

e-news November 2017



In this edition

Celebrating Carers... ALS Canada 2017 Virtual Research Forum... Coordinating practical help... Register now for Walk to d'Feet MND Sydney... Goulburn Toyota Gundaroo Music Festival wrapped up for another year... Hands on with new eye tracking/eye gaze features in the Microsoft Windows 10 Fall Creators Update... MND and olive oil research... and more

A Message from the CEO

Last week MND NSW held its AGM. We farewelled Phil Bower and Alex Green, both long term Board members, and they will be deeply missed. At the same time we are delighted to welcome Ann Tout and Elizabeth Rayment to the Board. Congratulations to Alex Green and Debra Larizza who were awarded Life Membership of the Association. You can read more about Phil, Alex, Ann, Elizabeth and Debra on pages 14-17.

You may have read something of the Productivity Commission's report on the rollout of the NDIS. Financially it is on track but a key concern is that the rollout has slowed and the full implementation may be pushed back. This has been made obvious by hurried telephone planning sessions and inadequate plans. MND Australia's submission and our lobbying and advocacy directly with the NDIA head office in Barwon have been highlighting these issues for the past year. Our advocacy efforts will continue into 2018.

Graham Opie



MND NSW provides information, support, education, services for people living with motor neurone disease, their families, friends and carers, health, community and residential care professionals in NSW, ACT, the Gold Coast and NT.



Binalong Brahmans RLFC Charity Day

The Binalong Brahmans Rugby League Football Club is a small sporting club in the village of Binalong. Throughout their 2017 season they have been raising funds at every home game and also held a charity day. A number of players and community members have been affected in some



way by MND. A very big thank you to the Club who raised \$4,000 for MND NSW. Thanks also to MND NSW Ambassador Nicole Papasidero who attended the Club's recent presentation dinner to accept the donation. Pictured are Alison Spencer (Club Secretary), Nicole Papasidero, Ben Spencer (Club President) and baby Ian.

3



Brenda Smith | Administrative Assistant NDIS I have recently joined the team at MND NSW as Administration Assistant focussing on NDIS tasks. The team here at MND have made me feel more than welcome and have impressed me with their professionalism, support and compassion. I come from a banking background so this is a

complete change of environment for me which is both scary and wonderful. I love that I am now working in an environment where I feel inspired by the amazing people I have contact with every day, my work colleagues, our members and our fabulous volunteers. I hope I can pave the way to a smoother experience for staff and NDIS eligible members.

Kristie Stamford | Coordinator of Support - South East Sydney and Inner West

It is an absolute privilege to join the inspiring team at MND NSW and contribute to their amazing work serving our members and their families. My passion is creating a world that is accessible to all and I look forward to bringing this and my experience from 15 years working in

community services to do the best I can for those I am supporting to navigate the NDIS. I'm also a big nerd especially for Wonder Woman, cooking shows, Harry Potter and pod casts.

Our MND NSW Shopping Bags have arrived!

Forget those nasty plastic bags. Look at our new lovely environmentally friendly shopping bags. <u>Get yours today</u>.











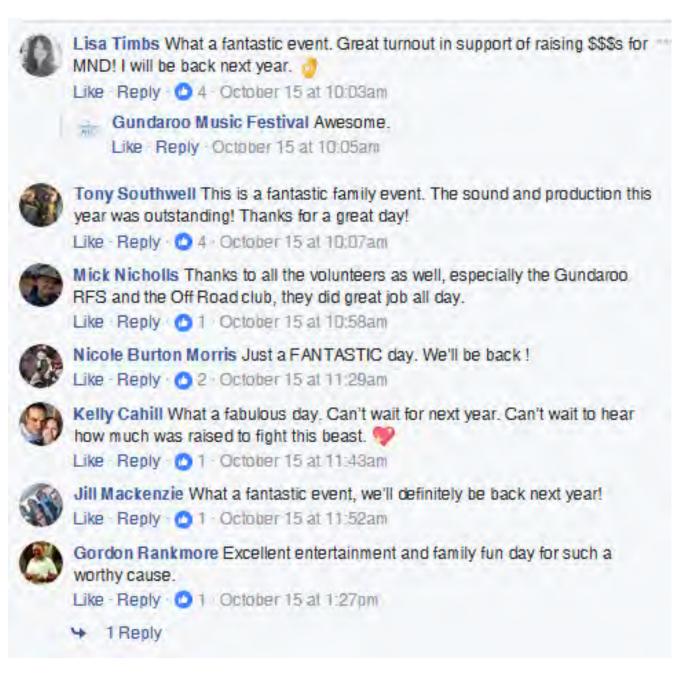
Goulburn Toyota Gundaroo Music Festival 2017

