If you know someone living with MS who has a personal goal, dream or project that they would like to achieve and they just need a little bit more support to get started – now is the time to apply for an MS Go for Gold Scholarship.

There are 25 MS Go for Gold scholarships to be awarded valued up to $2,000 each, and recipients have the freedom to choose how to use the grant.

No project, dream, goal, business idea or hobby is too big or too small. People have applied for many different reasons; from needing equipment to help them clean their house so they can spend more time with their family, to funding a course to help kickstart their business idea, to purchasing craft supplies to start painting as a hobby.

The application process has been simplified and is an easy-to-follow online application form. You even have the choice to start your application, save it and complete it at a later time. Applications close 10 September 2020. Apply today at www.ms.org.au/go-for-gold-applications

Local writer’s Memoir relates her MS story plus many other twists and turns before finding peace on our Far South Coast

If you’re looking for a good read while we are protecting ourselves from the winter cold and cautiously self-isolating, you can’t go past the absorbing memoir recently published by Jennifer Severn entitled Long Road to Dry River. Jennifer was diagnosed with MS in 1997. However, her story is about much more than her MS Journey. There’s lots to love about this book. Jennifer reveals a real talent for lyrical prose, a degree of insight and candour that is almost disconcertingly courageous and a talent for relating a good yarn as she offers us a lively description of her unconventional adventures from the suburbs of Sydney to an ashram in India. It is a book about coming of age and achieving a certain degree of peace. She explores her difficult childhood and her attempts to understand and resolve her feelings about complex family relationships, her quest to find the place and people where she feels she belongs and of course her quest to come to terms with living with a chronic and progressive disease.

The book is laced throughout with humour and self-deprecation. Some of the humour stems from the fact that for decades Jen lived her life through two identities…there was the successful career-oriented, business-suited university graduate named Jennifer and there was her alter ego, Sahi, who sought answers to the human dilemma and the meaning of life through enthusiastically exploring alternative lifestyles. Many in our region will remember Sahi as an early member of the “Taking Control of MS Group” and co-collator with Mary Webb of the Taking Control Recipe Book. The account of her investigation of anything that was going to help her manage the challenges of MS including probiotics, disease modifying drugs, meditation and symptom management strategies is instantly relatable.

The author has been profoundly touched by the overwhelmingly positive response to her book. After six years of work bringing this memoir to fruition, she says the best part has been the feedback from readers. “Whether it’s MS, or family issues or making a ‘tree change’, everyone seems to find commonalities.” Quoting author William Nicholson, she endorses his observation that “We read to know we’re not alone.”

Jen fell in love with the village of Quaama on the far south coast in 1998. This became her base as she progressively renovated a derelict cottage and eventually built a new one. However, for many years she continued to travel widely. These days she is happily ensconced there with her husband and two dogs. She still consults in web design, as well as volunteering for the local newspaper and writing short stories. The manuscript of this, her first book, was shortlisted for the Finch Prize for Memoir in 2018. Long Road to Dry River is available from online booksellers, or a signed copy can be purchased directly from the author at jennifersevern.com.au.
New International Progressive MS Alliance Global Webcast recording available:

The MS International Federation hosted a global webcast on behalf of the International Progressive MS Alliance on June 25. The Webcast was entitled “Answering Today’s Big Questions in Progressive MS.”

A Panel of internationally renowned experts, Professor Alan Thompson, Professor Maria Pia Sormani and Dr Timothy Coetzee, addressed two questions:

- How do we accelerate the development of new treatments? and
- What do we know about Covid 19 and MS?

The webcast is still available on either You Tube or on the Facebook site (video tab) of the MS International Federation using following links below:

https://youtu.be/uBkPieqGlgA
https://www.facebook.com/MSInternationalFederation/live/

MS Research Australia is one of the founding members of the International Progressive MS Alliance which is a global research collaboration of 19 member countries seeking answers on Progressive MS. You can find out more about the Alliance at: www.progressivemsalliance.org

Be a part of the ACT MS Symposium 2020

A range of multiple sclerosis (MS) themed discussions are being planned for this years Symposium and will be delivered over a series of online seminars (proposed for October/November).

