

# **ANNUAL REPORT**

2016-2017

Proud to distribute \$500,000 to our beneficiaries this financial year

MonSTaR Foundation Sarah.bunting@monstarfoundation.com.au

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#### From the Directors

#### MONSTAR FOUNDATION

**Directors** Mark Golding Greg Hargreaves Hamish Pearce

#### **Foundation Manager**

Sarah Bunting

#### **Greatly assisted by:**

Cheryl Golding Kim Hargreaves

#### Along with:

### Danny Bergan Memorial Foundation

Daniel Bergan Stuart Jamieson Lana Trivuncevic

#### **STaR Association**

Margaret Meaker Rai Chen Jacqueline Leach



We are delighted to present our first Annual Report.

We are truly grateful to everyone who has supported MonSTaR over the years – from those who have been involved since our inception in 2007 through to all our new supporters who join us each year.

The MonSTaR Foundation was formed over a round of golf when we decided we wanted to give something back. All three of us have our own successful businesses and been directly affected by either MND or have a sibling with a disability. We hoped that if we worked together with our collective networks, we could make a difference.

As a registered Charity our funds are shared between Motor Neurone Disease (MND) – both patients and research - and the STaR Association who enable special educators to work within mainstream childcare centres and assist children with disabilities to socialise and learn with other children. More detailed information about our beneficiaries and where the money goes is included in this report.

Over 11 years, we have now raised close to \$3million. This year along with the contributions from the Danny Bergan Memorial Foundation, we were able to distribute over \$500,000 to our beneficiaries in one financial year for the first time. The continued and generous support from our sponsors, friends and families sees this figure grow each year – far beyond anything we could have ever imagined.

#### Thank you for helping us make a difference.

Mark, Hamish and Greg

#### Who We Are



Mark Golding is the Director of GoldKey Financial Services and has operated successfully in the Financial Services sector for over 30 years. He was a board member of Pennant Hills Golf Club for a number of years and is a regular volunteer at the Matthew Talbot Hostel for the Homeless.

Mark's sister, Lisa, had profound disabilities and passed away at a young age. Mark is married to Cheryl and has three children, Cassandra, Lauren and Jonathan.



Hamish Pearce is a Financial Advisor with Mentor1 Financial Planning in North Sydney. Hamish's dedication to this cause came about through the MND diagnosis and subsequent passing of his wife Fiona in April 2007. The generosity and support that was extended to Hamish from family and friends during the tough times of Fiona's illness motivated him to establish the MonSTaR Foundation.

Hamish is now married to Kimberley and together they are raising Will, Angus and Jerry.



Greg is the Director of Hargreaves Property Group, a commercial property development business with over 30 years' experience in the property industry. He has served as a board member of Pennant Hills Golf Club along with being an active volunteer at Matthew Talbot Hostel providing services for the homeless.

Greg's sister, Carmel has a learning disability and helps us at the MonSTaR event each year. He is married to Kim and they have three sons, Matthew, Daniel & Luke.

#### Staff

2016 saw us take on our first employee – Sarah Bunting. Sarah has managed the event since 2014 on a contract basis and the decision to bring her on year-round was not taken lightly. The workload of running the Foundation has increased significantly due to the growth of the event over the past three years and the Directors felt that the additional operational costs were justified. Sarah is our only paid staff member and works part time during the quiet months through to full time as we approach event day each year.

Sarah worked with wheelchair tennis at the International Tennis Federation in London before coming to Sydney in 1999 to work on the Olympic and Paralympic tennis events. She has over 20 years of event management and administration experience, predominantly with sporting events. She lives on the Northern Beaches with Jason and their children Tana and Kaia.

# Our 2016-17 Sponsors

We are indebted to our sponsors and supporters – many of whom have been with us now over 10 years and without whom our event simply could not happen.



# Danny Bergan Memorial Foundation

We would like to acknowledge and thank the Danny Bergan Memorial Foundation whose incredible efforts add significantly to our fundraising total each year.

Daniel Bergan lost his father to MND in 2007 and together with his best friend Stuart Jamieson, they have been raising funds through their golf day and trots nights each year ever since.



DBMF is run solely by volunteer efforts and corporate sponsorship, allowing them to donate 100% of all of their net proceeds directly to MonSTaR. We are so pleased to be able to pass on these proceeds on their behalf to both the STaR Association and MND Clinics and Research.



Their amazing contributions have amounted to over \$525,000 over the last 6 years.

To Daniel, Stuart and their team – your efforts are truly remarkable. We are forever grateful for your incredible support of the MonSTaR Foundation.

