

10 year

Journey and Memories



ADSG

Australian Dystonia Support Group

Our History

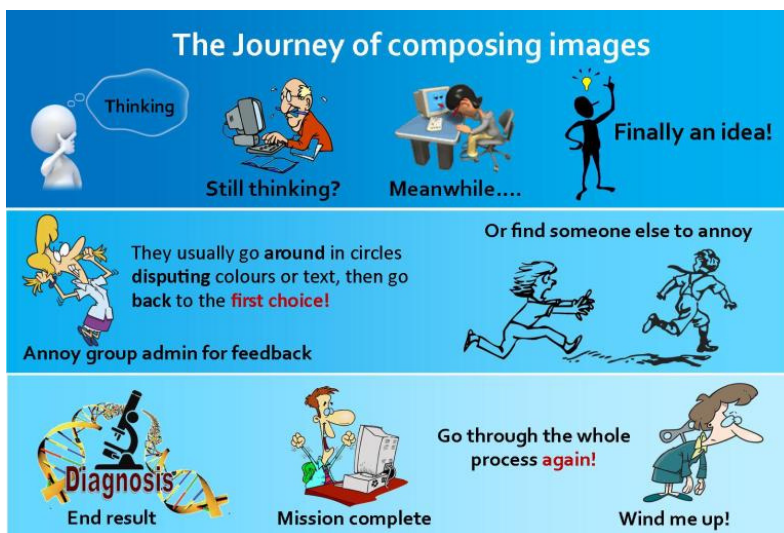
Lee Pagan, who was living with Dystonia, created the Australian Dystonia Support Group (ADSG) and described it as ‘A place where we come together to support each other, while sharing the good, the bad and the ugly’. Lee wanted it to be a place where people felt comfortable to share their experiences, to ask questions and to help each other. You can view the following posts for more details.

→ [Interview with Dystonia sufferer, Lee Pagan, ADSG Founder!](#)


→ [Lee Pagan's Story - Trapped](#)

The group now has 3 other Admins (Hariklia Nguyen, Lisa McInnes, and Sue Kennedy) who help run the group, including composing great images!

ADSG Behind the Scenes



Our imaginative image designers (Admins) – A funny snippet of how it all happens!

 **Our memorable Video - What do Admins really get up to?**

Link: [Secret Office Admin Video](#)

Our thoughts for the future

Data relating to the number of Australians who have Dystonia is needed and Research into other forms of Dystonia
Hariklia - ADSG Admin

We will continue to strive and advocate for needed research, better treatment and more awareness, so that others won't spend 15 years+ looking for a diagnosis of this Neurological Movement Disorder!
Lisa - ADSG Admin



Dystonia research is crucial to lead to a faster diagnosis and more beneficial treatment
Lee - ADSG Admin

We need a multidisciplinary team approach to Dystonia
Sue - ADSG Admin

2011

Support Group was formed

Four people from overseas groups and forums initially joined.

10 Years later we have around

1.2k Members



ABOUT US

We are a national group that provides support and information to Australians living with Dystonia, their family members, carers and parents of children with Dystonia.

JOIN OUR GROUP



No membership or joining fee



WHAT IS DYSTONIA

Neurological Movement Disorder occurring at any age. It affects part of the brain that controls movement. Signals are sent to muscles causing overactivity.



SYMPTOMS

It can affect many areas of the body. Results in pain, muscle spasms, twisting, tremors and other uncontrollable movements.



TREATMENTS

Botulinum toxin injections, muscle relaxant medications, complementary or physical therapy, Deep Brain Stimulation and other treatments.

NO CURE



MORE ABOUT US
Visit our website

www.australiandystoniasupportgroup.wordpress.com

Scan with mobile device



First set of cards made.
New designs over the years.

Other publications were composed such as flyers.

More here → [ADSG Publications](#)

www.australiandystoniasupportgroup.wordpress.com

2012

Support Meetings Started



First one was in Brisbane (QLD)

More followed across Australia



QLD End of year Gathering



Melbourne Gathering



First National Patient Event

In 2014, we had our first national Patient Event (Executive Director of Dystonia Europe was present).

Visit our website for more → [Events](#)

2014

Dystonia Awareness Month

In 2014 we had a very first Australian Dystonia Awareness Month (September).