Thank you to everyone who supported this year's <u>Gundaroo Music Festival</u> held on 14 October. A very big thank you to Scott Harding and his amazing team who work so hard to bring this great day together to raise funds for people living with motor neurone disease.



(Photo courtesy of Justin's Photo Works)

The fans say it all on Facebook.



MND NSW in the communications age

In the past year we have worked hard to support our members in achieving key communications needs. We have helped them with the communications challenges presented by daily life.

We have reorganised and augmented our team to facilitate the individualised pre-planning and third-

party communications necessary to help members aged under 65 years make the most of their NDIS plans. We have continued to work on communicating our cause to the public. Read more about our work in the <u>MND NSW Annual Review 2017</u>.

Have you recently been diagnosed with MND and would like more information about it?

Our Information Evening is designed specifically for people recently diagnosed with MND, and their family and friends to attend. This two hour session provides an overview of the impact of MND and answers some common questions.

Our next session is on Tuesday 5 December at the MND NSW Centre Gladesville. There is no charge to attend but you do need to register. <u>See here for more</u>.

MND Connect - 11 November at the University of Sydney

Do you want to know what's new in MND research, current clinical trials and effective treatments for MND?

Reserve your place at MND Connect, an interactive forum connecting people impacted by

MND, with Australia's leading MND researchers. People with a disability and their carers may reserve a disabled parking spot at the venue, or receive a wheelchair taxi voucher or subsidised travel from a regional area to attend this event. Find out more about MND Connect 2017 <u>here</u>.













Walk to d'Feet MND

The name of this event reflects the hope and inspiration these special days provide for the MND Community. Teams made up of family, friends, colleagues and individuals, regardless of age or fitness levels, walk to raise funds and awareness for research and support for people living with MND.

You can create your own online fundraising page to raise funds in an individual name or a team name. A huge thank you to Sun Sense who have come on board as a sponsor for all of our Walks. Make sure you drop by the merchandise table to get some sunblock on at the next Walk.





15 October, Apex Park

Another great morning in Wagga Wagga for our Walk to d'Feet MND held on Sunday 15 October. Thanks Wagga for your great support. Thank you also to our wonderful local coordinators Pat O'Hara and Denise Hart who



were generously assisted by many local volunteers.

A big thank you to everyone who attended and to our sponsors. Your support is greatly appreciated.





oil enriched diet and active swallowing

MND, olive oil and swallowing exercises

Professor Vicki Flood from the University of

Sydney is currently recruiting people living

with MND to take part in a pilot study running

from Westmead Hospital in Sydney. The study

exercises on swallowing ability, speech, and weight status of people with MND. Participants must be able to travel to Westmead Hospital and able to attend a treatment program up to 3 times per week over a 4 week period. Parking will be provided. For more information contact Professor Vicki Flood vicki.flood@sydney.edu.au. This project has been approved by the WSLHD Human Research Ethics Team Number: 5038.

You are invited

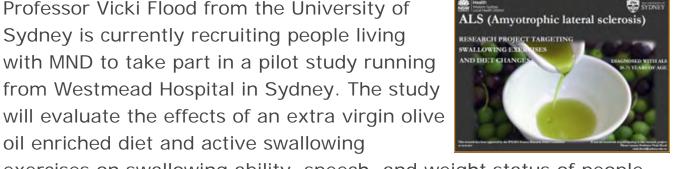
Come along to an afternoon Christmas Party at Ryde on Saturday 25 November to celebrate the beginning of the festive season with MND NSW. It would be terrific to see you, your family and friends there! Santa shall be taking a quick break from the North Pole to visit with gifts for the children. Adults will have a chance to win a lucky

door prize or to win one of the great raffle prizes. RSVP by 22 November. For more information and to reserve your place, click here.

