

TALKING POINT

MUSCULAR DYSTROPHY NSW
YOUR NEUROMUSCULAR SUPPORT COMMUNITY

MUSCULAR DYSTROPHY NSW NEWSLETTER FEBRUARY 2022



GROWING UP WITH MD:

Kobe shares his story

I think we can all agree that 2021 wasn't a great year. COVID-19 really limited our movements, brought periods of isolation, and fears for the future. But that's a lot like every other year for someone like me with muscular dystrophy. Still, I have a lot to be grateful for.

My name is Kobe, I'm 20 years old and live in a small rural area called Jaspers Brush, 2 hours south of Sydney. I don't know anyone who lives close by with muscular dystrophy, so when I joined Muscular Dystrophy NSW's (MDNSW) Summer Camp in 2013 it opened up my world. Initially, it was daunting to leave my family, but camp quickly became one of the only places where everything felt normal.

At camp I noticed most kids didn't even talk about living with MD because it was something we all shared, so we didn't need to explain ourselves. This was a time I could just have fun, and the incredible memories and best friends kept me going back every year.

Since aging out of Summer Camp I've looked forward to seeing my mates at the annual MDNSW Young Adults Weekend. We didn't get to meet up in 2020, so I was grateful to catch up in the Hunter Valley in March. It felt great to travel, learn some independent living skills and eat some cheese from the Smelly Cheese Shop, which wasn't even that smelly! The best part was being surrounded by my friends, mates who just get

each other. When we're together it's like our situation doesn't matter; we play games and just be ourselves.

Throughout the pandemic it's been difficult to stay connected. Which made me grateful that MDNSW created an online group called the Power Hour for all of us guys in power wheelchairs to catch up virtually every fortnight. It's a chance for people in the same boat to hang out, just the guys, and have some light-hearted fun...including a few bad jokes! It's also a place where we feel safe to share our feelings. Having MDNSW adapt their programs online was especially important to me as I live in a rural area and worry about missing out. Power Hour also motivated my mates to show up, and we even had a friend living in Europe dial in! During the toughest lockdowns we asked to increase our fortnightly sessions to weekly, and it became the time I look forward to the most.

My family and I benefit enormously from the programs offered by MDNSW, and I know many others do too.

Hopefully 2022 will be better for many of us as the restrictions lift, but one thing I know for certain will stay the same is the strong community and support from MDNSW.

All the best, *Kobe*

Pictured: Kobe out by the water



Our President Anthony Ball and CEO Charlotte Sangster

WELCOME FROM THE CEO & PRESIDENT

Welcome to your quarterly edition of Talking Point, and the first edition for 2022! As we start a new year, our President, Anthony Ball and I would like to reflect on the year that was and share with you our end of year message from the MDNSW 2020/21 Yearbook, which we revealed at our AGM in November.

Despite the continued disruption due to the COVID-19 pandemic, MDNSW remains positive about the future of the organisation and our plans for delivering on our mission to empower, connect and support the neuromuscular community.

This year we have continued to witness the incredible resilience of our community as they support one another through yet another very challenging time.

The health and safety of our members remains our top priority and while ongoing COVID-19 restrictions sadly resulted in the cancellation of many of our popular children's camps and face to face Peer Connect groups, we were able to harness technology and expand our reach across NSW. We did this through the online delivery of our Peer Connect groups and by expanding the number of online support groups available, thanks to funding via the Department of Social Services and the generosity of our donors. For this we are extremely grateful as these groups continue to be a core network of support for many in our community.

The online groups have continued to grow in popularity over the last 12 months with 58% of participants joining us from regional NSW! You can learn more about our Peer Connect programs in the Highlights section of the Yearbook.

Earlier in 2021, we were fortunate enough to be able to run Adventure Camp on the Northern Beaches of Sydney, as well as the Young Adults Skill Development Weekend in Lake Macquarie in March. Both programs were a huge success, with great attendance and really positive feedback from the participants. We look forward to running them again in 2022!