Organisers are looking for any MS topics relevant to you and/or your local MS community.

Forward suggestions on what you want to know more about: (i.e. latitudinal research, myelin repair or particular stages in MS (RR, SPMS, BMS, PPMS) – or even future therapies.

Don’t forget to nominate who you want to hear from: (i.e. researchers, medical specialists, inspiring speakers, community members, or health professionals).

Email your nominations by 7th August 2020 to: Professor Robyn M Lucas on robyn.lucas@anu.edu.au

Update on Research into MS at the Australian National University

The ANU Our Health in Our Hands (OHHOH) Group which is pioneering a major research collaboration between people affected by MS and a multidisciplinary team of scientists has released its first publications. The first is a Toolkit designed to guide collaboration and communication between scientists and PwMS. The link below will take you to the toolkit. The videos of conversations between many of our peers and the scientists on various themes form part of the Toolkit. To watch these, you click on the video links ( TIME, RISK, KNOWLEDGE, GOALS, CONSENT, WHAT WOULD YOU SAY TO MS RESEARCHERS? )


The OHHOH team has also had a very interesting and path breaking article accepted for publication. Several PwMS were involved in its research and preparation. The title of the article is “It Struck at the Heart of who I thought I was: A meta-synthesis of the qualitative literature examining the experiences of people with multiple sclerosis.”
Eli Haski who runs our Be Better Balanced and Wheels In Motion classes is running a course on Your Pelvis Your Health.

Workshop costs $65.00.

To attend please use the following link to workshop
https://clients.mindbodyonline.com/classic/ws?studioid=135076&stype=-8&sTG=29&sVT=15&sView=day&sLoc=0&sTrn=6&date=08/02/20

For further information email: Eli@livingsantosha.com.au

The MS Art Exhibition

The MS Art Exhibition has a long standing 14-year history with Multiple Sclerosis Limited (MSL). It was an integral part of our Social Support Day Program where our artists were able to display and sell their artworks for the public.

The Exhibition is usually held annually in August, coinciding with the birthday of Barry Allen. Barry Allen was a dedicated artist who bequeathed a sum of money for the Barry Allen Art Award. Art submissions are open to people with multiple sclerosis or other progressive neurological conditions in New South Wales, ACT, Tasmania and Victoria.

In 2020 due to COVID-19, unfortunately the art show will not be able to be held in the usual format due to Australian Government health restrictions on social distancing and the closure of Blackburn office.

To recognise the historical importance and value of the Art show to the MS community, MSL plans to host the Art Exhibition virtually in October, and we would like to invite families, carers and friends of people with MS with a focus on resilience through art and a celebration of creativity. Stay tuned for more information!

“Art talks, art connects, art heals!”
The education team at MSL continue to do all they can to meet the information needs of people with MS. They welcome any suggestions and recommendations, so please contact MS connect 1800 042 138 or msconnect@ms.org.au if you have a suggestion for an education topic. The team would love to hear from you.

**AUGUST WEBINARS** include advice and tips from the NDIS, and MS connect teams.

**Managing Fatigue**
Friday 7 August 10:30am - 11:30am

Fatigue management is an ongoing challenge for many people with MS, and we our webinar may help. The fatigue management webinar will be presented an MS Consultant Occupational Therapist, who will discuss the types of fatigue people with MS experience and explore fatigue management strategies, identify contributing factors and give advice on where you can access further information and support.

**Understanding the NDIS and Preparing for Your NDIS Plan**
Tue, Aug 11, 2020 2:00 PM - 3:00 PM

Do you need help in understanding the NDIS and the opportunities it offers? Are your current supports meeting your needs? Join Caitlin Ireland, MS Exercise Physiologist as she answers these questions and more. Caitlin will guide you through the process of developing your personalised goals ensuring you get the most from your NDIS plan.

**My Aged Care**
Wed, Aug 12, 2020 11:00 AM - 12:00 PM

If you, your loved one or someone you care about is over 65 (over 50 if Aboriginal or Torres Strait islander) and require formal supports, this presentation is for you! It aims to provide a clear starting point from which to understand the Australian Government’s support for older Australians.