This financial year the Danny Bergan Memorial Foundation contributed **\$143,500** to the MonSTaR Foundation.



### Finances

The MonSTaR Foundation has seen significant growth since our move to the city in 2016 for our 10 year anniversary celebration.

Year	Evening	Venue	Revenue	Expenses	Balance	Danny	Donated to
	Guests					Bergan	Beneficiaries
2015	330	Pennant Hills Golf Club	\$418,000	\$147,000	\$271,000	\$86,000	\$350,000
2016	470	Four Seasons	\$538,000	\$183,000	\$355,000	\$112,000	\$400,000
2017	630	The Westin	\$685,000	\$265,000	\$420,000	\$143,500	\$500,000

# For the 2016-17 Financial Year, we distributed **\$500,000** to our beneficiaries.

# Since then, we have already donated an extra *\$60,000* in August 2017.

# Keeping Costs to a Minimum

MonSTaR is very conscious of minimising our operational costs to ensure the absolute maximum raised can be given to our beneficiaries. These are some of the ways we aim to achieve this:

- No MonSTaR Foundation office Sarah works from home.
- Wages and salaries are just under 9% of our revenue.
- Less than \$50 stationery/office costs this year and no other overheads including phone, internet, utilities or car expenses are claimed by any staff or Directors.
- We use voluntary or heavily discounted services of MonSTaR business connections wherever we can for services such as accounting, website, media, designers, printing etc.
- We rely heavily on volunteers at both the golf and the MonSTaR Ball on event day and are strongly supported by the STaR Association and other volunteers in the lead up to the event, particularly Cheryl Golding and Kim Hargreaves who support Sarah year-round but particularly as we lead into the event period.
- The Directors are not paid any wage or salary and do not claim any expenses.
- We were extremely lucky to receive donated product which help our bottom line such as soft drink and water through Schweppes/Voss, flowers for the evening function through Wahroonga Flower Shoppe and the BBQ at golf provided by The Baristas' Shed.
- Incredible donations, auction and raffle items from our many supporters including House of Fraser and Renascent Australia who raise huge amounts for us each year.

## Wages and salaries are less than 9% of revenue.

Directors are not paid any wage or salary and do not claim any expenses.

### MonSTaR Summary Accounts 2017

		% of total
Income		Income
Sponsors/Golf & Dinner packages	\$ 176,250	26%
Individual Dinner Tickets	\$ 34,550	5%
Live & Silent Auctions	\$ 334,598	49%
Raffle/other event day funds raised	\$ 38,185	6%
Donations	\$ 98,679	14%
Merchant fees	\$ 3,338	Less than 1%
Total	\$ 685,600	100%
		% of total
Expenses		Expenses
Auction Costs (estimate)	\$ 54,691	21%
Golf Day	\$ 21,860	8%
Ball	\$ 98,686	37%
Other Event Expenses	\$ 11,072	4%
Operations & Staffing	\$ 79 <i>,</i> 335	30%
Total	\$ 265,644	100%
Net profit	\$ 419,957	
Danny Bergan Memorial		
Foundation	\$ 143,500	
Overall funds raised	\$ 563,457	

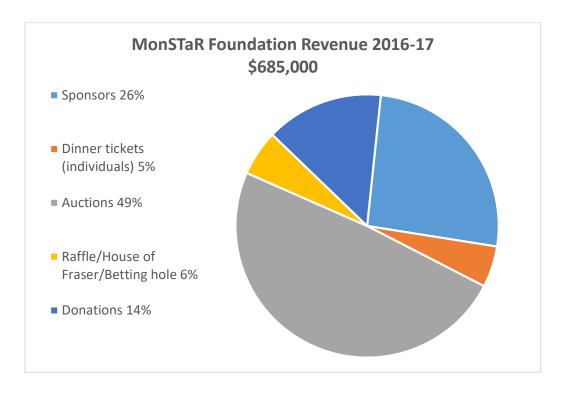
#### Beneficiaries

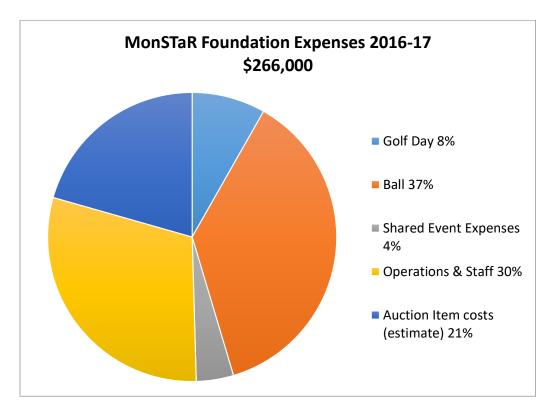
The funds we raise are shared between three beneficiaries:

- The STaR Association (50%)
  - Educational programs and the funding of special educators to support children with disabilities, in turn ensuring that they are able to attend mainstream childcare centres.
- The MND Research Institute of Australia (25%)
  - o Research into finding a cure for MND
- The Macquarie Neurology MND Clinic headed by Professor Dominic Rowe (25%)
  - Operating a Multi-Disciplinary Clinic which provides critical support to those suffering from MND.