A Dystonia awareness website and a Facebook page was set up. Group members joined in and helped spread the word and raise awareness. The awareness website had info on Dystonia, updates and events, Dystonia stories, an awareness video and links to further information. Following this an AD SG website was formed. More here → [Finally AD SG website is online!](#)



The Dystonia Awareness month runs yearly. Have a look at our webpage!

More here → [Dystonia Awareness Month](#)

www.australiandystoniasupportgroup.wordpress.com

Dystonia Awareness Month

Runs every year - More Memories!



September is Dystonia Awareness Month!

We need you to help make a difference and spread the word!

What are you going to do this September?

Lisa McInnes Designs 2015

Causes Muscle Spasms Uncontrollable Movements Tremors	Can be genetic
Affects Many body areas	Occurs any age
Not well known	Research Needed
Dystonia Movement Disorder Be Aware	Visit our website http://bit.do/ADSG

Hi my name is Brooke

I have had dystonia since I was really little. Dystonia for me was constant and often left threatening. My body twisted and turned into uncomfortable positions. My dystonia got really bad in the end, I was always in pain, I couldn't eat, walk or really go to school and it wasn't much fun. When I was 16 I had deep brain stimulation. Since I have had DBS I have been lucky because it helped control my dystonia and I have been able to go back to school again, I have learnt to walk again and I even can ride a bike now! I now try to tell everyone about dystonia so that they know about it and can help other people with it.

I have had Dystonia all my life but that hasn't stopped the joy from doing things I love.

Brooke

YOU'RE AMAZING!

www.australiandystoniasupportgroup.wordpress.com

Dystonia

Shaken, stirred or a little twisted

Neurological Movement Disorder

Uncontrollable movements
Muscle spasms
Abnormal postures

www.australiandystoniasupportgroup.wordpress.com



I'm McKenzie and I'm 9 and have generalised dystonia, a rare type of Dystonia that usually appears in childhood and affects the whole body. Before Deep Brain Stimulation (DBS) I would suffer Status dystonicus or severe muscle contractions. I spent every other day in ICU for medical intervention to help stop the storms and this was a constant battle. Although DBS saved my life, I continue to struggle daily with muscle spasms and pain.

I want Dystonia awareness because

"Dystonia....a real pain in the neck..."

I have Cervical Dystonia a type that affects my neck muscles causing spasms, twisting and excruciating unrelenting pain!

www.australiandystoniasupportgroup.wordpress.com

Dystonia

I live with Spasmodic Dysphonia. It robs me of my voice.

I have Hand Dystonia. The Disorder you can't shake off.

I have Cervical Dystonia. Not bitter. Just twisted.

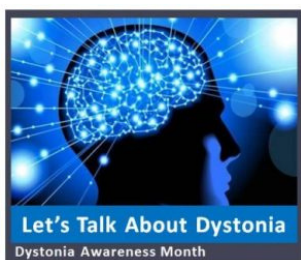
We share what it's like

I live with lower limb Dystonia. A headstrong twisted foot and leg.

It's a Neurological Movement Disorder which causes muscle spasms, twisting or tremors.

There are many forms of Dystonia affecting children and adults.

www.australiandystoniasupportgroup.wordpress.com



Dystonia Awareness

I live with Generalised Dystonia. It has seized many areas of my body.

From ripping muscles to vigor contractions to crushing pressure!

Generalised Dystonia
A rare form of dystonia affecting multiple areas of the body. Often starts in the lower limbs then spreads to other areas such as the neck and trunk.

www.australiandystoniasupportgroup.wordpress.com @AusDystoniaSG

We Want Dystonia Awareness Because.....

- Same diagnosis but many different symptoms
- The pain of Dystonia. It's always there
- We can look normal and suffer agonising spasms
- To give people an understanding of our symptoms
- For a quick diagnosis
- It is not well known
- We are just like you but we are strong and unique with our own quirks and twitches
- We need a cure in our lifetime
- For more research and treatments
- I may be jerky but I'm a lovely person inside

What is Dystonia
Neurological Movement Disorder which affects both adults and children
Causes uncontrollable movements and spasms

Australian Dystonia Support Group

www.australiandystoniasupportgroup.wordpress.com

September is Dystonia Awareness Month!

