

ASSOCIATION NSW

CLUB NEWS

Autumn 2023

FROM MICHELLE'S DESK

Hi all.

Welcome to the Autumn edition of Club News 2023. It does seem that Winter has arrived early, and I trust you are all keeping warm in this blast of cold weather.

As usual, we are extra busy preparing for NSW Stroke Awareness Week 2023 and information about all the events we have coming up is in the newsletter for you to prepare.

The big event for the week is something that members have constantly requested over the years, an Art exhibition at Royal Prince Alfred Hospital from 4th - 10th of September. I hope you will all get behind the idea and send us your wonderful artwork for display.

Unfortunately, we are three years in and COVID-19 is still with us and looks like it is here to stay. We have included an article on how to access anti-viral medication should you test positive. Remember, the sooner you have access to the medication the less time you will have symptoms and side effects, both short and long-term.

The other article I would like to draw your attention to is regarding short-term respite now being offered by Royal Rehab. This is a 'top-up' rehabilitation for long-time Stroke survivors. The program gives you the opportunity to use your respite package (be that as part of MyAged Care or NDIS) to stay in a rehabilitation facility and access physiotherapy, speech retraining, exercise physiology and occupational therapy while your carer has a well-earned rest.

This is a trial project, and I would very much appreciate any of you who may use the service to give me a ring and tell me what you think and how it could be improved. Royal Rehab is a long-time partner of the Association, and I am keen to offer them support and feedback on this new initiative.

We are getting more and more requests for members to be involved in research and have two more opportunities available to you advertised on page 7. Please keep an eye on our social media pages as Rachel is always uploading the information to these sites as soon as the Board approves our involvement.

There have also been some staff changes here at the Association. We farewelled Carolyn who was with us for two years and has gone on to bigger and better things. We welcome Alex Wells to join our small team in the office. Alex is a lovely and vibrant young woman who will no doubt be a great asset to the Association and the work we do.

Lani and Maria continue to get out and about to meet you all and, as a result of their funding, we are getting to know more and more about the support offered through our Clubs/groups/choirs. Keep up your great support of each other. Stay safe and warm.

Warm regards,

Michelle



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Stroke Recovery Association NSW



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Eligibility for oral COVID-19 treatments

Antiviral treatments taken as capsules or tablets may help stop COVID-19 infection from becoming severe. Courses of these antiviral treatments need to be started as soon as possible after symptoms from COVID-19 begin.

People at higher risk of severe illness are eligible for antiviral treatments. It is encouraged that you have an early discussion with your GP or nurse practitioner about whether an oral antiviral suit your health needs and to develop a COVID-19 plan if you test positive to COVID-19.

Senior Australians and First Nations people

If you test positive for COVID-19, you may be eligible for antiviral treatments if you are:

- 70 years of age or older, regardless of risk factors and with or without symptoms.
- 60-69 years of age or older with 1 additional risk factor for developing severe disease.
- 50 years of age or older with 2 additional risk factors for developing severe disease or have had past COVID-19 infection resulting in hospitalisation.
- First Nations people, 30 years of age or older and with 1 additional risk factor for developing severe disease or have had past COVID-19 infection resulting in hospitalisation.

Risk factors include:

- living in residential aged care
- living with disability with multiple conditions and/or frailty (but not limited to living in supported accommodation)
- neurological conditions like stroke or dementia and demyelinating conditions e.g. multiple sclerosis, Guillain-Barre Syndrome
- chronic respiratory conditions including COPD, moderate or severe asthma
- obesity or diabetes (type I or II requiring medication)
- heart failure, coronary artery disease, cardiomyopathies
- · kidney failure or cirrhosis
- living remotely with reduced access to higher level healthcare
- past COVID-19 infection episode resulting in hospitalisation.

People aged 18 years or older

If you test positive for COVID-19 and are moderately to severely immunocompromised, you may be eligible for antiviral treatments.

Conditions include:

- blood cancer or some red blood cell disorders (thalassemia, sickle cell disease)
- transplant recipient
- primary or acquired (HIV) immunodeficiency
- chemotherapy or whole-body radiotherapy in the last 3 months
- high dose corticosteroids or pulse corticosteroid therapy in the last 3 months
- immunosuppressive treatments in the last 3 months
- anti-CD20 monoclonal antibody treatment in the last 12 months/li>
- · cerebral palsy or Down Syndrome
- · congenital heart disease
- living with disability with multiple conditions and/or frailty.