Pudding time

Thanks to the amazing team at Pudding Lane, we are able to again offer our supporters the opportunity to purchase a Pudding Lane pudding at the very special price of \$34.95 with 100% of money raised from these sales supporting people living with MND. Stocks are limited at this price, so be quick and treat yourself to the best Christmas pudding around.















"The day clarified quite a few matters and it was a chance to talk to others in the same boat"

We had a great turn out for the *Living Well with* MND day held in Wollongong on 17 October. Over 50 people attended and the Wollongong Golf Club was the perfect location with sea and golf club views, but everyone managed to stay inside and listen to the local health care



professionals who presented on the day about MND, even with the picture perfect weather.

A big thanks to Dr Geoffrey Murray, Divisional Director Rehabilitation Medicine, Illawarra and Shoalhaven who presented twice, and to Dr Zivai Nangati, Staff Specialist, Palliative Care, Port Kembla Hospital who dispelled some myths about palliative care. Also presenting were Jessie Nicholls, Dietitian, Heather O'Brien, Occupational Therapist and Anna Fulford, Physiotherapist, all from Port Kembla Hospital. And a special thanks to Alexis McMahon, the head of Speech Pathology at Sutherland Hospital who spoke on swallowing, saliva management and communication. Ana Petrovic, the new MND Advisor for the area, and Sam Potter, the new MND Coordinator of Support for Illawarra, also attended and spoke to many of the participants.

One participant summed it up nicely - "The day clarified quite a few matters and it was a chance to talk to others in the same boat".

Thank you Carlingford Rotary

The wonderful crew from Carlingford Rotary will be attending our Sydney Walk to d'Feet MND again this year. Carlingford Rotary have been at every Sydney Walk. We greatly appreciate the support they have given us and the hundreds of sausages cooked each year. <u>Register today for</u>



the 2017 Sydney Walk to d'Feet MND to be held on 5 November

MND Awareness Trivia Night

A very big thank you to Casey Mitchell who organised an MND Awareness Trivia Night in Cooma. Casey said of the night, "I am very happy to announce that thanks to all the generosity of our local communities last night was a success we had a decent turnout of

near 50 people and all up raised \$1,723." Thank you Casey for your hard work towards this event and for your support of MND NSW.

New Sydney Walk to d'Feet MND T-shirts

Our new Navy Sydney Walk T-shirts look great. Register today to join us for our 10th Anniversary Walk to d'Feet MND on Sunday, 5 November 2017 at Homebush. But get in quick - you need to be registered online by 29 October to order your T-shirt.

Don't miss out...

Have a look at our new Christmas puppy. They are very cute. We only have a limited supply, so be quick. Visit our online shop to order.

Have your say - Transport Disability Incentives NSW **Government Review**

Do you use the NSW Government Taxi Transport Subsidy Scheme or need/use wheelchair accessible travel, either in your own vehicle, another vehicle or by a transport service provider? Would you like to use your subsidy with another provider (not a taxi?).

Do you use the centralised booking service for wheelchair accessible taxis in Sydney? Transport NSW is undertaking a review and you can have your say by providing a written submission by 30 November 2017. Read the discussion paper and find out more here.



and Subsidies Review

Discussion Paper









New App for coordinating practical help Palliative Care Australia has developed a mobile app, AllowMe!, to assist people to create a community of care around a person at the end of life. AllowMe! supports

communities to care for people with a serious illness by making it easier to help in practical ways.

Carers and care recipients can list tasks, events and visiting times to provide suggestions of how people can assist. Palliative Care Australia has developed this app with the support of nib foundation. Available in the <u>App Store</u> or get it on <u>Google Play</u> or <u>more info here</u>.

Bong Bong Picnic Races

We are so excited to announce MND NSW has been chosen as the charity for this years Bong Bong Picnic Races on 24 November 2017. A huge thank you to the committee for your support.

