

MS Update

Winter 2011

Inside this issue

CEO's Message	2
Information is Power Seminar	5
Events Update	6
MS Readathon	7
Research, Aids & Equipment Forum	8
Advocacy Update	11

Raise Your Voice – We're *Listening!*



Client Survey 2011 Results

In our autumn quarterly newsletter we reported that 196 clients had completed the client survey in February. The aim of the survey was to obtain information about the topics the clients would like to be included in future projects and their preferred style of delivery of information. The Client Services Team also wanted to ensure that our clients are aware that their interests and preferences will be considered when projects are being planned and to give our clients a forum in which to voice their opinions about future projects.

A summary of the findings of the survey can be seen here, and the full survey report can be found on the MS Tasmania website on the home page. If you would like a printed copy of the report, please contact Di on 6220 1111 and a copy will be sent to you.

Key Findings

From the survey responses it was possible to identify the following clear trends:

- While 58% of respondents were interested in attending events and 66% wanted to receive information through electronic media, the most popular preference for receiving information was by mail – 80%.
- The majority of respondents – 81% – expressed a preference for events that are casual and informal. There was also a preference for “events where I can just listen” – 76%.
- 58% of respondents were interested in learning how to access an online community or forum for people with MS and their carers
- Responses to the question about preferred times to attend events were fairly evenly distributed with a slight preference for weekday afternoons

Topics that respondents showed the most interest in are:

- Information on research (Very interested + Fairly interested = 95%)
- Information on treatment options (Very interested + Fairly interested = 94%)
- Fatigue management ideas (Very interested + Fairly interested = 90%)
- Exercise and MS (Very interested + Fairly interested = 89%)
- Eating for good health (Very interested + Fairly interested = 86%)

continued on page 4

CEO's Message



Word travels fast! It seems that this is very much the case in our closely networked MS community, and so you possibly already know that I will be moving on from my role with The MS Society at the beginning of July in order to accept an exciting new challenge as CEO of The Royal Hobart Hospital Research Foundation. While this is

a marvellously inspiring opportunity to contribute to development of informed health care in our community, while also building the research capacity of our local Tasmanian doctors, nurses and allied health professionals, I have to be honest and confess that the prospect of saying farewell to The Society, its clients and carers, our network of supporters and our marvellous internal team, really does leave me with a heavy heart.

Over the past two and a half years, I've had the enormous pleasure of getting to know and to work actively with so many people affected by MS, across Tasmania and also at a national level. While as you might expect, there are many instances where the impact of this condition leaves a personal sense of anger, frustration, anxiety and loss, what has inspired me so many times is an equal measure of 'getting on with it', taking control and doing whatever can be achieved to make quality of life with MS the best it can be. Many times I have heard people speak of the importance of a positive attitude, with many people living with MS describing their philosophy of this life as something along the lines of 'yes, I have MS and this affects me greatly, but MS itself does not define my life'. Fundamentally, I have drawn such an enormous degree of inspiration from working with those who show such positivity. These people, whether they are living with the diagnosis themselves, are carers, family or friends, or part of the wider MS community of external healthcare professionals and associates from across the communities of MS Societies, show an acceptance that yes, life with a chronic condition is challenging, but it need not take control of the future, there are many activities and approaches that may be employed to maximise life with MS. Guiding a team and working with a broader community of supporters, it has been my great pleasure to explore new ways and open new opportunities to getting the best out of life.

I have drawn such an enormous degree of inspiration from working with those who show such positivity.

So in reading through the contents of this issue of Update, I think you will join me with a sense that we are making strong steps towards achieving our vision and mission of the Society. We aspire to a vision that we live in a Tasmanian MS community that is engaged, informed, understood and supported. In seeking this, our mission states that we are committed to enhancing the quality of life for people in Tasmania with MS and to reducing the impact upon their families and carers by: enhancing the identification and awareness of the needs of people affected by MS; the pursuit of best practice at clinical, whole of person and research levels; supporting advances in the management and prevention of MS; leadership and advocacy; and enhancing our organisation. Every feature in this issue underlines

how we approach this task, working with many partners to achieve our aims. Importantly, I think that you will agree, we are equally living our team's values of respect, integrity, empathy and working together and, in doing so, we have achieved some strong results in recent times and are well-poised to continue to do so for a long time to come.