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Eligibility for oral COVID-19 treatments

How to get COVID-19 oral treatments

- If you test positive, you should contact your doctor for advice about eligibility first.
- If your doctor recommends oral antiviral treatments, you will need a prescription.
- The medications are available at your local pharmacy with a prescription.
- Your doctor can send the pharmacist your prescription electronically so the medications can be either collected by a friend or family member or delivered to your home.
- Find your <u>nearest pharmacy</u> with the oral treatments.

Finding an available GP appointment

To aid timely access to these treatments by vulnerable individuals, Medicare telehealth services are now available with any GP for patients with a confirmed COVID-19 diagnosis in the past 7 days. A long telehealth (phone) consultation by a GP for prescribing COVID-19

antiviral treatments is also available until 31 December 2023 If you can't get an appointment quickly to talk about treatments:

- you can call the healthdirect helpline on 1800 022 222
- use the Service Finder to search for one near you.

Who should not have antiviral COVID-19 treatments?

- If you are pregnant or breastfeeding you should not have oral COVID-19 treatments. Instead, ensure you are up to date with your COVID-19 vaccinations.
- If you have severe kidney or liver disease you should not have Paxlovid® COVID-19 treatment. Talk to your healthcare provider about alternative oral treatments.



This article was sourced from the Australian Government Department of Health and Aged Care (https://www.health.gov.au/health-alerts/covid-19/treatments/eligibility)

Australia Post - Parcel Notification changes

Australia Post is making changes to parcel delivery notifications. Starting 26 June, handwritten 'sorry we missed you' cards will be replaced by digital notifications. **Currently, this change only applies to people with a MyPost account with Australia Post.**



Here's what you need to know:

- If a delivery attempt fails, you'll receive notifications via email, the Australia Post app, or SMS.
- You can customise your notification preferences by registering with MyPost and providing your mobile number and email address.
- Cards will be left if the parcel can't be matched to a MyPost account.

For more details, visit Australia Post's website or contact customer support at 13 13 18.

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Short-term accommodation or respite

Are you looking for short-term accommodation or respite?

Royal Rehab Private Petersham are now offering short-term accommodation and respite services, whether funded through the NDIS or self-funded.



- As we are located within a hospital, you have peace of mind knowing that you will receive safe, high-quality care and supports.
- As we only accept a small number of guests at any one time, you will experience a more personalised and attentive service.
- We take pride in offering comfortable rooms and delicious food, so you feel at home.
- You have access to a variety of on-site allied health services including physiotherapy, occupational therapy, hydrotherapy (heated pool), and speech therapy, provided by expert professionals.



For more information, please call 1800 329 104 or email STA.RRPP@royalrehab.com.au

NSW Stroke Awareness Week Art showcase



We are seeking expressions of interest for any artists in our Stroke community who are interested in showcasing their artwork at Royal Prince Alfred Hospital, Sydney for NSW Stroke Awareness Week (4th - 10th September 2023).

These artworks will be showcased for the entirety of NSW Stroke Awareness Week at RPAH, and people will be able to vote on the 'audience's choice' artwork during the week. Great prizes and bragging rights are up for grabs, so don't miss this opportunity to showcase the creativity of our Stroke community.

To enter your artwork, please email admin@strokensw.org.au for additional details.

Conditions of entry:

- You must be able to transport your artwork to the Association's head office (PO Box 3401, Putney NSW 2112) before Tuesday 1st August 2023. If your artwork is too large to transport (such as a sculpture or large painting), you can take a photo of it which the Association can print off and frame for the showcase.
- A blurb of no more than 200 words must be submitted about your artwork and you as an artist.
- Entries are open to Stroke survivors, carers and Stroke Recovery Club/groups/choirs.
 Please note that individual paid carers or health professionals are **not** eligible to enter their artwork, however, are able to enter as part of an entire Stroke Recovery Club/group/choir submission.

Research Opportunities

High Intensity Interval Training POst-STroke (HIIT-POST): Stroke survivors' views - Australian Catholic University

What is the aim of the study?

 To better understand the barriers and facilitators to participation in exercise after Stroke, in particular, high intensity interval training.



Who can take part in the project?

- Diagnosis of single or multiple ischaemic or haemorrhagic Stroke
- Aged over 18 years
- Understand written or verbal english to complete the questionnaires

What will I be asked to do?