Finalist NSW Volunteer of the Year 2017

Congratulations to Patti Conway one of our valuable Hunter region volunteers. Patti was recognised as a Finalist - NSW Volunteer of the Year 2017 at an award ceremony on Tuesday 12 September.

This year there were a record number of nominations for the Volunteer of the Year Awards, with almost 110,000 volunteers recognised across the state in all categories.

Thank you for all you do for MND NSW Patti.

We know you don't do it for the recognition- but we appreciate your time speaking out and raising awareness and funds for MND NSW.











ALS Canada 2017 Virtual Research Forum presentations free online

Selected presentations from the ALS Canada 2017 Virtual Research Forum held in August 2017 are now available for on-demand viewing below. The purpose of the forum was to share information about ALS/MND research with people living with the disease.



- Biomarkers for C9ORF72-associated ALS
 presented by Dr. Tania Gendron, Mayo Clinic
- <u>Cannabinoid use in ALS</u> presented by Dr. Mark Ware, McGill University
- <u>Cognition in ALS</u> it's not what you think presented by Dr.
 Michael Strong, Western University
- <u>Getting to know pimozide in ALS</u> presented by Dr. Lawrence Korngut, University of Calgary
- <u>Lazarus by Lunasin? Untangling an ALS X-file</u> presented by Dr.
 Richard Bedlack, Duke University
- Masitinib for the treatment of ALS presented by AB Science
- <u>Protein misfolding in ALS</u> presented by Dr. Neil Cashman, Vancouver Coastal Health ALS Clinic; University of British Columbia
- <u>Skin models for the study of ALS</u> presented by Bastien Paré, Laval University
- <u>The role of ataxin-2 in ALS</u> presented by Lindsay Becker, Stanford University
- <u>Understanding the role of the neuromuscular junction in ALS</u> presented by Elsa Tremblay, Université de Montréal

Or read more here: <u>https://www.als.ca/research/webinars-and-</u> education/



Upcoming Support Service events

Click to find out more.

2 Nov A residential educational workshop held over two days and one night for carers
11 Nov MND Connect 2017 Community, researchers and clinicians in an interactive forum to discuss MND research University of Sydney
25 Members' Christmas Party Nov West Ryde
5 Dec Information Evening for people recently diagnosed With MND Gladesville

MND support groups and coffee mornings provide the opportunity for people living with motor neurone disease to meet together regularly to chat and learn from each other. <u>Find out more, including locations and dates, here</u>.

Celebrating Carers

In October MND NSW celebrated National Carers Week by holding three special events for carers. At Gladesville former and current MND carers made the most of the opportunity to forge some new connections and to reconnect with old friends over morning tea (see cover picture). In Newcastle, the MND Support Group celebrated carers week by including a



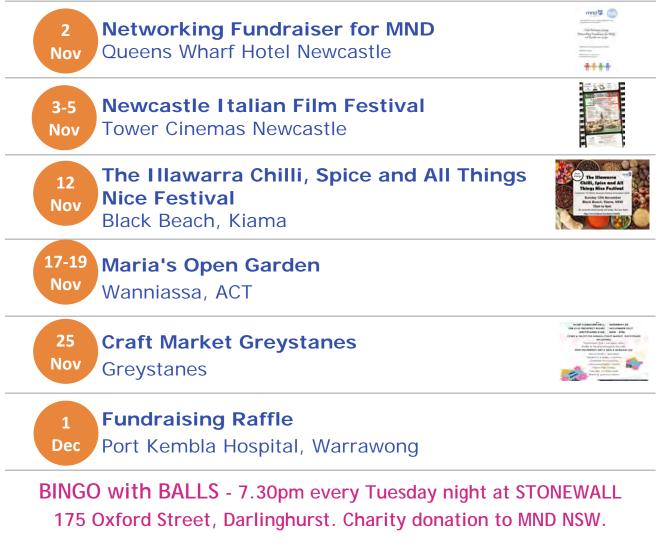
special morning tea in honour of the amazing carers who were present. In Ballina our MND carers enjoyed an abundant high tea. Many thanks to Carers NSW for providing grants towards the cost of these Carer's Week celebrations!