The MDNSW Board of Directors have continued to drive the organisation forward, maintaining focus and providing a flexible environment for staff as they too navigate the complexities of the pandemic. Sadly, this year we farewelled Director, Associate Professor Kristi Jones and Director Shannon Finch. We wish to thank them both for their many years of service to the community and outstanding contribution to MDNSW.

In June 2021, we welcomed two new Directors, Tait Jenkins and Associate Professor Michelle Farrar, who bring a breadth of knowledge and experience to the organisation. Tait will serve on the Finance Governance & Risk Committee and Michelle on the Research & Client Services Committee.

Throughout the last year the MDNSW team have continued to work diligently to deliver our Strategic Plan with an IT transformation project and CRM upgrade also in progress to support the continued expansion and improvement of our services.

Lockdowns across Sydney have been disruptive but have provided an opportunity to focus our energies on improving our internal systems and work on the development of new COVID-Safe NDIS services that our community indicated they want through our 2020 consultation process.

In late 2020, the team were able to successfully pilot our new Community Access & Recreation Service (CARS), which we hope to have fully operational in early 2022 due to delays caused by COVID-19 lockdowns in Greater Sydney. We are excited to showcase all of our other achievements this year throughout this report and we express our sincere thanks to our wonderful community and supporters for helping us to navigate these difficult and complex circumstances.

As always, take care and we look forward to engaging with you again this year.

ANTHONY BALL, President, MDNSW

CHARLOTTE SANGSTER (she/her), CEO, MDNSW

SUMMER CAMP CANCELLED DUE TO COVID-19

We have been working very hard to prepare a safe and fun Summer Camp for participants in January 2022. During this process, the Client Services team have been monitoring the COVID-19 situation in Greater Sydney closely.

Sadly, we received advice from the infectious disease unit at the Sydney Children's Hospital Network that it would be safest to not hold Summer Camp. Upon receiving this advice, we made the extremely difficult decision to cancel Summer Camp, which was scheduled for January 2022.

We understand how disappointing this is for everyone, but the safety of our community and camp participants remains our top priority and we feel that this is the best decision given the circumstances and health advice. We value your patience and understanding during this uncertain and very challenging time and we appreciate your support and trust.

We will continue to monitor the evolving situation with hope to reschedule the camp to a later date.

PEER CONNECT CALENDAR

January - March 2022

	MON	TUES	WED	THURS	FRI	SAT	SUN
JANUARY		11 JAN 6-7pm Power Hour Online - an online group for young men who are powerchair users	12 JAN 5-6pm Girl Power Online - an online group for girls aged 10-16				
		18 JAN 6-7pm Power Hour Online		20 JAN 7.30-9pm Mums Wine & Chat Online			
	24-27 JAN Summer Camp @ Narrabeen						
FEBRUARY		1 FEB 6-7pm Power Hour Online				5 FEB 12-3pm Peers in Action Dooleys Social Lunch	
		8 FEB 6-7pm Power Hour Online	9 FEB 5-6pm Girl Power Online		11-14 FEB Young Adults Weekend @ Swansea		
	11-14 FEB Young Adults Weekend @ Swansea	15 FEB 6-7pm Power Hour Online	16 FEB 10.30am MD Love, Life & Loss Morning Tea @ Lidcombe	17 FEB 7.30-9pm Mums Wine & Chat Online			
		22 FEB 6-7pm Power Hour Online	23 FEB 5-6pm Girl Power Online	24 FEB 11am-1pm Info Share Online Making the most of your NDIS Plan			
		1 MAR 6-7pm Power Hour Online			4 MAR 12-3pm A Celebration of Women in our Community High Tea		
MARCH		8 MAR 6-7pm Power Hour Online	9 MAR 5-6pm Girl Power Online				
		7.30-9pm SMARTies Online					
	15 MAR 6-7pm Power Hour Online			17 MAR 7.30-9pm Mums Wine & Chat Online			20 MAR Big Red Roll + Stroll @ Parra Park
	22 MAR 6-7pm Power Hour Online	23 MAR 5-6pm Girl Power Online		24 MAR 11am-1pm Info Share Online Let's Get Sporty!	25-27 MAR Mums Retreat For Sydney Metro Mums @ Wiseman's Ferry		
	29 MAR 6-7pm Power Hour Online				1 APR 11am-1pm Accessible Phone Photography		