Presented by Emily Austin, MS Connect Specialist. Emily worked in the aged care field for many years, assisting people to access services through My Aged Care to support them to maintain their independence both in the home and community.

**Brain Health**
Wed, Aug 19, 2020 12:00 PM - 1:00 PM

This webinar is presented by MS Executive Manager, Client Engagement and Wellbeing, Jodi Haarsten. Jodi has a background of MS nursing and has been involved with the MS Brain Health Initiative as a member of the global steering committee for 3 years. Jodi is passionate about the brain health initiative and what it means for the care of people living with multiple sclerosis. Jodi will provide a background on how the MS Brain Heath Initiative began, the aims of the project and what it means for people with MS now and in the future. We will also chat about some strategies to improve brain health for those living with multiple sclerosis.

**Learn about Multiple Sclerosis – For Family and Friends**
Wed, Aug 26, 2020 12:00 PM - 1:00 PM

We also understand that an MS diagnosis affects the person and very often the family and friends and it is important to them to have some understanding of what the disease is, and how best to provide support. While each person and circumstances are unique, the MS Nurse Advisors will shed some light on MS and some tips and advice on what may be helpful. This webinar gives you the opportunity to ask questions and be informed.

For more information on Webinars please email education@ms.org.au or call MS Connect (Freecall 1800 042 138).
**Meditation Group**

As we are all living in stressful times, some of us are stepping up our meditation practice and our online meditation sessions are proving popular. The Mindfulness Meditation Group is meeting weekly on Fridays at 3.30 pm by Zoom for about an hour to chat and then to do a guided meditation. (All suggestions welcome).

If you're not receiving alerts and an invitation for the online Meditation Group meetings at the moment and would like to be advised when sessions are being scheduled, please contact: vanessa.fanning@gmail.com or Richard Wilmott lisrich@gmail.com

**Taking Control Group, People with MS Group & Virtual Coffee Group**

In view of the pandemic, and our need for self-isolation, The Taking Control Group, the People with MS Support Group, & the Coffee Group have all teamed up to have a regular meeting by Zoom every Friday fortnight at 12.30 pm.

The meetings are informal and open to all people with MS and their families and partners. The Zoom meeting invitation is sent out to our normal mailing lists each fortnight but, as it is a recurring meeting, the link is the same.

The Zoom link is normally easy to use. If anyone would like to be added to the mailing list please contact vanessa.fanning@gmail.com or Mary Webb at denmar@netspeed.com.au. If you would like a practice run using Zoom please contact us. We are using a Professional version of Zoom which has higher security than the free online version. It's just a way to stay in touch with each other, to catch up on news and information and to offer each other support.

Sometimes we will also have invited speakers. See you online!

**2020 REGISTRATIONS ARE NOW OPEN!**

Embark on an epic adventure this August! The MS Readathon inspires kids to read as much as they can, all for an incredible cause. The rules are simple. Read whatever you like, as much as you can, in August. This year's MS Readathon will be a magical quest, and the adventure kicks off on 1 August and wraps up on 31 August. Children can register with their school (teachers, you can register your class) or individually.

Best of all, by joining our quest, not only will you awaken a love of reading, you will also be helping kids who have a parent with multiple sclerosis.

Register Now at [www.msreadathon.org.au](http://www.msreadathon.org.au)
Opportunity to engage with MS research in the ACT region

We are a team of researchers at the Australian National University (ANU) working to improve the health and wellbeing of people living in the ACT and nearby regions who have been diagnosed with multiple sclerosis (MS). We are seeking people aged 18 years or older in two groups: those who have been diagnosed with MS, and also people who have never been diagnosed with MS (perhaps family and/or friends of people with MS). The two groups of people will form the ACT MS Cohort Study.

The ACT MS Cohort Study will follow people over time to monitor changes in health and wellbeing. We are recruiting people with and without MS so that we can see what changes occur as a result of just getting older, and what changes are more closely linked to having MS.