So why am I moving on – a question that I have often asked myself in recent months! Well, it's a combination of factors. As described in my Autumn column, the national disability community is at the threshold of major reform if the Productivity Commission's report, to be released in the next few weeks, is accepted

by government and implemented within the proposed swift timeframes. If, as is currently mooted, the new disability care and support system is piloted in Tasmania in 2014, this will demand an extensive degree of focus and flexibility to ensure the opportunities presented are maximised. In doing so, MS Australia will also need to assume a stronger role as a peak organisation in order to ensure the needs of its clients are well met during times of change, again elevating the need for flexibility by those that lead state Societies. Beyond this, in recent years I have enjoyed the opportunity to be the representative of all Societies' CEOs contributing to the Board of MS Research Australia and also as the executive sponsor to the National Services Leadership Group (the group comprising all Client Services Managers). Again, there are great things on the immediate horizon for both groups, not least of which is a new initiative designed to see far more social and applied research undertaken at grass-root levels in Societies, acknowledging that while advances driven through findings from the pure science level are eagerly anticipated, those living with MS now are equally keen to see enhancements to daily life through more practical, evidence based solutions. A new reference group to drive this program will form in coming months

and begin to progress this with vigour, both nationally and at state Society level.

As you can see, there are exciting times ahead and those that know me will agree that I love a challenge, especially along the lines of those above. But during the midst of these many developments in our MS community, my own circumstances have changed too and with an enduring commitment to being a hands-on mum to two young children, the scope to be so fully focused and completely flexible was not one that I could see being balanced easily. Fortunately though, there is a marvellous old adage that talks of clouds with silver linings though and it seems the cloud I found my future under did indeed have a luminous edge. The Royal Hobart Hospital Research Foundation has been active for over a decade now and in its most recent round of grant funding, provided over \$700k of funds to research projects and ongoing fellowships, taking the total funding provision to close to \$6m. With a

personal background in research and a commitment to enhancing quality of care, you can see the link that has me hooked when approached to see if I might be interested. As a staunch Tasmanian, the chance to play a role in offering talented clinicians the chance to pursue their research aims while remaining at the RHH or at UTas' Menzies Institute or Medical School is also a challenge that I'm keen to accept. Who knows, maybe I can play a part in inspiring a budding researcher to explore further the impacts and management of MS as displayed in southern Tasmania.

So, in closing my final column, I bid farewell and hopefully not goodbye. I do hope that our paths will continue to cross many times and that we can continue the many friendships built over these past few years while continuing to watch the growth of The Society for the benefit of those living with MS across our community. With best regards and warm wishes for all that the future holds, Heather.

On behalf of all staff and clients of The MS Society we wish Heather all the best for her future endeavours. Heather's contribution to the Society has been immeasurable, her enthusiasm, professionalism and friendship will be greatly missed.



Fathers Day Raffle Draw
2009 with Hobart Lord
Mayor Rob Valentine

Can-Can at the
Red Diamond
Cocktail Party



Modelling at Blue Illusion
Shopping Night



Hobart Mega Swim
with Emily



Planting the Betty Cuthbert Rose at the
Royal Botanical Gardens.

cover story continued



- Tips and strategies for coping with MS (Very interested + Fairly interested = 82%)

Topics that respondents showed the least interest in are:

- Information suitable for children (Very interested + Fairly interested = 22%)
- Parenting and MS (Very interested + Fairly interested = 23%)
- Peer support sessions (Very interested + Fairly interested = 38%)
- Employment issues (Very interested + Fairly interested = 39%)

(Note: Observations by the Client Services Team and experience with clients, together with research from national and international sources, suggest that the low level of interest in employment-related issues might not necessarily reflect the situation in the Tasmanian client community. It might, however, reflect the demographics of the client group that completed the survey.)

Written Suggestions – A Summary

The clients had the option of writing other ideas, suggestions or comments to indicate their preferences in the way information should be communicated. The most common responses indicated that clients prefer to receive information by telephone, personal contact with the staff of the MS Society, and through support groups, as well as via the internet.

When asked for other suggestions for topics that would be of interest, the most frequent responses asked for information on research, treatment options and other therapies. Dealing with change, emotional issues, financial issues, information on assistive aids, advice on access to facilities and suggestions for recreational and social activities were also frequently mentioned.

The Next Step

The Client Services Team, in consultation with Management, will now discuss the findings of the survey and its implications for future project planning.