Thank you to Innovate Architects and Shirley Cripps

Congratulations and thank you to Shirley Cripps who won the Innovate Architects annual 'Top 4' NRL Tipping Competition. Shirley was able to nominate a charity close to her heart to receive the \$1,000 winner's prize. MND NSW was nominated by Shirley, and she was presented with the winners cheque by Cameron Jones of Innovate Architects.

Upcoming community fundraising events Click to find out more.



Do you have a great idea for an event or activity that will raise funds for motor neurone disease care, support and research? <u>See here for how you can get started</u>.

Architect



Our retiring Board members...

Farewell to Alex Green - Life Member

My first engagement with MND NSW was through a small fundraising consultancy around 2002. I clearly remember meeting the board at that time who all relayed their personal commitment to the organisation. I was impressed by what I saw.



Fast forward two years and my mum was diagnosed with

MND. Given that previous work, unlike most people who heard her diagnosis, I knew immediately what was in store. My parents lived in the UK and from the other side of the world I was disappointed to see how little tangible help she got. The NHS doctors seemed fairly clueless (at least initially via several misdiagnoses) and the local association was very limited in what it offered. So not only did my dad have to support her through her illness, they had to carry the full financial burden of equipment and navigate the messy bureaucracy and health service.

As I engaged with MND NSW, initially by giving a few dollars, then later talking with Graham Opie, I was impressed by the quality and breadth of support offered by the Association and with a strong organisational reliance on fundraising, I felt I could add value by offering to join the board. A vacancy came up, I was elected and it's now been over ten years. It has been great to see the continued outstanding quality of service provided as measured by stakeholder feedback. We have near 100% coverage meaning almost anyone who could benefit from our help, does. That's impressive. The Association's ability to operate at a high level is thanks to an expert team and strong governance function. I tip my hat to the dedication and professionalism of the staff - well led by Graham, Gina and Kym- thank donors for their selflessness and generosity, and thank Lara, Phil and my board colleagues for their commitment and expertise. It's been a pleasure to serve such an excellent organisation.

(Continued on page 15)



(Continued from page 14) Farewell to Phil Bower - Life member

Phil Bower has represented members of MND NSW for more than 20 years.

When his wife contracted MND he used all his knowledge as a scientist and his organisation skills from his business as well as his extensive work with International Lions to see if he could find a way of

assisting his wife- and others with MND. In the early days Phil travelled NSW voluntarily delivering equipment from the small MND equipment pool to people in regional areas.

Phil joined the Board in 1995 and has represented MND NSW on the MND Australia Board. Phil was President of MND NSW from 2007 to 2015. During this time Phil has seen the Association grow from a small three person office to an organisation that has nearly 98% of people with MND in NSW and the ACT as MND NSW members.

Phil has travelled huge distances from his home in northern NSW to attend our meetings and his wry sense of humour and intelligent and personal insights to the plight of people with MND have always helped us keep on track and on message.

Our new Board members...

Welcome to Ann Tout

I am so pleased to have been appointed to the Board of MND NSW. My connection to MND and MND NSW began with the diagnosis of my husband Paul with ALS in 2002. So in addition to Paul's endurance of this terrible disease, we experienced the struggles associated with keeping Paul living at home, navigating the health system and getting assistance to optimise his health and well-being.

I started volunteering with MND NSW last year and so far have met a

(Continued on page 16)





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lot of people with connections to MND, including those living with MND and many wonderful, dedicated staff and volunteers. I've been hearing about their experiences and the impressive advances and improvements that are being made in research and support services.

I plan to continue this contact and based on my personal experience with MND and what I've learned through over 20 years in senior management roles, will do the best I can to contribute on the Board to improvements for those living with MND.

Stop Press: We will include Elizabeth Rayment's introduction in the next edition

And congratulations to Life Member Debra Larizza

In 2003, after her uncle had been diagnosed with MND and while volunteering at Concord Hospital Debra walked into the MND NSW office and asked if we needed volunteers. The answer was a resounding yes. Debra commenced as a volunteer with the Association the following week.

A few months later Debra described her role as 'Girl Friday'. She said at the time, "given that technology challenges me, it has been interesting coming to terms with computers, photocopiers, fax machines and a telephone with more than one line. I suppose things are going well because I haven't

been sacked yet which is great because I really enjoy what I do and look forward to my day at the office."