What will I need to do if I take part in the study?
If you might be interested in taking part in the ACT MS Cohort Study, we will first provide you with more information about the study, answer any questions that you have, and ask you to sign a consent form. The study aims to collect information about you once every year. At the first interview, we will ask you questions about yourself (such as your age, where you were born, your education and work history, and so on), and your past health. At this interview, and the following annual visits, we will ask questions about your current health and lifestyle (e.g., diet), take measurements of your height, weight and blood pressure, and take a blood sample. If you are a person who has been diagnosed with MS, we will ask you to let us know if you experience a relapse.

Due to the COVID-19 pandemic, we cannot conduct a face-to-face interview. For now, we are hoping to build a list of people who might be interested in participating in the study. This is not a commitment to participate in the study – just letting us know that you might want to discuss taking part. Once the study is ready to start data collection – hopefully later in 2020 – we would contact you to discuss whether you are interested in taking part, would prefer your name to stay on the ‘maybe-in-the-future’ list, or have your name taken off the contact list.

If you would like to put your name down on our study contact list, please provide your contact details to: Contact: Dr Jo Lane on 02 6125 1485 or email: ACTMScohortstudy@anu.edu.au

MS Community Visitors Scheme

MS Community Visitors Scheme (CVS) was developed to meet the needs of Aged Care recipients who, for a variety of reasons, are isolated and whose quality of life may be improved by regular visiting. At this time, we also seek to coordinate virtual matches whereby visitors and recipients can connect via internet, phone or letter.

If you know of a family member or friend living in an Aged Care Home who might benefit from this service please contact us on 1800 042 138 or email CVSAdmin@ms.org.au

For more information and online referrals please visit our website www.ms.org.au and search CVS.
Peer Group support continues to be vital in these uncertain times. Adaptability and versatility by most of the Peer groups set up around Australia has meant that many people have been able to stay connected in some way. Some groups in places such as the Australian Capital Territory have enjoyed an opportunity to meet again, supported with guidelines from the Peer workers at MSL and adhering to their local and Australian guidelines.

In August, the MSL Peer group team will be hosting a new Telelink group. The focus will be on giving people with the MS the skills and information they need to empower them to live life making their own choices. A range of guest speakers are invited on the link to share information & support including expert MS Nurse, Dietician & Psychologist. Contact MS connect if you are interested 1800 042 138 or msconnect@ms.org.au.

Program:
- 10 people are connected through teleconference
- 1.5 hours per week
- 6 weeks

Topics include:
- Understanding multiple sclerosis
- Managing fatigue and other symptoms
- Diet and exercise
- Supporting emotions

In Memory of Amanda

“I choose MS because MS chose Amanda”. Amanda was diagnosed with MS back in 1990. Since then, Multiple Sclerosis Limited has been close to Peter’s heart.

He always admired her strength and willpower to minimise the effect MS had on her life. “She fought the illness and was determined not to let it define her or limit her life.”

Amanda passed on over a decade ago due to an unfortunate car accident. Life cannot always be predictable. Peter’s motivation was spurred to continue her legacy. Her determination inspired Peter to help others with MS. He wants them to also live their life with the assistance they need.

Peter was born in Nhill, Victoria. He grew up here on a farm until the age of 10 then his family moved to Frankston, Victoria. His parents worked hard to give him an education and all the things he needed growing up. He later went to University to pursue a career in finance and continued to work in this industry for 40 years.

Now retired, Peter volunteers at a regional hospital. He also enjoys spending his time with his wife, Margaret. They both currently live on a farm, which is home to many animals, some are pets, some are working animals. Yet, of all the animals he has owned past and present it is a horse named Astro he regards so highly. Astro once belonged to his late wife, Amanda.

Peter’s decision to leave a gift in his will to Multiple Sclerosis Limited is something that gives him peace of mind. Amanda’s memory can be continued. “I see it as a dedication to Amanda. There are so many fine causes which seek to improve the life of others. I choose MS because it chose Amanda.”

“My wife Margaret is most understanding of this wish.” For more information on how you can also leave a legacy please call Laura Henschke or Michael Knox on 1800 443 867 (1800 GIFTMS). You can also write to futureplanning@ms.org.au and check www.mymslegacy.org.au