While all project planning is dependent on resourcing, the Client Services Team will endeavour to include the preferences of the majority of clients in the topics and method of delivery of future projects so that they are appropriate and beneficial to clients.



With 2010 its inaugural year, The Novel Challenge raised almost \$100,000 nationally for people living with MS. So The Novel Challenge is returning for 2011 and with your help we hope it will be even bigger this year!

The Novel Challenge provides a fantastic opportunity for adults, book clubs, and community groups to get involved and help raise funds for the 20,000 Australians living with MS.

To take part:

- Register at www.thenovelchallenge.com.au,
- Select a book challenge,
- Read for 30 days in July, August and September
- Seek sponsorship from friends, family, and colleagues!

You can register as an individual or create a team from amongst your work colleagues, book club, sports team, mothers group, friends or even family.

So book worms, save the date and read for a reason!

For more information contact Stacey at the MS Society of Tasmania on 6220 1111 or email stacey.king@mstas.org.au



Information is Power

SEMINAR SERIES 2

“She knows her stuff!”

“Very informative.” “More seminars please!”

“Very impressive and knowledgeable.”

“Excellent relevant information for MS.”

“(A) particularly good presentation.”

“Very friendly and approachable (speaker).”

“Excellent – (I) would love to attend another one if it was offered to gain more knowledge.”

The second Information is Power seminar was held around the state in April, following on from the first seminar in November 2010. All clients of MS Tasmania were invited to the seminars and a total of 67 people attended in Launceston, Hobart and Ulverstone. The seminars were made possible by the generous sponsorship of **Biogen Idec Australia Pty Ltd.**

Eating for Good Health

The session on Eating for Good Health was presented by dietitians Sonia Valtas (in Hobart), Emily Gatenby (in Launceston) and Sara Beyer (in Ulverstone). This presentation included general information on healthy eating and wise food choices, incorporating foods from all the food groups. The role of nutrition in managing MS was also explored, together with suggestions for healthy meals and snacks and tips for making food preparation more manageable.

Exercise

The presentation entitled Exercise for Health and Well-being featured physiotherapists Karen Ashworth (in Hobart), Scott Beeston (Launceston) and Edwin

Roberts (Ulverstone), and included information about exercising to maintain fitness, strength and flexibility with MS.

Discrimination

Discrimination was the subject of the presentation at all three venues by Kim Hambly, who is the Manager and Principal Solicitor at the Launceston Community Legal Service. Kim discussed Disability Discrimination Law and explained the jurisdiction of Federal and Tasmanian State authorities in this field. She discussed the types of discrimination – both in the workplace and in other areas – and the grounds for applying anti-discrimination laws. Kim also outlined the avenues and processes of discrimination complaints, and the role of the Community Legal Service.

Disclosure

Case Managers Lynsey Spaulding (in Hobart) and Helmuth Seidensticker (Launceston and Ulverstone) spoke about MS and Employment – Disclosure. Lynsey and Helmuth emphasised that the decision to disclose a diagnosis of MS to an employer

and work colleagues is a personal choice, although there are some circumstances in which disclosure may be compulsory. They outlined the advantages and disadvantages of disclosure and the issues to be considered when making the decision about disclosure.

Stress Management and Dealing with Emotions

Counsellors Sharon Wilkinson (in Hobart) and Nicky Snare (Launceston and Ulverstone) spoke on the subject of Stress Management and Dealing with Emotions. Sharon and Nicky identified the many stressors faced by people with MS and the warning signs of stress. They also gave practical information on stress reduction, including fast “stress-busters” and relaxation techniques.

The evaluations from all three days indicated a very high level of satisfaction among those who attended, with many indicating that they would recommend the forum to others. The participants in Ulverstone were even lucky enough to see dolphins pass by the surf club where the seminar was held!

EVENTS UPDATE



TDT TEN MUD DASH FOR MS

The TDT Ten MS Mud Dash for MS is an exciting new event on the MS Society of Tasmania's fundraising calendar.

The first Mud Dash for MS was held on Sunday May 8 at Fulton Park, Forth. Being Mothers Day didn't stop almost 150 participants from coming along and getting down and dirty for a great cause.

The Mud Dash for MS is a fun run along a cross country course filled with plenty of natural and muddy obstacles that challenged participants. The course traversed through beautiful native bushland including grasslands, creek crossings, hills, a waterslide and many muddy bog holes.

