



Spinal Muscular Atrophy AUSTRALIA INC.



SPINAL MUSCULAR ATROPHY AUSTRALIA INC.

2017/18 ANNUAL REPORT

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Talia, Type 2



Our Vision & Purpose

Our vision is for our community to be aware of SMA and supportive of those individuals and their families.

We aim to be the first point of contact as well as the specialists on support for the SMA community.

To promote awareness of Spinal Muscular Atrophy to the general public, professional services and support networks.

To promote and provide ongoing support and information to families and sufferers of Spinal Muscular Atrophy.

To establish a specialist pool of equipment not provided by hospitals, to assist families with Spinal Muscular Atrophy to ease the burden of the disease.

To help promote and fund care options, possible treatments and research of Spinal Muscular Atrophy.

SMA Facts

SMA is the childhood version of Motor Neurone disease.

1 in 35 people in Australia unknowingly carry the faulty SMA gene. Being a carrier does not mean you are affected by the disease.

One in 10,000 live births in Australia are affected by SMA.

60-70% of all SMA patients have the most severe form (Type 1).

SMA is a physical disease only. Children with SMA have reduced movement.

There is no known cure for Spinal Muscular Atrophy but with recent drug advancements there is some new treatment options for SMA.

Babies (Type 1) don't often reach milestones like sitting or rolling in early infancy, have hypotonia (weak muscles), progressive weakness and loss of motor function.

Babies born with SMA appear perfectly normal in every way except they are extremely weak. They are bright, alert, interested in people and what's going on around them. They enjoy music and being played with – just like other babies.



SMA Facts cont'd

A person is born when BOTH parents are carriers of this gene, neither parent is to blame. There is a 1 in 4 chance of this couple having future babies with SMA.

SMA Children's intelligence is unaffected. Many people with SMA have above average intelligence. Children go to main stream schools, adults work (ie: graphic design, lawyer) and even have children themselves.

New genetic testing technology using saliva samples is now available Australia wide. The test costs \$385 and is available through www.vcgs.org.au (this test screens for SMA, Cystic Fibrosis and Fragile X).

Children with SMA catch germs very easily so washing hands before having contact is very important. Avoid visits by anyone suffering a cough / cold or anything contagious, due to their weakened immune system.

Infants / Children / Adults diagnosed with Type 2 and Type 3, have a good survival rate, but mobility and dexterity are compromised. Most sufferers are wheelchair bound by early childhood. With some requiring steel rods in their back to allow them to sit upright and prevent scoliosis. All sufferers require assistance with activities of daily living such as grooming and feeding etc.

Around 630 people die from Motor Neurone disease every year in Australia. (ABS)





Foundations

The Spinal Muscular Atrophy Association of Australia Incorporated was founded by Julie Cini and her late partner, Ross Brownlaw after their first daughter Montanna died from SMA Type I at ten and half months of age in June 2005 in Australia.

While searching for information on this chronic, genetic disease Julie and Ross realised that there was no support group dedicated to supporting families affected by SMA here in Australia. Not wanting other sufferers and their families to feel as isolated as they did, SMA Australia was founded in August 2005, in honour of their daughter Montanna.

In early 2006 when Julie was expecting their second child, Ross was tragically killed in a car accident, near their home in Heywood Victoria.

Julie and Ross' second daughter, Zarlee Brownlaw arrived in December 2006, and was quickly diagnosed with Type I SMA. Julie made sure that Zarlee's life was a happy one with the help of family and friends. Unfortunately she succumbed to the disease on Christmas day 2007.

Through all this tragedy, Julie's passion to help other families and to continue the fight to create awareness of SMA has never faltered. Her intimate knowledge and experience with the disease first hand drives her to expand SMA Australia, so that the disease is recognised on a national level through education, public awareness and fundraising.

Committee of Management 2017/18

President	Diane Ford
Vice President	Shane Thorneycroft
Secretary	Georgia Clarke
Treasurer	Robyn Tabone
General Members	Sarah Andrew, Rosemary Watkins, Jason Pickles, Zoe & Hilary Watson

Staff

(as at 30/06/2018)

CEO/Founder	Julie Cini
Administrator	Jo Harlow



CEO Report

This past 12 months I didn't think I could get any busier – but I did. There has been so much to do! The SMA community has had so many highs and lows this past 12 months, it's hard to keep up at times. With the ever-changing treatment space, although it is an extremely exciting time for our disease, recent announcements left many families with pure jubilation and others with utter devastation. I know that this is a very bitter pill to swallow, but we must come back to the big picture and continue to celebrate the wins not the losses.

