

## 2021 ANNUAL REVIEW

This year, we are marking 40 years since we first started as an organisation so it's a very special time for all of us here at MND NSW.

It's a time for us to pause and take stock of just how far we've come, and stop to reflect on all the amazing work that our staff and volunteers do. None of which would be possible without the generosity of our supporters. To mark our 40th Anniversary, we are sharing the stories of some of the people involved with MND NSW over the years. You can read about them in this report, and find more of their stories here:

<https://mndnsw.asn.au/history>

We've come such a long way in our 40 years, but there is still so much more that needs to be done. That's why we continue to focus on the future and the work that will have the greatest impact.

One of the things we are working towards is increasing our equipment pool to provide more comprehensive and diverse equipment options to people living with MND, regardless of the stage of their disease. We are also increasing our efficiency and finding better ways to deliver our services. We pride ourselves on partnering with other organisations to increase the impact we can make while avoiding duplication of services.

We've always advocated really hard, at both the state and federal level, for better services for not only people with motor neurone disease, but for those with rapidly progressive neurological disease, and we're looking forward to continuing that in the years ahead as well.

I'm acutely aware that only 15% of our recurrent funding comes from the Government. This means that we rely heavily on the generosity of our supporters to fund the rest. It's also why it's incredibly important that we are mindful of how efficient and effective our support services and programs are in making a difference to as many people as possible, at a time when they need us the most.

I've been the CEO of MND NSW for around 16 years now and am still amazed and inspired by our participants' stories. It's what drives our passion here at MND NSW and gives each of us purpose every day.

40 years is a long time and there's a lot for us to be proud of with everything we've achieved to date. We're also grateful to our supporters. We know it's only through their generosity that we can continue to be there for people living with MND for as long as they need us. The support we have received from you all, and notably Pat Parsons, Lady Fairfax Foundation, Kerridge Foundation, Schwinghammer Foundation, and Fight MND, as well as those of you who donated to or attended Walk to d'Feet MND, My Naughty Dad, Beat the Beast, Isabella Jolly, Riddla Golf Day, and Dale's Day, recently has been an immense help for us to continue assisting people living with MND, and their families.

So I would like to extend a heartfelt thank you to everyone who has supported and been involved with MND NSW over the past 40 years. Each of you are an important part of our story and will help us continue to ensure that no one has to face MND alone.

Thank you.

**Graham Opie**  
CEO, MND NSW



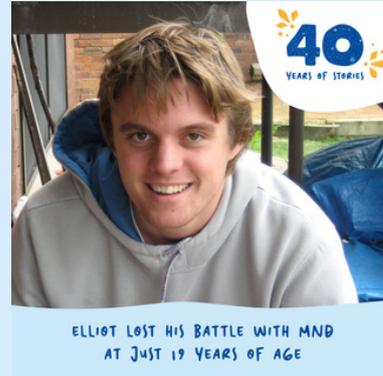
**MESSAGE FROM THE CEO**

# 40 YEARS OF STORIES



## Marjorie Harrap

Marjorie is a one-of-a-kind, very special person. She started MND NSW back in 1981 (then known as Amyotrophic Lateral Sclerosis Society of Australia) after her husband, Bill, was diagnosed with ALS, the most common form of motor neurone disease (MND). Marjorie's objectives were clear from the beginning: "Our aim was to provide practical information and support to people with MND and their carers, to promote public awareness of the disease and to encourage medical research into the cause and treatment of the disease." And it's these key pillars that were built way back in the beginning that still remain the focus of MND NSW today.



## Elliot Jay

Elliot was diagnosed with MND whilst just a teenager. He was enjoying his first semester at university and working one day a week at a local financial advisory firm. A short time later, his Dad dropped him at work. However that day, Elliot could only limp to the stairs. He stopped at the base of them and then turned, struggled back, eyes filling with tears, he said to his Dad "take me home." That day was Elliot's last day at work and sadly he was never to return. Sadly, after an eight-month battle with MND, Elliot passed away at just 19 years of age.



## Judy Featherstone

Judy was diagnosed with Motor Neurone Disease in 2020. For now, it's the simple things that mean the most to Judy. Being able to read, listen to music or spend time with loved ones. Judy says supporting MND New South Wales is incredibly important to her. "I would say it's vital, because people with this condition don't make a recovery." She says.



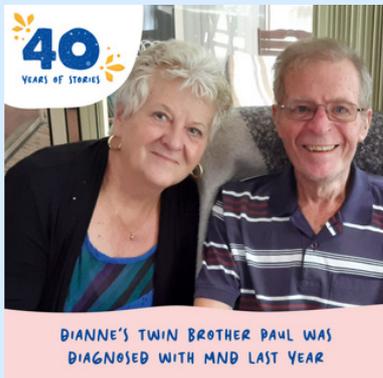
## Julie Becke

Julie has been working for MND New South Wales for eight years. It's the needs of our clients that are the driving force behind Julie's passion for what she does. "We can't help people with MND get better but what we can do is make people comfortable, confident, independent, all those things that we want for ourselves and for people with disabilities."