For more info or to register contact:

- Jenny on 0431 690 629 or jenny.smith@mdnsw.org.au for Family Fun, Girl Power & Mums Chat
- Mitch on 0417 062 212 or mitch.taylor@mdnsw.org.au for Summer Camp & Power Hour
- Carolyn on 0408 472 510 or carolyn.cm@mdnsw.org.au for all other events

mdnsw.org.au

Please note that event dates may change - visit MDNSW website or contact Carolyn for the latest updates

NEUROMUSCULAR Information & Research Day

RECORDINGS & PRESENTATIONS
NOW AVAILABLE

Did you miss the MDNSW Neuromuscular Information & Research Day? Or perhaps you want to download a specific speakers presentation? We have the full recordings from the event, along with speaker presentations, now available for you to download.

Thank you also to everyone who completed our NIRD survey. Your feedback and comments were really supportive and we're delighted to see that you enjoyed the event, with 100% of respondents saying they would come to the NIRD again!

Watch the NIRD recordings on the NIRD page on our website located under the Medical Info tab –

www.mdnsw.org.au/medical-info

**MUSCULAR
DYSTROPHY NSW**
YOUR NEUROMUSCULAR SUPPORT COMMUNITY

ADVENTURE CAMP 2022

SAVE THE DATE!

Our much-anticipated Adventure Camp, for 6 to 18 year old's living with a neuromuscular condition will be held from 21 - 25 April at the Collaroy Centre in the Northern Beaches.

Registration launching soon, so stay tuned!



Thur 21 - Mon 25 April 2022

Contact Mitch at mitch.taylor@mdnsw.org.au or on 8986 9004, or Jenny at jenny.smith@mdnsw.org.au or on 0431 690 629

mdnsw.org.au

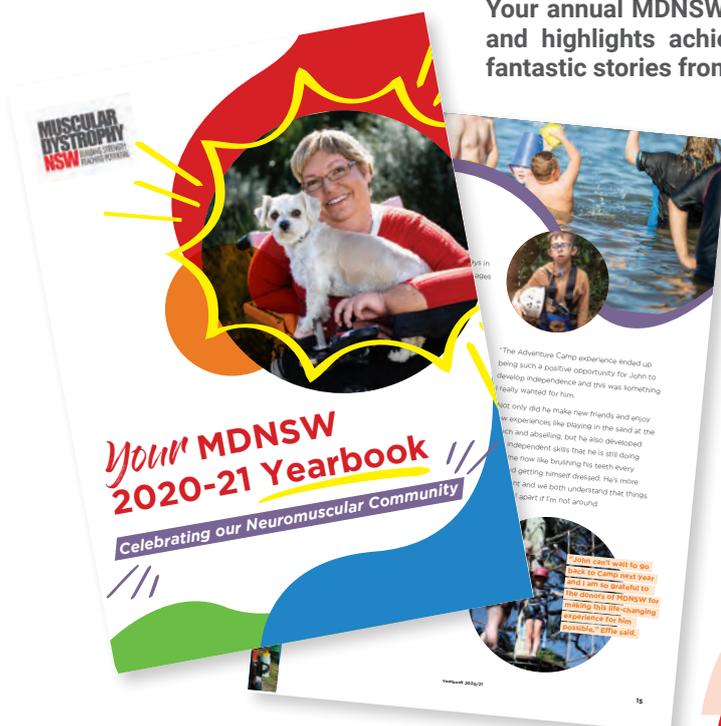
Your MDNSW Yearbook is out now!