#### 2016-17 Summary of MonSTaR Foundation Revenue and Expenses

Please note these figures do not include donations from the Danny Bergan Memorial Foundation which are accounted for separately.



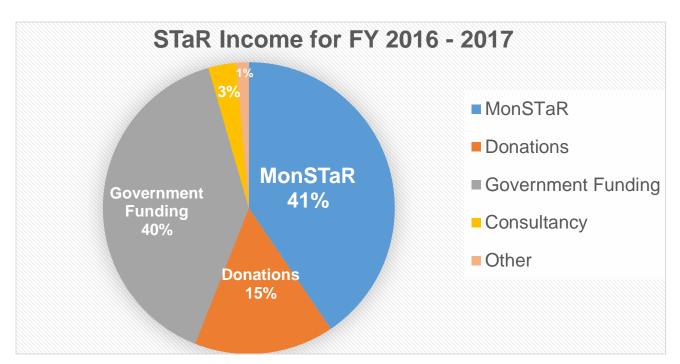


# The STaR Association Received \$250,000 in 2016-17

STaR provides access to mainstream childcare centres for children with disabilities, opportunities for them to reach their full potential and acceptance of their difference. We often support children with very complicated needs who otherwise would be refused care. We don't promise to fix the children but we do promise to teach them. STaR is grateful to MonSTaR for recognising the importance of what we do to include as many children with disabilities as possible in mainstream child care centres. Being a small and specialised charity makes it difficult for us to compete for the charity dollar, and we prefer to invest in the children and families who need us instead of expensive marketing.

#### The support we have received during FY 2016 - 2017 has enabled us to:

- support 86 children and their families
- continue working with 9 child care centres
- commence planning to expand our services into 3 new centres
- recruit 2 additional special educators and 1 release teacher to join our dynamic team



Our government funding meets only one third of our expenses, MonSTaR's generous donation helps STaR to fill the significant funding gap on an annual basis.

#### Saeed's STaR Story

I am Saeed and I'm three years old. My family are refugees from Sudan.

I love playing with my friends at Kids Early Learning – Rooty Hill. I'm Cheeky, curious, fun loving and Can be a bit stubborn sometimes. I have Down syndrome but that doesn't define who I am. I'm often sick because my medical condition is complicated.

At STaR. I'm learning to:

- join my friends to enjoy books
- use my new big bottle to drink water and juice, to keep me hydrated throughout the day
- use a spoon to eat lunch, like my friends do
- draw, play with my friends in home Corner, and pack away our toys after playing
- go to the toilet by myself. My mum is really happy about that.☺

My sisters, Sabaa, Nabaa and Simaa love their new bikes that you gave them this year. They are riding them all the time! My family struggles to make ends meet. They Can't afford my child Care fees. If it wasn't for your generous donations, I wouldn't have a place there.

Since I can go to child care three days a week, mum is able to attend English lessons in the hope to get a job. You are making a huge difference to me and my family.

#### Thank you MonSTaR!



# MND Research Institute of Australia Received \$125,000 in 2016-17

The Motor Neurone Disease Research Institute of Australia (MNDRIA) is the research arm of MND Australia aiming to understand the causes, find effective treatments and discover cures for MND. MNDRIA funds more MND research projects than any other organisation in Australia and awards research grants each year. These projects are in areas as diverse as genetics, cell biology, translational research and social research. During 2017 MonSTaR Foundation is funding two MND Research Grants through the MND Research Institute of Australia. Below are brief summaries of these projects:

#### **Dr Rachel Tan**

Brain and Mind Centre, University of Sydney

#### Is ATXN2 a potential therapeutic target in MND?

The death of neurones in MND is caused by a normal protein called TDP-43 becoming toxic. Cell and animal models have shown that another protein, called ataxin-2 (ATXN2), may be involved, a concept that appears

more certain as genetic variability in the ATXN2 gene increases the risk of getting MND and also shortens survival. This study will assess whether variability in the ATXN2 gene impacts on protein levels (different forms of ATXN2 and toxic TDP-43) and neuronal integrity in patients with MND in order to provide critical information on whether therapeutic strategies for MND should target ATXN2.