# 40 YEARS OF STORIES

When Lily's Dad was diagnosed with Motor Neurone Disease in July last year, at first she thought he was going to say that he had cancer. Lily was preparing for that, as she'd already lost so many family members to cancer in recent years. But when she found out her Dad had MND, she realised that she had no idea what it meant. Even though she had participated in the ice bucket challenge years earlier, she realised she didn't know anything about the disease or what impact it would have on her family. Lily is also still firmly focused on raising awareness. "The goal, for me, is to educate the people that don't know what MND is, so they can provide support for those who are experiencing it." Lily recognises the invaluable support she's received from MND NSW as well. "They've provided ongoing, hands-on support, constantly checking in with Dad, and keeping in contact. They're so supportive."

## Lily Starr



## Dianne Brown

In April 2020, the global pandemic had just hit and in the middle of a global lockdown, Dianne's twin brother Paul was diagnosed with MND. The whole family was devastated. From the day Dianne heard about Paul's diagnosis, she did as much as she could to support him. She even attended an MND support group meeting with Paul, where she witnessed him sharing his wisdom and encouragement with others who were struggling. Dianne is continuing to support MND NSW through sales of a children's book she created and Paul helped her name, called "What Do Cows Do?".



In September of 2002, Margaret's husband was diagnosed with MND. At first she thought she would have at least a few more years with him but his illness progressed quickly. "I think the biggest thing that helped me was talking to people about it." Margaret decided to volunteer with MND NSW as a way to give something back to everyone who had helped her so much, during such a difficult time in her life.

## Margaret Orr



## Julie Labra

Julie has been working as a Service Coordinator at NSW Health for 14 years. Her role works closely with staff and volunteers at MND NSW via a two-way referral system to help people living with MND, especially those who are newly diagnosed. "The support that MND NSW provides to people is amazing on many levels. So even when you're first diagnosed, they're the best group to go to, to get reliable information about the disease."

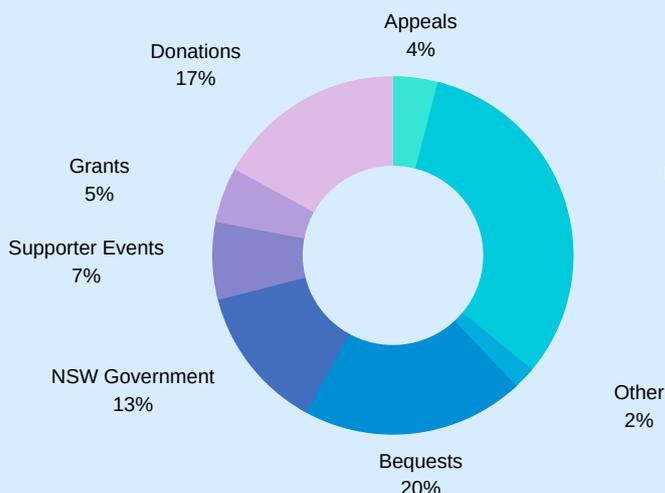


## Ann Bradstreet

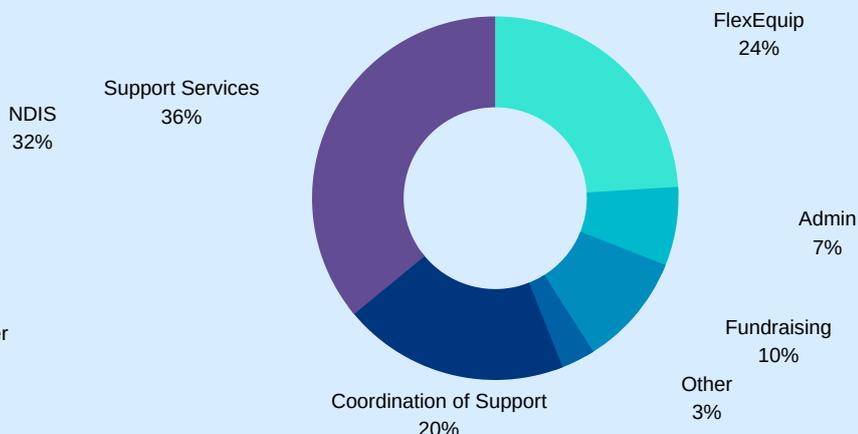
Ann, from Botany Access, has been raising funds for MND for many years, after her husband John was diagnosed with motor neurone disease in 2002. John was an incredibly strong, inspirational person. "He thought he was still going to live forever and find a miracle cure. Not give into it. He wouldn't give in." Ann recalls.

# THE IMPORTANCE OF YOUR SUPPORT

## Income



## Expenditure



## WE NEED YOUR SUPPORT!

We have been assisting people with motor neurone disease and their families for 40 years because of your support. We cannot do what we do without your donations and assistance, particularly with COVID-19 adding extra challenges for our MND community, and increasing the demand for our support and services. If you would like to help people with MND and their families please consider becoming a community fundraiser, a volunteer, a public awareness ambassador or make a life enhancing donation.



Title: Mr/Mrs/Ms/Miss/Dr

Full Name: .....

Address: .....

Suburb: .....

State: .....

Postcode: .....

Phone: .....

Mobile: .....

Email: .....

**Amount: \$10 \$20 \$50 \$100 Other (please specify):** .....

Credit Card Number: \_\_\_\_\_

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CVV Number: \_\_\_\_\_