- Screening you will be asked questions about your social and medical history.
- Questionnaire complete a series of questions about your exercise habits before and after your Stroke and what you think may be affecting these habits. This should take ~10 minutes.
- Semi-structured interview via Zoom or in person interview with a member of the research team about your opinions on HITT exercise and how Stroke has influenced your exercise habits. The interview should take ~30 minutes.

For more information, or to get involved, scan the QR code above, go to https://redcap.acu.edu.au/surveys/?s=TCAXD4KTYMATNRAM or contact Sarah Ashcroft on (02) 9071 4739

Developmentally-attuned language treatment - University of Sydney

What is the aim of the study?

 To design more specific effective treatment for speaking after Stroke.



You may be eligible to participate in this study if you:

- Have difficulty speaking in sentences because of Broca's aphasia/Stroke.
- Are between 18 and 80 years of age.
- Were a fluent English speaker before experiencing aphasia.

What does the study involve?

The entire study will take 18 weeks. They will do treatment for 10 weeks:

- Weeks 1 2: Assessment 3 to 5 times for 45 minutes
- Weeks 3 7: Treatment 45 minutes, 2 times a week for 5 weeks
- Weeks 8 9: Break
- Weeks 10 14: Treatment 45 minutes, 2 times a week for 5 weeks
- Weeks 15 17: Break
- Week 18: Assessment 45 minutes.

For more information, or to get involved, contact the research team at 0431 416 936 or kirrie.ballard@sydney.edu.au.

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Staffing update



Welcoming Alex Wells

Hi everyone,

My name is Alex Wells and I am the new Information & Administration Officer at the Stroke Recovery Association NSW.

I am a 36-year-old mother of two adorable children, Beau (5) and Ashlan (4).

I feel very privileged to be working with the Association and hope my time here sees through some amazing connections with beautiful people. My aim in this role is to be a helpful, understanding and approachable person who can assist with any questions you may have.

My previous role was with Strathfield Golf Club as both Membership and Administration as well as assisting with events.

I would say the most valued part of any job I have held has been the dealings with customer's face to face and creating good relationships where people feel safe, heard and understood. I look forward to meeting you all throughout my time here.

Farewelling Carolyn Armstrong

After 2 years working at the Stroke Recovery Association NSW, staff farewelled Administration Officer, Carolyn Armstrong in early April. Her dedication, hard work, attention to detail, and sense of humor have been invaluable to both our team and our members.

We wish her all the best as she moves on to a new position at the Land and Housing Corporation in the NSW Department of Planning and Environment. Staff celebrated her new job in style and did an escape room together, followed by a farewell lunch.



Membership fee increase - 2023/2024

At the Stroke Recovery Association's 2022 Annual General Meeting, members were given the opportunity to vote on a change of the price of memberships. The Board of the Association still believe that our memberships should be kept affordable and accessible to everyone who has experienced a Stroke, their carers and families.



As a result of this change, memberships for the 2023/2024 year (to be renewed in August 2023) will have a price increase as follows:

Single Club membership = \$22.00 Family Club membership = \$27.00

If you have any questions about this change, please contact the Association on 1300 650 594 or admin@strokensw.org.au

Around the Clubs

North Coast Building Capacity Workshop

Executive members from our Northern Clubs/groups/choirs joined together for the inaugural North Coast Building Capacity Training Workshop. The event was held at the Quest, Newcastle West on Wednesday 17th May 2023, and livestreamed to other executive members online who did not join in person.

The day commenced with a presentation on legislation, compliance and financial reporting at Stroke Recovery Clubs. This was then followed by an interactive discussion about ways to make your Club/group/choir more inclusive.

Following lunch, delegates talked about the importance of embracing change and then grant writing, accountability and opportunities for funding.

Thank you to eveyone who attended the event, either in person, or online. We hope that the workshop was valuable and provided you with some ideas to take back to your local Stroke Recovery Club/group/choir.



Launch of Kempsey/Dunghutti Stroke support group

On Wednesday 24th May 2023, staff travelled to Kempsey (Dunghutti country) to launch the new Kempsey/Dunghutti Stroke support group! The launch was a wonderful way to meet Stroke survivors, families and health professionals in the local area, hear their stories and make plans for the future of the group.