Over the past 14 years Debra has not only mastered all things tech, she has also become an integral part of our team at the MND NSW Centre at Gladesville. Debra has provided key assistance at many fundraising events including the 2005 Cornflower Blue Ball, the 2006 Hugo's Bar Cocktail Party and Art Auction and the 2013 Cromer Golf

(Continued on page 17)





Debra, with

husband Robert

Larizza





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Club Ladies Charity Day to name just a few. Debra has very short hair now, having shaved her hair in 2016, raising funds for MND NSW.

The voluntary administrative assistance Debra provides to the Association is invaluable. Debra usually attends the Gladesville Centre three days a week. She often manages the registration table at MND NSW education events for people living with MND and at our events for service providers, including the Special Interest Group Workshop, conferences and trainings. She provides a warm welcome to people attending our Information Evenings at Gladesville and the Member's Christmas Party. Debra also coordinates the packaging of the quarterly news print edition and manages the submissions for the MND NSW March of Faces Banners. Debra has also provided much needed assistance to other projects such as the development of the MND Aware online training in 2012 and is currently involved in the work we are undertaking with business and design students on augmentative and alternative communication.

There would not be many members and supporters of MND NSW who have not had contact with Debra Larizza during her involvement with the Association. We thank Debra for her huge contribution to the lives of people with MND and their families.

Get your Christmas Cards today Stocks limited so don't miss out



Christmas cards - Three

Kings 10 pack

\$10.00



Christmas cards -

\$10.00

Pattern Trees 10 pack





Christmas cards - Dog

and Tree 10 pack

\$10.00





Christmas cards -Aussie Tree 10 pack \$10.00



Christmas cards - Three Wise Men 10 pack \$10.00

\$10.00

www.online.mndnsw.asn.au

Christmas cards -

Presents 10 pack



Hands on with new eye tracking /eye gaze features in the Microsoft Windows 10 Fall Creators Update 1709

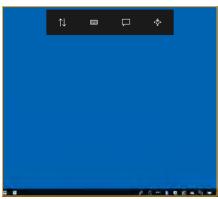
At MND NSW we have been giving the new eye tracking /eye gaze features in the Microsoft <u>Windows 10 Fall Creators Update 1709</u> (rolling out October 2017 onwards) a bit of a road test. The short story is that the Eye Control feature in this standard Windows update, when used together with an eye tracking camera (we bought ours for AU\$200 - see below), allows you to use your eyes on your Windows computer instead of a keyboard, mouse or touchpad.

The new Windows Eye Control feature is a huge leap forward in mainstreaming accessibility options in everyday Windows 10 laptop/ computers. It's not perfect - <u>even Microsoft describes it as beta</u> - but even this version has enough going for it to make us want to tell you about our road test. In no time we were using Eye Control on a laptop to browse the internet, get on Facebook, send an email, install other software, watch YouTube, Netflix, ABC iView or whatever took our fancy.

Usability-wise, we had a couple of issues. The Eye Control toolbar got a little in the way of the videos we watched because it only has two positions on the screen (top or bottom) and cannot be docked or minimised. Also, scrolling up and down a page involved several new eye movements every scroll - up to the toolbar, down to the scroll, select the scroll, then read the screen, then up to the toolbar etc.

Although Windows Eye Control also has a very basic no frills text-to-

speech generator (which we think could become a much more useful tool with a bit more development) it is the very low cost mouse replacement accessibility component of Eye Control that is the standout for day-to-day computer operation. We did, however, very briefly try out another speech generating app



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with Eye Control on the device and we were able to use Eye Control to navigate that app with no problems.

For people with MND there are, of course, other considerations and problems to solve including head and neck support while using Eye Control and mounting for the laptop so it is in a comfortable viewing position for the user. If you try Eye Control and like it, you can get advice from your occupational therapist about positioning and mount options. We found the Eye Control worked just as well in a light room as a dark room but we didn't use our laptop with Eye Control outside. It worked okay when we used it wearing glasses.