The highest fundraiser was Pam Roles from Scottsdale who raised \$300. A special mention goes out to Team Brady Bunch for winning the best dressed team and the muddiest individual. Great effort!

We hope that the Mud Dash will become a regular and successful fundraising event on the MS Society of Tasmania's event calendar.

A big thanks also goes out to Scouts Tasmania, Forth Volunteer Fire Brigade and SEA FM Devonport for their fantastic support of the event.

Stay tuned for information regarding our next Mud Dash for MS event!



MS AWARENESS WEEK and WORLD MS DAY

World MS Day took place on Wednesday 25th May. The aims of World MS Day are to raise awareness of MS and to mobilise the global movement. The staff at the MS Society of Tasmania marked this day by wearing red to work to support our clients and their families living with MS. Red lipstick, red scarves, red dresses, red tops and even red shoes were all seen.

MS Awareness Week began after World MS Day and continued on through until Sunday June 5th. We encouraged individuals and businesses to take part by wearing red lipstick or a red item of clothing on either World MS Day or at any time during MS Awareness Week to raise much needed funds.

With the focus of MS Awareness Week 2011 on employment, the MS Society of Tasmania organised the Multiple Sclerosis and Employment Forum to inform employers and decision makers of the issues around MS and the workplace, with sponsorship provided by Novartis.

The program for the Forum included presentations by experts in the fields of research and employment, including Dr Rex Simmonds, coordinator of the MS Life Longitudinal Analysis. Participants also had the opportunity to hear about the workplace experiences of people living with MS and employers who have a staff member with MS.



www.msreadathon.org.au

Whilst many schools and students are preparing to start reading for a reason for the 32nd year, there is still time to register and help people living with MS!

Its easy to get involved! Here's how:

FIRST: REGISTER!

Log on to the MS Readathon website at www.msreadathon.org.au.

SECOND: READ!

As much as you can between 1 – 30 July 2011.

THIRD: FUNDRAISE!

Asking your friends and family is a great way to start. They may even be able to help you think of other ideas to raise money for people living with MS.

FOURTH: BE REWARDED!

This year you can choose your own rewards! Rewards will come in the form of Target gift cards. Participants can use these to buy whatever they like at any Target store.

Through a new relationship, all those schools who have at least 10% of their students registered and raising at least \$10 each, go into the draw to win 10 Apple iPads! These schools also get 10% of the funds they raise back to spend on products at Target stores.

The MS Readathon teaches students the importance of developing their reading skills, learning about people in their community who live with MS, and helps develop their sense of community spirit. Its a great program to be involved with!

Log onto www.msreadathon.org.au for all the latest news, some great reading ideas and special competitions.

For more information please call Stacey on 62220 1111 or visit www.msreadathon.org.au

Community Fundraising



Hudsons Coffee is keen to expand their community involvement so each store has selected a local charity to support. The store and coffee kart at Launceston Airport selected the MS Society of Tasmania as their chosen charity.

So get your sugar and spice while supporting something nice! Swing by either of the Hudsons Coffee stores in Launceston Airport and ask for their Caramel Cappuccino or Vanilla Latte! Between May 23 and July 3, MS Tasmania receives a \$0.50 donation from each sale! Every cup counts.

Thank you to the Hudsons stores at the Launceston Airport for their kind support.



RESEARCH, AIDS and EQUIPMNET FORUM

On 24th March 2011, the MS Society held a Research, Aids an Equipment Forum in Launceston, generously sponsored by Bayer Healthcare.

Megan Varlow – MSA and Hanna Steel – forum participant

The Forum aimed to provide people with MS and their families with information about moving towards self-management, by acquiring up-to-date and relevant information about current and future research including clinical trials in Tasmania, and also to provide information about and practical experience of assistive aids and equipment.

All registered clients of MS Tasmania and their families were invited to attend the forum, which was provided at no charge to the participants. To allow for maximum participation, coach transport from Burnie and from Hobart was arranged at a small charge which a number of people chose to use.

One hundred and nine clients and supporters attended the Forum, with many people travelling from the South and North-West of the State. The inclement weather on the day did not deter people from attending and this was a clear reflection of the level of interest in the Forum's research focus.