The event opened with a Welcome to Country and traditional smoking ceremony by Uncle Graham, followed by presentations from guest speakers: Michelle Sharkey (CEO, Stroke Recovery Association NSW), Amy Thompson (Stroke survivor, Registered Nurse and co-founder of the Kempsey/Dunghutti group) and Victor Zander (Stroke survivor and co-founder Kempsey/Dunghutti group).

Thank you to everyone who came to the launch, and we are excited to see the Kempsey/Dunghutti Stroke support group continue to grow!





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Around the Clubs

New England Stroke Recovery Club

In honour of St Patricks Day, the New England Stroke Recovery Club held an art session that was enjoyed by all members. This was a wonderful opportunity for all members to come together and celebrate their creativity. Led by Sue, members were able to learn new tips and tricks in leprechaun drawing and colour techniques. It was a



joyous occasion filled with fun, laughter, and plenty of green! Overall, the art session was a great success, and we look forward to more event like this in the future.

Bega Stroke Recovery Club



We love this photo of Kimone, Judi, Faye and Fred from the Bega Stroke Recovery Club. Members recently enjoyed an outing to the stunning Panboola Wetlands, where they enjoyed a delicious lunch and a lovely walk around the wetlands in the sunshine!

The Bega Club meet on the 1st Wednesday of every month from 12pm – 2pm and they would love to welcome new members. Call 1300 650 594 for more information.

Port Macquarie Stroke Recovery Club

In recognition of the ongoing support from the Port Macquarie Hastings Library of the Port Macquarie Stroke Recovery Club, members donated two books about Stroke to the local library.

- 'Beyond Stroke: Living Independently with One Arm' - by Kate Ryan
- 'Finding Yourself After Stroke' a compilation by Letisha Living

The library has been generously supporting the promotion of NSW Stroke Awareness Week over the past couple of years and assisting in the promotion of Stroke awareness in the local community.



Around the Clubs

Hornsby/Ku-ring-gai Stroke Recovery Club

The Hornsby/Ku-ring-gai Stroke Recovery Club have been busy working on their Art Project over the last few months! The Club have put together a timeline of the project to share with you.

- 3rd February 2023 Club members met to approve the colours of the tree - it's colours will reflect the Blue Eucalyptus Gum Tree. Members were also give the opportunity to choose their favourite bird/animal from a list to add to the tree.
- 17th February 2023 Three tables were set up with coloured and watercolour pencils, paint brushes and jars of water. Members were given drawings of their chosen bird/animal and set to work! The blue, grey and violet shades of blue were added to the branches and trunk of the tree sketch.
- 24th February 2023 Full steam ahead on the third session of the art project! Most of the individual member birds/animals were complete, and now the scissors were brought out to carefully cut around each image.
- 3rd March 2023 The cut-out images found their place on the gum tree, representing each individual member of the Club! Everyone was delighted with each of their artworks, and the group got a chuckle out of two cuddling koalas on a branch.
- 8th March 2023 Leafy eucalyptus foliage was painted on the tree branches to fill in the gum tree's open spaces.
- 24th March 2023 In the last stages of the project now! Members decided that adding extra animals and birds will make the tree look overcrowded and too busy, so the group compromised and added three butterflies and a diamond python! The title "Our Stroke Club Family Tree" and the name of the Club were printed on the canvas. Once the final fixative is added and a frame is chosen, the project will be complete!

Members of the Club have taken great pride in their work during this project. A great accomplishment that is already attracting richly deserved praise! Congratulations to the Hornsby/Ku-ringgai Stroke Recovery Club members on a wonderful artwork!



















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In Memoriam

Harbans Bhuller - Hornsbyl Ku-ring-gai Stroke Club

Harbans was a well respected member of the Hornsby Ku-Ring-Gai Stroke Recovery Club, whose immaculate personal presentation led to being dubbed the 'beautiful lady'.

The suffering she endured through pancreatic cancer has now ended and this talented Club member will be remembered for all her achievements at both Club and Association activities.

The accompanied photo is of Harbans wearing her first prize hat at the club Easter hat competition, one of many wins at Club level. Harbans was also a multimedal winner at the Sydney games each year.



Our condolences are extended to her family and our heartfelt sympathy and gratitude are extended to her devoted husband Harbajan, also a Stroke survivor, who was her sole carer after her Stroke.

Valmai Higgs - Woy Woy Stroke Recovery Club



It is with great sadness that the Woy Woy Stroke Recovery Club reports the passing of one of their members, Valmai (Val) Higgs. Val was born on 24th June 1936 and passed away on 30th April 2023 at 86 years of age.

