPROPRIATION	119,758	65,966
RETAINED PROFITS	119,758	65,966

HSP RESEARCH FOUNDATION INCORPORATED
ABN 46 648 875 912

BALANCE SHEET AS AT 30 JUNE 2011

	2011	2010
	\$	\$
CURRENT ASSETS		
Cash Assets	118,958	64,366
Receivables	-	-
TOTAL CURRENT ASSETS	<u>118,958</u>	<u>64,366</u>
NON-CURRENT ASSETS		
Intangible Assets	800	1,600
TOTAL NON-CURRENT ASSETS	<u>800</u>	<u>1,600</u>
TOTAL ASSETS	<u>119,758</u>	<u>65,966</u>
TOTAL LIABILITIES	<u>-</u>	<u>-</u>
NET ASSETS	<u>119,758</u>	<u>65,966</u>
EQUITY		
Retained Profits	119,758	65,966
TOTAL EQUITY	<u>119,758</u>	<u>65,966</u>

A full copy of the Audited Financial Report 2011 is available to members on request by emailing admin@hspersunite.org.au (2.3MB PDF file; 12 pages) or by writing to:

HSP Research Foundation
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