Of those in attendance on the day, 92 people completed the evaluation form. The feedback on the day was overwhelmingly positive with 95% of the participants saying that they would recommend the Forum to others. The responses relating to each individual presenter were also very positive, with participants indicating a high level of satisfaction with the content and presentation style of every session.

There were four presenters on the day, including:

Megan Varlow

Clinical Psychologist, MS Australia

Active Strategies to Manage Pain

Megan discussed the incidence of pain in MS, citing studies that demonstrate the prevalence of pain is high in people with MS, with between 48% and 66% reporting pain among their symptoms. Megan said that 40-57% of people with MS report constant pain.

Megan explained the impact of pain on the lives of people with MS, including lower quality of life, increased doctors' visits, increased levels of stress and an impact on employment.

She then discussed the recommended treatments for pain in MS, outlining the importance of consulting a general practitioner and neurologist for help with pain management, together with the role that can be played by the support of family and friends. Megan also discussed types of medication that might be beneficial in pain management.

Finally Megan emphasised the importance of utilising practical, active pain management strategies to maintain function despite pain, including eg activity pacing, relaxation and stress management, and challenging unhelpful thoughts. Megan also mentioned specialist pain clinics as well as accessing publications that are available through the MS Society.

Sue McGregor

Clinical Research Nurse, MS Society of Tasmania

MS Clinical Research in Tasmania

Sue began her presentation by explaining that an opportunity arose almost three years ago for the collaboration between the Neurological Department of the Royal Hobart Hospital (MS Clinic) and the MS Society to assist in providing patients access to clinical trials in new and emerging therapies for multiple sclerosis. This collaboration has allowed patients, for the first time, to access clinical trials that previously had only been available on mainland Australia. Under the leadership of Dr Michael Dreyer, Director of Neurology and principal investigator, the first clinical trial commenced recruitment in 2008.

Sue went on to describe the following clinical trials that are currently being undertaken with Tasmanian participants:

- The CARE MSCAMMS 323 and 32400507 trials are two related 2-year world wide studies comparing Intravenous Alemtuzumab Subcutaneous Interferon Beta-1a (Rebif). Tasmania has recruited three patients to participate in one of these trials, and another 6 are participating in the other.
- The CAMMS03409 (CARE MS EXTENSION TRIAL) is an extension of the previous two studies and it is hoped that Tasmania will have 100% recruitment in to this trial – the only site in Australia to do so.
- For the TOPIC Trial HMR1726 (Teriflunomide), one person in Hobart has been recruited, and recruitment has been extended to 2012.
- Three patients have commenced screening in Tasmania for the INFORMS FTYD2306 (Fingolimod) trial and another two have been randomised and have commenced treatment.
- The ORATORIO STUDY is a Roche-sponsored clinical trial to investigate the efficacy of Ocrelizumab. There will be 630 patients worldwide involved in this study at 207 sites, including 3 in Australia. The Royal Hobart Hospital is likely to be recruiting for the trial beginning in late June. A number of patients have already been identified and ‘tagged’ as possible candidates and will be contacted and provided with information to consider.

Sue went on to explain that the factors impacting on patient participation in clinical trials are extensive and complex, and that the participants need to be fully informed of such factors as the required time commitment, inconvenience and invasiveness of the testing process.

She concluded by emphasising that the clinical trials adhere to the conditions of Good Clinical Practice (GCP), which is an international ethical and scientific quality standard for designing, conducting, recording and reporting trials that involve the participation of human subjects.

Dr Jim Stankovich

Biostatistician, Menzies Research Centre

The Genetics of MS

Jim explained the genetic complexity of MS and discussed the current research into genetic risk factors and the genes that affect the immune system. He went on to explain the latest genetic testing procedures and the genes that have been identified as possibly being causative factors in MS.

Jim also discussed the studies currently being undertaken by ANZGene – the Australian and New Zealand MS Genetics Consortium. He also pointed out the interconnectedness of research into the role played by vitamin D, ethnic ancestry and genetics in causing MS.

Associate Professor Bruce Taylor

Menzies Research Centre

MS Research in Tasmania – Looking Forward

Bruce began his presentation by discussing the incidence of MS in history, naming historical figures who showed evidence of the symptoms of MS. He then mapped the typical activity of MS over time in a person who has been diagnosed.

Bruce went on to explain the likely causes of MS, pointing out the interplay of infectious agents, environmental factors and genetic factors. He described the geographic gradient that is evident in describing prevalence of MS worldwide and within Australia, and the associated high prevalence of MS in Tasmania. He also pointed out the incidence in females, the risk in relatives and the effects of smoking.