BOTOX PAIN SPASMS DBS TWISTING

SUPPORT ADVOCATE RESEARCH CURE

Lisa McInnes Designs 2018
Our ADSG Website: <https://australiandystoniasupportgroup.wordpress.com/>

Dystonia
NEUROLOGICAL MOVEMENT DISORDER

Awareness!

FOR A CURE!

Lisa McInnes Designs 2016
ADSG@live.com.au

September is Dystonia Awareness Month!

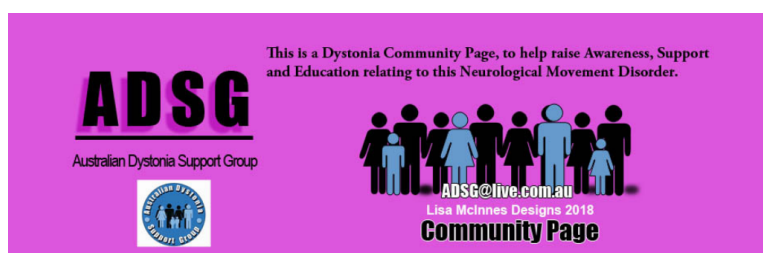
EDUCATION SUPPORT RESEARCH CURE

Our ADSG Website: <https://australiandystoniasupportgroup.wordpress.com/>
Lisa McInnes Designs 2019

2015

Social Media Pages

In 2015 we launched a Community Facebook and Twitter Page. The AD SG website was also updated and revised over the years.



1.1 Million Reaches

Not bad for a support Group!

 Find us on 
Facebook

2.5K Likes 



Find us on Facebook
[ADSG Facebook](#)

 **Follow Us On**
twitter

Visit us on Twitter
[@AusDystoniaSG](#)

[Join Our Free Support Group](#) 

Australian Dystonia Support Group



Our Facebook Community Page - Many posts!

Dystonia Research . . .
Effective Treatment . . .
Cure . . .
All lead to . . .
Hope, Health and Happiness
 Dystonia - Neurological Movement Disorder
 Australian Dystonia Support Group

#BrainAwareness #Dystonia
Support Brain Research
Dystonia Research is important

To learn more about the disorder and boost diagnosis
 Helps discover new treatments or therapies

www.australiandystoniasupportgroup.wordpress.com

What is Dystonia?
 Neurological Movement Disorder which causes muscle spasms, tremors or other movements
 There is no cure

Did you know?
 Dystonia can affect many body areas
 Any age
 Male or Female

www.australiandystoniasupportgroup.wordpress.com

DYSTONIA AWARENESS
 Pain
 Twisting
 Spasms
 Botox
 Dystonia
 Cure
 Support
 I'VE MADE IT MY MISSION
 Lisa McInnes Designs 2015

What is Dystonia?

Dystonia is a Neurological Movement Disorder which causes muscles to contract and spasm involuntarily causing pain, tremors, twisting and other uncontrollable movements.

Dystonia can affect any part of the body including the arms, legs, neck, eyelids, face or vocal cords. Dystonia has no cure. Please help us to spread awareness of Dystonia, which affects the lives of thousands of Australians on a daily basis.

Lisa McInnes Designs 2015

Dystonia
 Muscles and Struggles
 Pain and Strain
 Twists that Persist
 Brain is to Blame!
 Neurological Movement Disorder

www.australiandystoniasupportgroup.wordpress.com
 Composed by Haniklia Nguyen

Dystonia

A Neurological Movement Disorder

Affects the Brain and Muscles
 Causes uncontrollable movements

www.australiandystoniasupportgroup.wordpress.com

Support Advocate Cure

DYSTONIA!

The Third Most Common Movement Disorder after Essential Tremor & Parkinson's Disease!
 Lisa McInnes Designs 2016

#DystoniaAwareness
 Dystonia is not well known and often misdiagnosed

There are rare forms of Dystonia
 Myoclonus Dystonia
 Dopa-responsive Dystonia
 Generalised Dystonia
 Rapid-onset dystonia parkinsonism
 Paroxysmal Dystonia
 #RareDiseaseDay

www.australiandystoniasupportgroup.wordpress.com @AsaDystoniaSG

Dystonia Awareness

The first step forward to a future cure.
 Make it your Mission to spread the word!