Your annual MDNSW Yearbook is here, providing a complete summary of the impact and highlights achieved throughout the 2020-21 financial year, along with some fantastic stories from our MD community.

Members got a first look at the Yearbook at the MDNSW Annual General Meeting, which was held on the 23 November.

The Yearbook features:

- Stories from your MD community
- New impact stats
- Important highlights from our programs and events
- Lots of photos from throughout the year
- Acknowledgment to out volunteers, partners, staff and board
- Tributes remembering those we've lost
- And more!



You can download your copy of the Yearbook from our website at www.mdnsw.org.au/news-media

Fun for the whole family at our virtual **COMMUNITY DAY!**



Snapshots from the virtual Community Day fun

Our first ever virtual Community Day was held on Saturday, 20 November and saw MDNSW families gather online to have fun, play games, be wowed by a magician, get presents from Santa and more!

We hope everyone enjoyed the fun day and would like to thank all of the families who attended and got involved in our virtual activities. Hopefully next year, we can have just as much fun (if not more!) at a face to face Community Day.

COMMUNITY NEWS

Say hello to the

NEW MEMBERS OF THE MDNSW TEAM

Alex Marshall, NDIS Service Development Manager



“ Hi, I'm Alex. I have been working in the disability sector for the last 14 years and within the NDIS since the initial rollout. I have had a variety of roles over this time and love seeing programs and organisations evolve and grow into what the community needs. My role will look at opportunities for MDNSW to offer NDIS based activities and programs in the future.

Travelling the world is my absolute favourite thing to do. I have travelled to many corners of the world and I am always planning the next trip. I also love to bake, get arty/crafty, and enjoy a good DIY project most weekends. ”

Laura Howard, Client Services Coordinator



“ Hi, I'm Laura. I believe in providing people with disabilities equal access to opportunities across all aspects of life. Outside of MDNSW, I work with individuals as a disability support worker. I'm also heavily involved as a member and volunteer with Girl Guides Australia where I run programs for girls and young women that focus on empowerment and service to their communities.

In my role at MDNSW, I'll be working with the team on planning Camps & Weekends and Peer Connect programs. You'll see me at some of the online peer connect meetings and I'll be working behind the scenes to help deliver the fantastic programs that MDNSW is known for. I look forward to getting to know more of you in the next few months. ”

Roisin O'Hagan, NDIS Support Coordinator



Roisin decided to leave her career in law behind her and combine the skills she has acquired both professionally and personally to join the Client Services Team as an NDIS Support Coordinator in late 2021. Roisin brings with her many years lived experience of having a child with a neuromuscular condition and the challenges and opportunities that brings.

She has been actively involved with Muscular Dystrophy NSW for some time through fundraising and other activities.

She is passionate about supporting others with neuromuscular conditions and very much looks forward to the opportunity to meet and support members of our community and help them achieve their goals.

Joyce Moretti, Community Fundraising Coordinator



“ Hi, I'm Joyce. I am very excited to be part of the MDNSW community, learning and connecting with wonderful people! My role involves coordination of community fundraising activities and events; building and maintaining relationships with supporters, volunteers, internal and external stakeholders, and people living with neuromuscular conditions; assisting to motivate and facilitate supporters to fundraise; and help raise awareness about neuromuscular conditions generally. I believe together we can make a huge difference!

Outside of work, I love outdoor activities, nature, travelling, learning new cultures, and spending time with my family and friends. I look forward to getting to know more about you and the organisation in the next few months. ”

INTERNATIONAL MEN'S DAY CELEBRATED

Asif with his sons Faisal and Hamza



International Men's Day was held on the 19th November and celebrates positive male role models and the love and strength that men bring to their families and their community. We thought we'd tell you a bit about a male role model from our MD community, Asif.