Bruce then talked about the current research into the role of UV radiation and vitamin D in MS, explaining that there is evidence at an ecological level that vitamin D may be important in preventing relapses and onset of MS.

Assistive Aids and Equipment

During the lunch break the Independent Living Centre of Tasmania presented an interactive display of assistive aids and equipment to enable clients, families and friends to look at the latest items available.

Starring Staff Profile



Viv Jones
*Manager
Corporate
Services*

Date Joined Society: March 2006

Interests: Spending time with family and friends, sport and the community, member of Carlton Park Surf Life Saving Club.

Favourite Food: Anything she doesn't have to cook herself.

Favourite Music: Ballads, Cold Play and Cary Lewincamp.

Favourite Book: Stieg Larsson Trilogy and anything by Jodi Picoult.

Background: Viv currently lives in Dodges Ferry with her husband Brian whom she married in 1986, their daughter Casey who is currently at University in Launceston and is only home on weekends and holidays, and their 13 year old border collie, Nala.

Viv attended Bowen Road Primary School and then went on to Clarence High School after which, at the tender age of 15, she joined the then Bank of New South Wales, where she spent 13 years. Viv was the first and youngest female to be promoted to a Westpac Management position in Tasmania. After returning to the Bank from maternity leave, her role had been moved interstate and as she didn't want to leave Tasmania, Viv moved into the aged care sector as CEO of St Ann's Aged Care Facility.

Viv joined the Society in March of 2006 as our Human Resources Officer and has since been promoted to the role of Manager Corporate Services. Viv's passion and interests are in people and culture. Viv has brought a wealth of knowledge and experience to the Society which has helped us to develop our workplace environment into one that supports our vision, mission and values.

General Practitioner Education Seminar

A series of three General Practitioner Education seminars have been held across Tasmania this year, supported by sponsorship from Sanofi-Aventis.

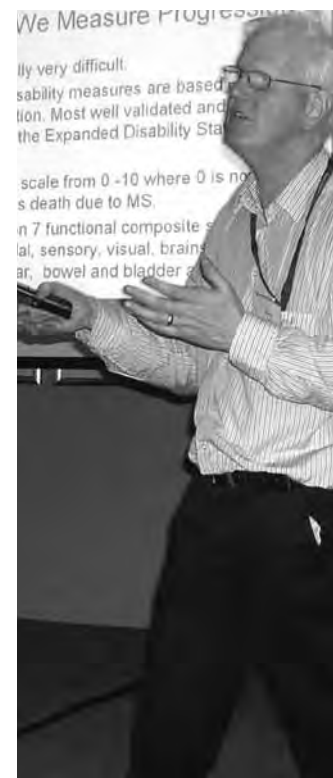
The purpose of the seminars was to educate GPs and Practice Nurses about the complexities of MS, the latest research, diagnostic indicators, treatment options, the referral process and the support services provided by the Multiple Sclerosis Society of Tasmania.

The seminars were organised in collaboration with the three General Practice divisions – GP South, GP Northwest and GP North, a partnership that also has the benefit of strengthening the relationship between MS Tasmania and these organisations.

Across the three venues – Hobart, Ulverstone and Launceston – Associate Professor Bruce Taylor, who generously donated his time and expertise, addressed a total of 88 GPs and Practice Nurses on The Contemporary Management of Multiple Sclerosis. His presentation included information on the types of MS, symptoms, diagnosis and disease progression. He also discussed the incidence of MS in Tasmania and across the world, as well as current thinking on the causes of the disease and treatment therapies.

MS Society Nurses Teresa Warren and Kim McCarthy clearly described the referral process, and reinforced the presentation with a handout to summarise the process that GPs need to follow if they suspect a diagnosis of MS. MS Society's Senior Case Manager Lynsey Spaulding was also in attendance at each venue, and the MS Society provided a table of resources and brochures for the GPs and Practice Nurses to take with them.

The evaluations completed by the attendees were very positive, with all respondents indicating a high level of satisfaction with the overall presentation and content of the seminar. All respondents also felt that the event increased their understanding of the complexities of MS, diagnosis review and available treatment, and their knowledge of current MS research and trials and referral pathways.