Advocacy, advocacy and more advocacy was the main focus of the last 12 months. Without this important step we would not have achieved the result we did with access to treatment for the under 18 community. We will continue our advocacy work as long as it takes to make sure that the whole community gains access to treatment. Recently whilst visiting Parliament House, Chris Crewther – Member for Dunkley said to me that our campaign of individualising each letter to each politician was meaningful and a fabulous way to not only raise awareness but try to gain access. It was this that set us apart from the other groups who were also campaigning for their causes. To those who went to see your local federal member we thank you for taking ownership in this very important step to get to know your local member and advocate for access to treatment. Your voices definitely stood out. To all those who have yet to do this step, it is an important one, and we urge you to get involved.

Our other focus this past 12 months has been our Wellbeing Program, and it will continue to be our focus over the next few years as well. We hope that we can streamline the delivery of this program with the injection of some funding, and really sink our teeth into this area of focus.

One step to the left, and we also know that we were successful at gaining support from the government in regards to a genetic screening program called Mackenzie's Mission. Over the next few years 10,000 couples will be screened in the pilot program, with the big picture of making screening available to couples in the future on a Medicare rebate, so that there will be no out of pocket expenses for this resource for families in the future. I have been working closely with Cystic Fibrosis Community Care and Fragile X Association in relation to genetic screening and education resources for the future, and you will see these communication pieces shortly.





CEO Report cont'd

I have been grateful and humbled to be on various committee's over the past 12 months and beyond, where my knowledge about SMA has assisted the wider sector in gaining much needed information about access to services, or how to advocate. Collaborating with these organisations has been a fantastic experience, and the knowledge that I have gained has put us in the position we are in today.

2018 has proven to be the biggest year yet for Spinal Muscular Atrophy. Let's hope we can continue this run well into 2019 and beyond. For this to happen we need our families to become more involved, and take ownership of wanting access to treatment. I have learnt in the past that one voice is just not loud enough, its many voices that need to talk for the message to be loud and clear. I look forward to working with all those voices in the future.

Treasurer Report

As the Treasurer I am pleased to present my report on the financial activities of SMA Australia for the year ended 30 June, 2018. This is my sixth year in the Treasurer's role and once again had both challenges and rewards.

Total income for the financial 2017/18 year of \$340,955, which is growth of approximately \$40,000 from the previous year. Each year, we rely solely on fundraising and donations with no regular re-occurring means of income.

For the year 2017/18 the charity was able to secure \$56,000 in Grant Funding to support our Wellbeing program series that has been run Australia wide.

We have once again realised a small surplus for the year, which has been used in part to purchase an additional cough assist machine.

The continuation of our sharing of premises with other businesses has enabled us to remain cost neutral in our rental overheads and we thank these tenants for their continuing support.



Treasurer Report cont'd

The last twelve months have seen a significant change in the source of income for the Association with donations reducing by 50% and Grant funding being sort to cover programs. Our fundraising has increased by \$60,000 this year which has been achieved through the continued hard effort and the support of our volunteers and our community.

Once again I would like to thank the staff and all the families, volunteers and committee members especially for their efforts and their dedication to SMA Australia – there are many outstanding contributors who deserve our thanks, but without you all we would not be able continue the most important aspect of our core values to provide the support, equipment and research moneys for our families

“Giving is not just about giving a donation, it's about making a difference”.