Lisa McInnes Designs 2015

DYSTONIA
 MUSCLES BEHAVING BADLY

It may not be a famous ACTION film
 But it has more ACTION than you think!

ADMIT ONE
 Concession for
 Haniklia Nguyen

DYSTONIA
 It's in the Brain
 Causes overactivity
 Uncontrollable movements

#DystoniaAwareness #DystoniaAUS

Follow us
 Did You Know?
 www.australiandystoniasupportgroup.wordpress.com

Dystonia
 Are you aware?
 There are rare forms of Dystonia

Myoclonus Dystonia
 Dopa-Responsive Dystonia (DRD)
 Paroxysmal Dystonia

Australian Dystonia Support Group
 RAREDISSEASDAY

Dystonia Awareness!
 Neurological Movement Disorder

PAIN SUPPORT TWISTING
 CURE BOTOX SPASMS

Lisa McInnes Designs 2015

2014 Present

Yearly and Quarterly Reviews

In 2014 we published our first yearly review. In 2018 we expanded to quarterly reviews.

Connecting & Supporting

A look back at 2017



Australian Dystonia Support Group

During 2017 we connected with more networks, health professionals, researchers and supported people with Dystonia. We now have close to 650 members! To join our group please click link [Join our Group](#). You can contact us via the 'Contact Us' page or at ADSG@live.com.au. It is free to join and there is no ongoing membership fee.

Support meetings and presentations

Members had the opportunity to meet and share experiences, provide emotional support or connect with people who have Dystonia, as well as attend presentations from a variety of health professionals. Two information sessions were hosted by the Asia-Pacific Centre for Neuromodulation, part of the Queensland Brain Institute (QIBI) for patients and carers living with Dystonia, Parkinson's Disease, Essential Tremor and Tourette's. A thanks for inviting ADSG members to attend!



It was a very informative Movement Disorders information session

Visit Our Page 'Support Meetings'

www.australiandystoniasupportgroup.wordpress.com

Dystonia Awareness Month 2017

Thanks for Caring and Sharing!

We reached 37,044 people

Our Dystonia Awareness Slideshow reached close to 14,000 people - Link: [Dystonia Slide](#)

Great images & info shared

A popular image reached 3,500 people!

Link to image: [September is Dystonia Awareness Month](#)

Most popular posts by members!

[McKenzie's and Brooke's](#)
[How to make a Hot Chocolate with Dystonic Tremor](#)

A BIG thanks to all who participated!

Australian Dystonia Support Group

Yearly Review 2018



News

Supporting, Linking and Sharing

During 2018 we supported people with Dystonia and their family members. We linked further with networks, health professionals or researchers and shared information as well as updates relating to Dystonia. We would like to give thanks to organisations and networks who have connected, collaborated with or supported ADSG.

We are now listed on the [Healthdirect National Health Services Directory \(NHSD\)](#). There is a diverse group of people using the directory and since our details are included to the search options they can reach us. It is also connected with health professionals and other health services. They can find us and refer their patients or clients to us if they wish to for support.

We are pleased to announce that ADSG was selected for preservation by the National Library of Australia and listed under [Pandora Australia's Web Archive](#). The Pandora is a selective archive. The National Library and its partners select those that they consider are of significance and have long-term research value. We are grateful to be listed!

Please read this yearly review for more!



Join Our Group

(Open to Australians)
Click link: [Join our group](#)

Once directed to group page click 'Join Group' tab. Please check for a reply in your Facebook messages inbox. The other option is to email us at ADSG@live.com.au. Jan 2019 - 800 members

www.australiandystoniasupportgroup.wordpress.com

Australian Dystonia Support Group

Yearly Review 2019



Who are we?

We are a national group that provides support and information to Australians who have Dystonia, their family members, carers and the parents of children with Dystonia.

It is free to join our group.

Join Our Group 

Another Productive Year!

During 2019 individuals with Dystonia and their family members connected with our group. We received daily requests to join our group and numbers increased by 15%.