#### **Dr Adam Walker**

Macquarie University

# *New proteins and pathways contributing to TDP-43-mediated neurodegeneration*

In almost all patients with MND, a protein known as TDP-43 misbehaves in the brain and spinal cord. I have created genetically modified mice that develop TDP-43 pathology and disease very similar to human patients, to allow the analysis of brain and spinal cord tissues at early stages of disease development. In collaboration with other researchers, my team is using advanced biochemical analyses to narrow down the biochemical changes involved in disease in these mice. This project will characterize the role that newly identified proteins play in disease, with the goal of identifying new ways to treat MND.



# Macquarie University MND Research Centre and Clinic Received \$125,000 in 2016-17

The multidisciplinary MND service led by Professor Dominic Rowe AM and his clinical team treats 10% of all Australians living with MND. Their integrated approach means all patients have access to expert neurological care as well as to a range of allied health professionals – all in one location.

All patients and their families are invited to supply DNA and tissue samples that are stored for ongoing analysis in the Macquarie MND Biobank which is the centerpiece of the research program and is the largest of its kind in Australia with more than 17,000 samples collected since 2013.

"We mean it when we say that we couldn't run the Macquarie University MND Clinic without the support of the MonSTaR Foundation.



The Clinic currently looks after 200 patients with MND. In 2016, we have been able to care for 72 new patients. The support from The MonSTaR Foundation enables us to run MND Clinic every Wednesday, with multidisciplinary clinic on the 1st and 3rd Wednesdays of every month.



The generosity that we receive from The MonSTaR Foundation supports the MND Clinic team, including our MND Coordinator and allied health clinicians. It also helps to buy assistive and adaptive equipment for the clinic that helps to improve the lives of our MND patients.

MonSTaR Foundation's support of the Macquarie University MND Clinic is crucial to our work with MND patients and their families. We wouldn't have made the progress we have to date without this invaluable support" – Professor Dominic Rowe, AM

The research team at Macquarie is made up of:

- Genetics Team led by top geneticist Associate Professor Ian Blair
- Biomarker and Cellular Street Team led by Associate Professor Julie Atkin
- Protein Aggregation Team led by Neuroscientist Professor Roger Chung
- Neuroinflammation and Neurotoxicity Team led by Professor Gilles Guillemin
- Zebra Fish Team led by Dr Angela Laird
- Mouse and Pathology Team led by Dr Adam Walker (recipient of our MNDRIA grant above)

Dom Rowe is also leading **clinical trials** including a world-first testing a novel compound developed in Australia, called Copper-ATSM to aim to redress the imbalance of metals that occurs in the brain of patients.

# How you can help

- Become a Sponsor
  - The MonSTaR Cup simply could not happen without the support of our amazing sponsors and supporters. We have a variety of sponsorship packages available and you can also buy individual tickets to the evening function. Visit http://www.monstarfoundation.com.au/events/monstar-cup-2018 for info.
- Donate
  - A single donation allows us to help with day to day items that are needed by both STaR and MND throughout the year.
  - A regular monthly donation allows us to fund longer term projects to make a real difference to the lives of many children and adults.
  - Visit <u>http://www.monstarfoundation.com.au/get-involved/donate</u> to donate.
  - All donations over \$2 are tax deductible.
- Volunteer
  - We need a variety of volunteers on the day and in the lead up to the event. To volunteer, please call Sarah on 0432 719210 or email sarah.bunting@monstarfoundation.com.au
- Invite friends
  - Do you have a friend, family member or a business associate such as your firm of accountants or lawyers who might like to support MonSTaR alongside you? We'd love to hear from you.
- Help source products or donate an item
  - Could you, or someone you know, help us source items for the event such as beer for the evening function, signage, stationery or even a fabulous new auction item? Large or small, they all make a difference.

### Looking Ahead - 2018 MonSTaR Cup

The next MonSTaR Cup will take place on Friday 23rd March 2018 and will comprise of a Golf Day at Pennant Hills Golf Club for 144 golfers followed by a black-tie ball at The Westin Sydney for around 650 people.

The day involves a round of golf with a few on-course activities, followed by a spectacular evening of free-flowing drinks, delicious 3-course meal, fabulous entertainment finished off with dancing into the early hours to a live band.

We have golf and dinner sponsorship packages available or you can join us for the evening function as a Table Sponsor or buy individual tickets and come with friends. Golf always fills early so please register through our website or call Sarah on 0432 719 210 if you'd like to join us for 2018. We'd love to see you there.

# Contact Us

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Call Sarah: 0432 719 210