Thank-you Robyn





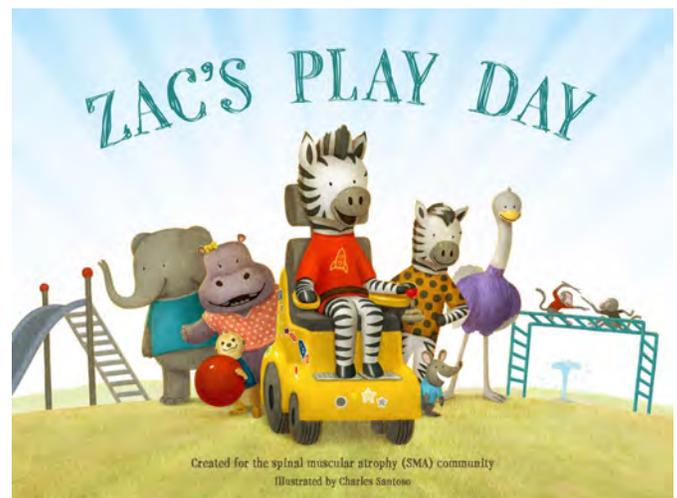
SMA Wellbeing PROGRAM

The Wellbeing Program was developed out of a need to support our families holistically. Our first round of workshops were held in Melbourne (27/01/18), Brisbane (3/02/18), Sydney (10/02/2018), Perth (17/02/2018), Adelaide (24/02/2018) and Darwin (25/02/2018).

Participants listened and interacted with speakers about best practice for living with SMA today. This family friendly event allowed the opportunity for connecting with other SMA families in their State. Everyone took home a booklet outlining the topics covered during the day and lunch was provided at every Workshop. As a direct result of the Workshops, the membership of SMA Australia increased.

We anticipate the Program continuing if funding is successful to provide Wellbeing topics and services. This may include but not limited to; webinars, videos, seminars and podcasts. Each avenue can only be successful with the involvement of the SMA community to move forward and look forward to their interaction at different events.

The pharmaceutical company, Biogen, in conjunction with SMA Australia released a book 'Zac's Play Day', which is a fun (and beautifully illustrated) book aimed at young children about living with SMA. The book was launched at the Melbourne Zoo in February 2018.





Stephanie, Type 2

Volunteers

As well as people volunteering to organise fundraisers and our volunteer Committee of Management; we also have volunteers who help out in the office during the year and we are very thankful for this. Two volunteers that have helped out on a regular basis over 2017/18 are; Jenni McKay and Diane Ford. We really appreciate the time you give to the Association. Thank you.

Heartfelt 
THANKS
TO OUR VOLUNTEERS!

Cough Assist Machine Program

Currently, there are 16 machines rented out to families. 4 x CA3200 (older) machines and 12 x E70s. There are 4 x E70s available and 1 x CA3200 for rent. (as at 30/06/2018)

As of June 2018, the CA3200 machines were no longer able to be serviced by Philips as they have transitioned to the newer machines. All machines in the Association's equipment loan pool will eventually be an E70.



Chantel, Type 3



Fundraising & Events Report



Melbourne Gala - held on 5th August 2017 at the Fenix Events Centre Richmond. The theme was Dress to Impress, James Bond style. Toby Price was the guest of honour and as usual there was dancing, silent auctions and raffles.

Brisbane Gala - held on 26th August 2017 at the Royal on the Park. The theme was Dress to Impress with a touch of purple.

Oaks Day - held on 9th November 2017 at Sandy's on the Bay.

AHA (NT) (Australian Hotel Association) President's Lunch held on 21st November 2017 at the Skycity Darwin. Over \$110,000 was raised at this event!

Million Steps - held on 25th March 2018 at Lysterfield Park.

Made in May - Again many hand made items were donated and put up for auction on Facebook.

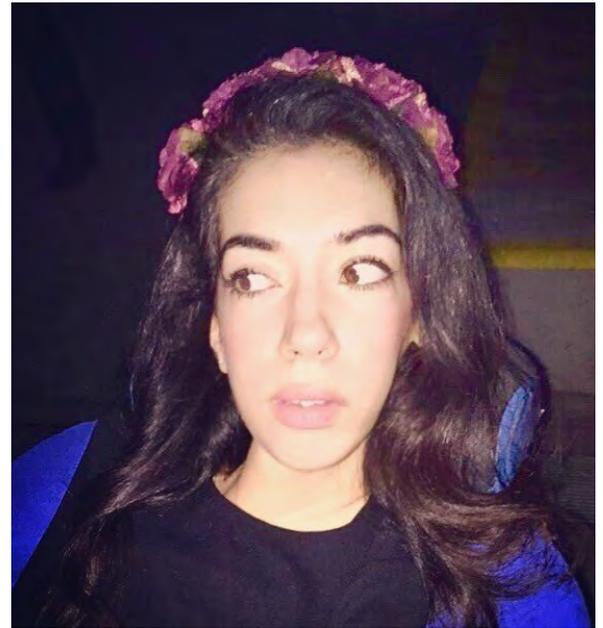
There are a few events organised by others, and we thank every one of them for their support and efforts. We would like to thank two in particular for the 2017/18 year; Gillie Ruddell from Queensland and Allan Roark from Tasmania.