*Associate Professor
Bruce Taylor*

ADVOCACY UPDATE

On 18 May in Launceston Helmuth Seidensticker (Northern Coordinator) Mary Langdon (Manager Client Services) and three Advocates, met to discuss the Advocacy program in Tasmania and a range of related issues. Whilst there were a few apologies, including Robert Pask, the National MS Advocates Co-coordinator, it was a very productive meeting and many issues were discussed.

Amongst these were:

- Arrival of a Northern Neurologist, including development of linkages with the MS Society.
- Helmuth gave an update and overview of the Productivity Commissions' report on the National Disability Insurance Scheme (NDIS); highlights included the preliminary estimate of approximately \$12.6 billion in additional funding (which is double the current amount applied through the existing National Disability Agreement), the broad public and political support demonstrated for the NDIS at the recent Disability & Carer's Congress held in Melbourne, and the focus on encouraging people to register their support for the NDIS through the "Every Australian Counts" campaign, as described in the last *Update*.
- Neuro Muscular Alliance of Tasmania (NMAT) and the "Getting In Touch Survey".
- The Society's successful submission to the Consumer Advisory Panel, now allowing an opportunity for us to employ a part time campaign officer to run the "Keeping Cool Campaign", a campaign to lobby for a medically based concession for the cost of running air conditioning for Tasmanians with MS and other neurological conditions.
- Discussion of National Policy Issues that are the formal statements issued by MS Australia, and which thereby provide a platform for our national advocacy work. These include statements on: employment and workplace flexibility, aids and equipment, the disability care and support scheme, universal housing design, research, National Disability Strategy, health and community services, carers and also energy use and climate change.
- Greater support for our advocates, including the development of a business plan that will provide direction, goals and expected outcomes. Work will progress on this plan with the collaboration of all Tasmanian advocates, the Manager Client Services and our Northern Co-ordinator.
- The Advocates Conference that will be held in Canberra on the 21st and 22nd June. This is a great opportunity for our advocates to network with other advocates from other State MS Societies, as well as receiving policy updates and information on media and campaigns, presenting State reports, sessions on issues and strategies, research updates, meeting with our local federal members in Parliament House and the opportunity to sit in on Question time in Parliament House.

1 in 4 POLL

1 in 4 Australians has a disability or cares for a family member with disability. These people have the right to have their voice heard in the ongoing national debate that informs government policy. The 1-in-4 Poll is a regular national survey that lets people with disability express their views on a range of social issues. The first Poll focuses on Social Inclusion.

The information that comes from these polls will be used by the researchers – Deakin University, Scope and by National Disability Service (NDS) – to influence government policy and inform future practice and research.

To complete the survey go online to the website:
www.1in4pollaustralia.com

There are 3 ways you can do this survey:

1. You can do the survey online
2. You can download a pdf of the survey.
3. We can mail you a paper version of the survey.

The Poll can be completed by:

- People with a disability
- A carer who is a family member or paid carer

If you have any queries about the project please access the website in the first instance at:
www.1in4pollaustralia.com



AUSTRALIA
Giving life back

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South: 1800 676 721
North: 1800 654 872

www.msaustralia.org.au/tas

Main North & North-West Support Groups

Enquiries: 6343 1240

Launceston Support Group

Meets the 2nd Thursday each month at the Branch Community Centre next door to the MS Society Office (opposite the bowling alley).

18/2 Innocent Street, Kings Meadows
Time: 11am to 1pm

Ulverstone Support Group

Meets the 4th Wednesday each month at the Ulverstone Surf Life Saving Club, Beach Road, Ulverstone (Lift access is available)

Time: 11am to 2pm

Circular Head Support Group

Meets the 1st Monday of each month at Circular Head Rural Health Services Inc 68 Emmett Street, Smithton

Time: 7.30pm

Contact Jenny on 6452 1594

Southern Support Groups

Enquiries: 6220 1111

Eastern Shore Support Group

Meets the 2nd Friday each month at Bellerive Yacht Club (entrance to function room off lower car park).

Time: 10 am to 12 noon

Glenorchy Support Group

Meets the last Friday bi-monthly at Glenorchy Community Health Centre, Meeting Room 3 – 1st Floor, Terry Street, Glenorchy.

Time: 10.30am – 12 noon

Note: Some days may change due to public holidays (please check your calendar).

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YouTube

www.youtube.com/MSSocietyAustralia