How we got started

Step 1 - Make sure your Windows 10 laptop/computer can run Windows 10 Fall Creators Update 1709

We first tried installing this update on a six-year old Acer Aspire S3-951 notebook but could not get the Eye Control feature to work. We were a bit hopeful about it working but not really surprised when it didn't because this notebook had previous unrelated Windows 10 driver compatibility issues and not even Acer lists it as compatible with Windows 10. Tobii tech support worked very hard to help us get Eye Control going on this notebook but, in the end, we gave up.

Our next attempt was on a HP Spectre x360 notebook. We didn't select this model or brand particularly, it was just one that we had available to use. This model is a Windows 10 compatible notebook and it is also listed by Microsoft as one of the many laptop and computers compatible with the Fall Creators Update 1709. There is a list you can check here to see if your computer is compatible with the Fall Creator Update 1709.

Step 2 - Get the Windows 10 Fall Creators Update 1709 Our Windows 10 Fall Creators Update 1709 install on the Windows 10 compatible notebook was trouble-free. The 1709 update only started

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rolling out on 17 October 2017 through Windows Update and it rolls out to newer laptops and computers first. You can wait for it to be

offered to your laptop or computer or there are <u>tips from Microsoft for people</u> <u>who don't want to wait for the update</u> to roll out to them.

Windows specifications

Edition	Windows 10 Home
Version	1709
OS Build	16299.19

To check your Windows version go to

Start > Settings > System > About > and scroll down to Windows specifications.

Step 3 - Get an eye tracking camera

Although in the future Microsoft expects more suppliers of compatible infrared eye tracking cameras, the only cameras currently listed as compatible with Windows Eye Control are the <u>Tobii Eye Tracker 4C</u> and the <u>Tobii EyeX</u>. We tried Eye Control with the Tobii Eye Tracker 4C infrared camera and you can watch an <u>unboxing of the Tobii Eye Tracker 4C infracker 4C here</u>.

tobii

We couldn't locate a supplier in Australia and shopped around a

bit for price and ended up buying ours <u>online from Amazon</u> at US\$149 + \$US7.23 standard shipping and it was delivered 12 days later. It included a one metre USB extension cable that we haven't needed to use. There are other suppliers and you can also <u>purchase directly from</u> <u>Tobii</u> but shipping was more expensive, so we went for the Amazon option.

Step 4 - Install the camera

The Tobii Eye Tracker 4C comes with magnetic mounting strips that we heard can be difficult to remove once attached to a device so we just used blue tac to position it at the bottom of our screen for testing purposes. For general use though, the magnetic strips would definitely assist with ease of positioning and use.

(Continued from page 20)

To install the Eye Tracker camera, plug it into to a USB port and let

Windows do it's thing. Then go to the <u>Tobii website and download the latest</u> <u>Tobii Eye Tracking Core Software</u> - we used v2.10. Install this and once the software is installed follow the Tobii

software prompts to calibrate the device for the user. The calibration sets the range of the screen for the user's eyes. You can have multiple users and you can also can go back and recalibrate if needed.

Once you have finished this you get a demo from Tobii where you can use your eyes to navigate in space. Hit escape to exit this. To get going on Windows Eye Control you need to enable Eye Control in your Windows settings and to do this go to Start > Settings > Ease of Access > Other options > and toggle on Eye Control (beta). This feature only appears there when the eye tracking camera is connected. The regular mouse and touchpad on the laptop we were using still worked, even after we turned Eye Control on.

Once your camera is installed and connected, and with Eye Control

enabled in your Windows settings you should expect to see the Eye Control toolbar on your screen. Microsoft refer to this as the launchpad.

Step 5 - Using Windows Eye Control The Microsoft <u>Get started with eye control in</u> <u>Windows 10</u> information and help page covers using the launchpad and how to change the settings. Browse away.

We hope this brief overview of our experience helps you if you are thinking about trying out Eye Control on a Windows 10 laptop or computer you might already have at home. As development in this area continues there are sure to be improvements and updates in both the Windows Eye Control feature and in the availability of infrared eye tracking cameras.



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Office Coordinator Petra Sammut

Admin and Receptionist Arja Aladjadjian

Accountant David Radford

...and many valued volunteers