Val was a much loved member and wife to ex-president Noel Higgs. She will be sadly missed by Noel, family and friends.

Noel and Val joined the Woy Woy Stroke Recovery Club in June 2005 after Noel had his Stroke and Val was his carer.

Val loved her family, music and line dancing and kept it up until the end. She is now boot scooting to Van Morrison's "Brown Eyed Girl".

The Woy Woy Stroke Recovery Club will miss Val dearly and sends their condolences to Noel and family during this time.

"Line Dancing in the Clouds"

In Memoriam

Coralie Fisk - Westlakes Stroke Recovery Club

It is with deep sadness that we were informed of the passing of our dear friend and the coordinator of the Westlakes Stroke Recovery Club, Mrs Coralie Fisk.

Coralie passed away after a very long illness which she faced in her usual manner, with grace and courage. Coralie was able to attend her last Stroke Club meeting earlier in the year where she was warmly welcomed by her long-time friends at the Club.

Coralie was also a very important member of the Hunter Stroke Olympics Committee where she assisted in the organisation of the games over the past 10 to 15 years.



One of Coralie's proudest moments was when she was recognised as the 2011 Volunteer of the Year for her work at the Westlakes Club.

Coralie enjoyed many community interests including the Men's Shed and the local car club at Cessnock.

Coralie will be missed greatly by all who knew her, but particularly her friends at Westlakes and those of us who worked with her at the Association over many years. Our deepest sympathies are with Coralie's loved ones and the Westlakes Stroke Recovery Club.

Hidden Disabilities Sunflower

Do you know about the Hidden Disabilities Sunflower?

As a Stroke survivor, you may face challenges that others can't see such as aphasia, cognitive impairments, fatigue, and sensory changes. This is where the Hidden Disabilities Sunflower comes in. It's a simple symbol, like a lanyard, badge, or wristband. By wearing the Sunflower, you can discreetly let others know that you may need some extra support or understanding without having to explain it all the time.

You can wear the sunflower symbol when shopping, in workplaces, on public transport, in public spaces, or wherever you may want people to know that you could need assistance or patience.



The Hidden Disabilities Sunflower is a powerful tool that makes the invisible visible and fosters understanding and support from those around you. You can purchase hidden disability sunflower merchandise at: https://hiddendisabilitiesshop.com.au/shop/sunflower-wearer.html

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Upcoming Events 2023



Sydney Stroke Olympics *Thursday 15th June 2023*

Club Burwood (Burwood, Sydney)



South Coast Olympics Tuesday 18th July 2023

Kiama Leagues Club (Kiama)



Combined Clubs Morning Tea
Saturday 5th August 2023

Mingara Recreation Club (Tumbi Umbi, Central Coast)



NSW Stroke Awareness Week

Monday 4th - Sunday 10th September 2023



Art Showcase - NSW Stroke Awareness Week Monday 4th - Sunday 10th September 2023

Royal Prince Alfred Hospital, (Camperdown, Sydney)



Reps to Recovery Stroke Challenge Monday 4th - Sunday 10th September 2023

<u>Online</u>



Creating Connections Stroke Conference Wednesday 6th September 2023

Online & Club Burwood RSL (Burwood, Sydney)



Hunter Stroke Olympics *Tuesday 10th October 2023*

Raymond Terrace Bowling Club (Raymond Terrace)



South Coast Building Capacity Workshop *Thursday 19th October 2023*

Online & Quest Nowra (Nowra)



Annual General Meeting Friday 3rd November 2023

Online & Sydney location (TBC)



Combined Clubs Picnic Friday 10th November 2023

Sydney location (TBC)



Clubs Trivia Challenge Tuesday 21st November 2023

Online



STROKE RECOVERY ASSOCIATION NSW



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Contributions

We welcome contributions to Club News, especially in our "Around the Clubs" section of the newsletter

Submissions should be sent to admin@strokensw.org.au.

Contributions may be edited, either to reduce size, to assist with readability, or for legal/liability reasons. To include something in our next Club News, please send it into our office before **31 July 2023**.

Memorial gifts & bequests

A bequest is a gift in your will. If you would like to consider how you can include the Stroke Recovery Association NSW as a beneficiary in your will, please contact the office at admin@strokensw.org.au or on 1300 65 594.

We can also supply 'In Memoriam' donation brochures with pre-paid addressed envelopes for use at memorial services.

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