We also thank the businesses that have supported us during 2017/18 by hosting chocolate fundraising boxes and donation boxes.



Family Story - Yasmeen El-Shawy

My name is Yasmeen, a 27 year old graphic designer from Melbourne. I was diagnosed with SMA (Spinal Muscular Atrophy) when I was one year old. The onset of SMA may have come when I was around 4 months old cause I was never able to sit up independently or reach the normal milestones of rolling over and crawling. So my parents took me to many different doctors. Some said, 'Don't worry, she's just flexible, she'll be a ballerina', others said 'Just put her in the sun, all she needs is some Vitamin D then she'll be just fine.' It obviously didn't work. The doctors, in the end, told them that I have Spinal Muscular Atrophy, a very severe disability which will greatly impact my mobility to the extent that I cannot even shoo a fly. The doctors informed my mum that I wouldn't live more than four years, but as you can see, I lived a lot longer than that!



As a result of my muscle wasting, I also have scoliosis of the spinal column. I was supposed to have a spinal fusion operation when I was 10, but at the last minute, the doctors decided not to operate, as it was too dangerous for me and my respiratory system wouldn't be able to endure the operation. They didn't want to take the risk, so I didn't do the surgery. To this day I'm only living with 15% of my lung capacity. Which is a miracle.

I'm convinced that when God takes something from you, He gives you things that are much better in return. In my case, some of these things are my friends and family. Without them, I wouldn't be where I am today.

The other thing is my hobby. My mum imagined that my hobby would be reading like her, but to her dismay, it's not reading! Ever since I was young, I've loved to draw, and my mum would encourage me by looking for lightweight drawing materials or supporting my arm when I draw. When I was 13, she enrolled me in a summer art program with my cousins. Within the first week, the teacher was astonished by the quality of my work and recommended that I take part in an international exhibition (for artists with disabilities). Ever since then, I've realised that art is not just my hobby, it's the only way that I feel like I'm the same as everyone else. Despite my weakness, It's something that I'm able to do independently. It makes me feel free and that I can do anything without boundaries. I feel like I can pour out all my energy into it and everything inside me comes out in my art. I knew that I could never live without it.



Family Story - cont'd

After a few years, I got a bit weaker, and I was no longer able to hold a pen or brush. But I found other ways to do my art. I could never give up art that easily. I taught myself Photoshop and Illustrator. My dream was to study applied arts. I got offered a place at Grenadi School of Design and graduated 2013.

Now I work as a freelance designer/illustrator. I also volunteer at a few NGO's internationally. In 2012 I was given the opportunity to give a TEDx talk at TEDxCairo.

<http://www.youtube.com/watch?v=IUyC37uqccw>

Just like anyone else I go through periods when I feel I can't go on and I lose hope. Realizing how weak I am and how not being able to do the simplest things, like a little cough, could end my life in a moment.

Up till now I've somehow got through all of the hospitalisations and close to death experiences miraculously.

I truly believe that I was given a second chance for a reason. A reason which I may not know now and I may never know it, but it is due to God's will that I am still here.

Getting access to Spinraza is crucial for someone like me. Seeing a small improvement or even just preserving the tiny movement I still have would make the world of a difference. I'm thankful that I'm still able to do my art with the limited movement I have in my fingers and I hope I never lose it.

Despite the difficulties I experience, I want to use my art to do something that brings joy to people's hearts, and to do something that makes a difference in their lives. To make a positive difference that people will remember me by before I leave. I don't want anything more out of life.

Every one of us has circumstances in their lives; everyone has trials and obstacles that God gives us for a reason. A reason which may not be apparent to us. But we have the choice, either to break down, give up and fear tomorrow or to get up and live each moment to the fullest and try our utmost to make a difference in this world, a difference that can begin by the simplest of things like just a smile.

Thank you for reading our annual report.