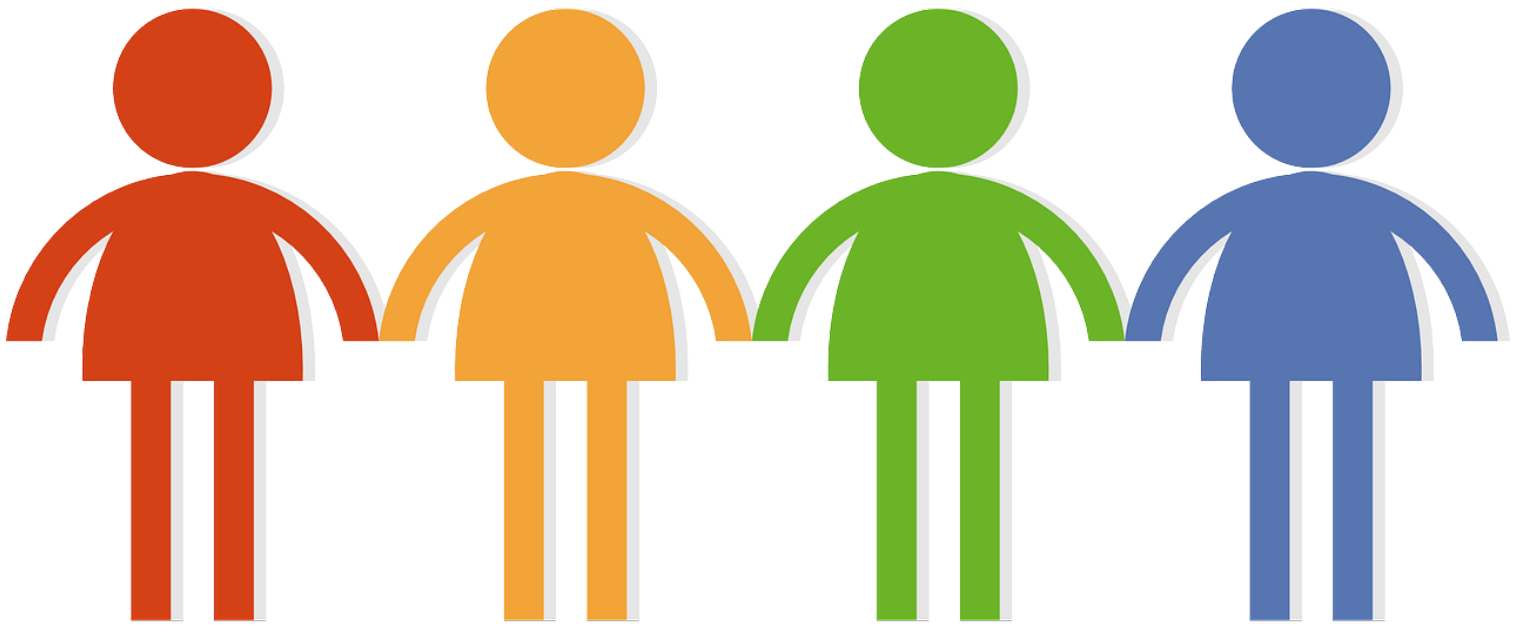


Australian Dystonia Support Group

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!

Gatherings and Events



Support Meetings and information sessions

Support meetings were arranged by ADSG or group members. Our founder of group, Lee Pagan, visited Melbourne and it was great to catch up with her and some of our Melbourne members!

There were info sessions by other networks, which included information about Dystonia, treatments or therapies and updates on research.



Melbourne Gathering with Lee Pagan!

It takes time and effort to organise these valuable gatherings or info sessions so a BIG thanks to those who organised them.



QLD End of Year Gathering



Visit our pages for more!

Meetings



Events



Dystonia Awareness Month 2019

It was another great Dystonia Awareness Month in September.

We reached 26,701 people!
(via Facebook)



Thank you to Lisa McInnes one of our admins for providing her amazing awareness images. One of her images reached 5,352 people!



Make it your mission to raise awareness in 2020!



Quick Tips

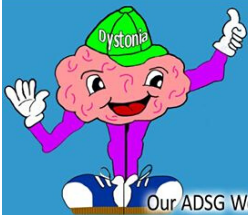
Share our Dystonia Awareness Slide

Have a Dystonia awareness display at a pharmacy or chemist

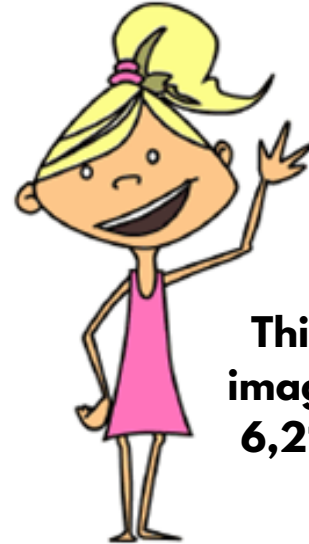
Leave Dystonia flyers or posters at a clinic or Hospital

September is Dystonia Awareness Month!