Living in Mount Druitt, and originally from Pakistan, Asif is father to two sons Faisal and Hamza who both have Duchenne Muscular Dystrophy. Asif describes his sons as always happy and smiling, with Faisal who's 12, being very outgoing and chatty with a large circle of friends. And Hamza, who's 16 and the quieter of the two, a very clever and articulate boy growing up quickly into a young man.

The two have a lot in common. Both enjoy math's as their favourite subject at school, they're willing to always try new things just like the other kids, and they're very loyal to each other (especially when one is in trouble, the other will stick up for him).

They are a testament to their father, Asif, who is their primary carer and works hard to give them a fulfilled life, one where he hopes they grow old and one day get married.

When we asked Asif what he'd say to other male role models and father figures who care for children living with disability, he said:

“ Love is the most important thing you can give them and always be there, because they need you. ” ♥

On that touching note, thank you to Asif and all the male role models in our MD community for the love and strength you bring.

Acknowledging leaders in our MD community

for International Day of People with Disability (IDPwD)

IDPwD, held on the 3 December, encourages everyone to work together to remove barriers for the 4.4 million Australians living with disability so that everyone can participate and feel included in their community.

Last year's theme was 'Leadership and Participation of persons with disabilities toward an inclusive, accessible and sustainable post-COVID19 world.'

We'd like to highlight four of our members who demonstrated their leadership within our MD community by sharing their experience on the Lived Experience Panel at our recent Neuromuscular Information & Research Day.

LISA BROWN



Lisa spoke about her experience purchasing an accessible vehicle and how assistive technology has opened up her world and given her new freedoms. This comes with accepting her condition as it progresses and how she creates and nurtures the right team of support workers.

JAMES DUNSTAN



James spoke about transitioning to being a fulltime wheelchair user after recently receiving his first power wheelchair, and how this has facilitated his passion for getting out into the community, catching-up with friends and doing the things that he hasn't done for many years.

ABRAHIM DAROUICHE



Abraham shared about his employment experiences after graduating with both a Bachelors and Masters in Business and Commerce. He has recently become an ambassador for Ability Links NSW and uses this role in promoting inclusion for people with disabilities and from the CALD community.

JACK WASON



Jack spoke about transitioning from living in a small country town to living on campus at university and studying Computer Science. He spoke about his great gang of friends and awesome team of support workers who help him live independently.

COVID 'Freedom Day'

IS A TERRIFYING PROSPECT FOR SOME PEOPLE, *I am one of them*

Article from ABC Western Plains
By MDNSW member, Kate Thomas

I recently received a text from a friend asking: "Are you excited for freedom?" A beat skipped before I replied – I struggled to find the words to say.

To be honest, I am terrified.

For some, the reopening roadmap is exciting – it means picnics, open dance floors, a return to a sense of normality. But for others it can muster a sense of fear and countless lingering questions, like "How will COVID-19 affect me?"

Everyone has felt the weight of this pandemic. We've been estranged from friends and family, lost work, worked from home, have played parent and teacher, our healthcare system has been pushed to the limits – the list goes on.

I understand why we need to reopen. I'm just as excited as the next person to leave my house, to book a table at my favourite restaurant or even have that first awkward in-person interaction (how to act around other people again?).

That first taste of freedom will be sweet. But right now, I'm worried about what "living with COVID-19" actually means.

At 18 months old I was diagnosed with spinal muscular atrophy type 2, a condition where your skeletal and

Kate Thomas, MDNSW member



respiratory muscles weaken over time. According to the literature, I have an "increased risk of manifesting severe symptoms of COVID-19." I've been put into ICU over a seasonal flu.

I am by no means the only one with this fear. A friend of mine is receiving chemotherapy for the next 12 weeks. They said they had "mixed feelings about coming out of lockdown". She said that her "immune system is shot" due to her cancer treatment and multiple sclerosis. That means she "can't afford to catch any bugs".

I am one of the many people in our country who make up priority groups but are left out of the conversation. In some ways, I'm just as excited as the next person to reopen and have a sense of normality again.