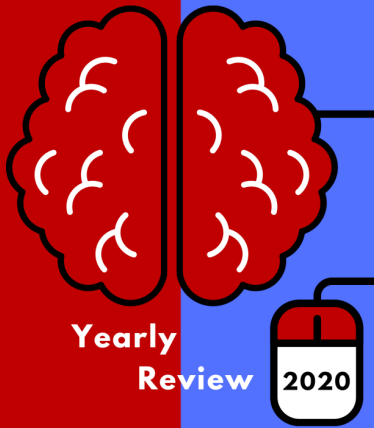
We communicated with networks and researchers as well as shared global information or updates relating to Dystonia.

Admins of our group or members have also helped to raise awareness!

We thank those we have collaborated with for their support.

Please read our recap of 2019 for more!

Australian Dystonia Support Group



Yearly Review 2020

www.australiandystoniasupportgroup.wordpress.com



Quarterly Review

November 2019



QUARTERLY REVIEW

APRIL 2020



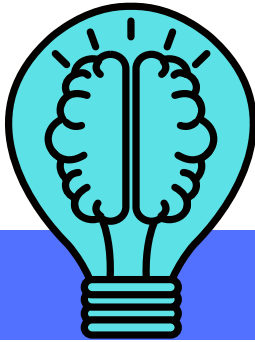
View more here!
→ [ADSG Reviews](#)



www.australiandystoniasupportgroup.wordpress.com

Research Involvement

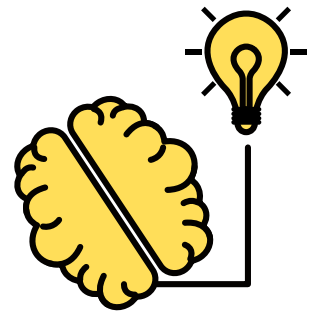
ADSG has made connections with researchers. We were selected for preservation by the National Library of Australia and listed under Pandora Australia's Web Archive. They select those they consider are of significance and have long-term research value.



We have listed some of the research topics we shared or were connected with.

Research Topics

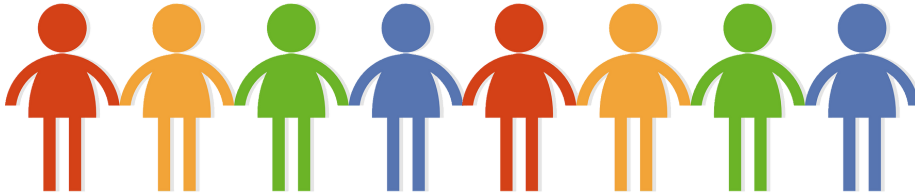
- [Movement and postural control in dystonia patients](#)
- [Dystonia Coalition Project](#)
- [Cervical Dystonia Non-invasive Brain Stimulation](#)
- [QBI Longitudinal Study of Movement Disorders](#)
- [Functional screening tests in cervical dystonia](#)
- [UTS Dystonia and Pain](#)
- [Exploring the interaction between the brain & the mind in dystonia](#)
- [Investigating vision in relation to Dystonia](#)
- [Physical Activity Motivators and Benefits in People with CD](#)
- [Sequencing the genomes of people with Cervical Dystonia](#)
- [Frequency of medication use in patients with dystonia.](#)
- [Investigating attention and decision-making in motor disorders](#)
- [How Do Individuals with Chronic Dysphonia Cope?](#)
- [Physical activity in people with Dystonia](#)
- [Tele-yoga Study for CD](#)
- [Impact of COVID-19 on people with dystonia](#)



[Visit our
Research
page](#)

Community Connections

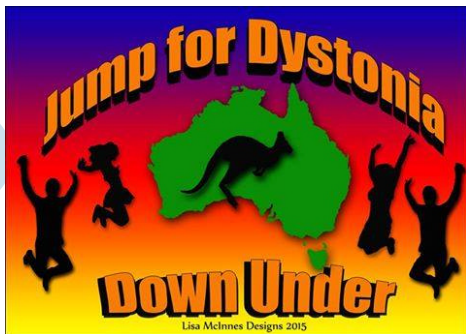
We communicated with other networks and advocated as well as supported people with Dystonia and their families. We have shared information or events and our details were listed with directories.



[Visit our Recent News Page](#)



Lovely Memories and Events



QLD - Associate Prof Bradnam spoke about Dystonia research



Dystonia Program – Parkinson's Australia National Conference



Dystonia Awareness - South Australia



Dystonia Awareness - Melbourne



Nolan & Juls - Dystonia Fundraiser Rickshaw Run