We have all been doing what we can to survive lockdown, holding tightly onto those dreams we all have. But, for some of us, it might be longer before we can experience them.

New Australian Disability Strategy welcomed

Australia's peak disability representative organisations have lent their support to the new Australia's Disability Strategy 2021 – 2031, which was released earlier this month by the Australian Government to coincide with the International Day Of People With Disability.

The new strategy is Australia's national disability policy framework and sets out a plan for governments and stakeholders across Australia to improve the lives of people with disability in Australia over the next ten years.

For the first time, the strategy's implementation and monitoring will be overseen by a government-appointed

council comprising people with disability from the community and disability sector. The strategy – which has been endorsed at the highest level by the Australian Government, state and territory governments and the Australian Local Government Association – was developed in consultation with community members and stakeholders across the disability sector over the last two years, including a range of disability representative organisations, including Muscular Dystrophy NSW.

We welcome the new strategy and the new features it contains to drive action and change over the coming decade. All organisations look forward to



working with community members, governments, industries and other stakeholders to maximise its value and impact.

Extracted from a media release published by People with Disability Australia

Ask a SCIENTIST



Question from Justin

“ I was just reading about stem cell research and wondered if there is any trials with any types of muscular dystrophy yet? ”

Answer from Michaela Yuen, PhD – Postdoctoral Research Fellow at Kids Neuroscience Centre

“ Stem cells and their use for the treatment of muscular dystrophies are a rather complex topic. There are a several different approaches to using stem cells as a treatment for DMD. Some strategies aim at fixing the underlying problem (e.g. stem cells help regenerate the muscle and restore dystrophin expression) while others appear to provide symptomatic relief (probably via anti-inflammatory action) similar to steroid treatments. Also, some treatments use cells from the body of the patient (autologous stem cell therapy), while others use cells from a healthy donor (heterologous stem cell therapy). ”

Submit your question to Ask A Scientist at info@mdnsw.org.au or mail it to us at MDNSW, Studdy MS Centre, 80 Betty Cuthbert Dr, Lidcombe NSW 2141

Looking For A Fun New Sport This Summer?

GIVE BOCCIA A GO!

*Pictured:
Daniel Michel competing
for Australia in Boccia*



As you may be well aware, the Australian Boccia team did us proud at the Tokyo Paralympics, with MDNSW member, Daniel Michel, winning Australia's first ever individual medal in the event, taking home a well deserved Bronze medal. Well now it's your chance to give this fantastic sport a go!

Boccia NSW and Boccia Australia are calling all members of the neuromuscular community to get involved, with Sydney-based clubs in Penrith, the Northern Beaches and Cronulla-Sutherland. Their Mission is to provide people with severe disabilities, who have significant physical impairments, a once in a lifetime opportunity to experience the joys of sport, socialise with others, and quite simply have some fun.

You can play both competitively or socially with weekly training sessions and upcoming come try days to be confirmed. The Clubs are looking for players of all ages, who meet the eligibility criteria of Boccia.

Want to give it a go? You might even get to meet Paralympian bronze medalist Dan Michel, who often plays at his local club in the Cronulla-Sutherland Shire!

Please send your Expressions of Interest in an email to:
Sasha Ulasowski, Pathways General Manager
at pathways@boccia.com.au or call on 0439 788 352

Once they have your interest you will be then directed to the club that is most accessible to you, and the club will be in contact and details will follow about dates and venues of their next events.

Contact and Feedback

We value your feedback!

If you have any feedback on what we are doing well or how we can do things better, please contact us.

Feedback, including complaints is an essential part of our improvement process.

You can provide your feedback through the following channels:

by post Muscular Dystrophy Association of NSW; 80 Betty Cuthbert Drive, Lidcombe NSW 2141

email info@mdnsw.org.au

phone 02 9888 5711 or

free call 1800 635 109

website mdnsw.org.au/contact-feedback

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BUILDING STRENGTH REACHING POTENTIAL