● EDUCATION ● SUPPORT ● RESEARCH ● CURE



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



This popular image reached 6,217 people!

To all who participated!

 **THANKYOU**

Visit our Dystonia Awareness Month Page



Causes
Muscle Spasms
Uncontrollable Movements
Tremors

Can be genetic



Affects Many body areas



Dystonia
Movement Disorder
Be Aware

Occurs any age



Not well known



Visit our website
<http://bit.do/ADSG>



Research Needed



Online Review



Our Website

Views to page steady

 **9,264 Visitors**

How did they find us?

Popular Referrers



Google Search

Facebook

Brain Foundation

Australian Dysphonia Network

Popular Pages/Posts



[Movement Disorder Specialists](#)

[How is Dystonia diagnosed?](#)

[Types of Dystonia](#)

['Can't hold my head up!' Story](#)

[Physical activity in people with Dystonia Survey](#)

We have updated our flyer. Visit the AD SG Information Page to view or share the flyer.

AD SG A5 Flyer 

Our Community Facebook Page

2,210 Likes



13%



Page Reached

151,475 People

Popular Posts

[Did you know - Dystonia](#)

[Dystonia Awareness Month](#)

[Image](#)

[Dystonia - Movement Disorder](#)

[What causes Dystonia](#)



Find us on

Facebook

[Trust It or Trash It?](#)

Use this tool to judge the quality of information online

Our Twitter Page

Followers

13% increase



[@AusDystoniaSG](#)

Connecting and Sharing

Information and Articles

Healthdirect - [How to get the most out of your doctor's appointment](#)

Dystonia Europe Newsletter (Winter) 2019
[Research and news](#)

DMRF - [Eyes on Me: Dystonia & Social Anxiety](#)

DMRF - [Dystonia Dialogue Newsletter Winter 2019](#)

BEBRF - [Blepharospasm: Quick tips to calm eyes spasms](#)

Webinars, Videos and Podcasts

EAN 2019 | [The Clinical Evaluation of Dystonia](#)

MDS Podcast - [The Treatment of Upper Limb Tremor with Botulinum Toxin: An Individualized Approach](#)

MDS Podcast - [Congress 2019 Special Issue: Dystonia](#)

Have you missed updates or information during 2019?

Read our Quarterly Reviews!

[Quarterly Review Nov 2019](#)

[Quarterly Review August 2019](#)

[Quarterly Review May 2019](#)

For Noting

MBS Review Taskforce

A new MBS item for Botulinum toxin treatment of focal dystonia was recommended. An [Implementation Liaison Group \(ILG\)](#) for Neurosurgery and Neurology has been established to support the effective implementation of the Government endorsed recommendations. PBAC and MSAC evaluations would likely be required to support the creation of these items, after a suitable sponsor submits the relevant applications. Community members or patients can submit their feedback also. We will keep you updated!

[Link to Final Report](#)



Lee Pagan, our admin received an award for her community achievements, including for Dystonia support and awareness. Congratulations!



Australian Charter of Healthcare Rights

Have you seen the updated Edition?



Click to view

My healthcare rights

This is the second edition of the **Australian Charter of Healthcare Rights**.

These rights apply to all people in all places where health care is provided in Australia.

The Charter describes what you, or someone you care for, can expect when receiving health care.

I have a right to:

Access

- Healthcare services and treatment that meets my needs

Safety

- Receive safe and high quality health care that meets national standards
- Be cared for in an environment that is safe and makes me feel safe

Respect

- Be treated as an individual, and with dignity and respect
- Have my culture, identity, beliefs and choices recognised and respected

Partnership

- Ask questions and be involved in open and honest communication
- Make decisions with my healthcare provider, to the extent that I choose and am able to
- Include the people that I want in planning and decision-making

Information

- Clear information about my condition, the possible benefits and risks of different tests and treatments, so I can give my informed consent
- Receive information about services, waiting times and costs
- Be given assistance, when I need it, to help me to understand and use health information
- Access my health information
- Be told if something has gone wrong during my health care, how it happened, how it may affect me and what is being done to make care safe

Privacy

- Have my personal privacy respected
- Have information about me and my health kept secure and confidential

Give feedback

- Provide feedback or make a complaint without it affecting the way that I am treated
- Have my concerns addressed in a transparent and timely way
- Share my experience and participate to improve the quality of care and health services

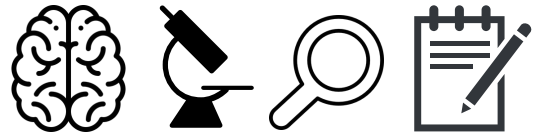


PUBLISHED JULY 2019

AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

For more information
ask a member of staff or visit
safetyandquality.gov.au/your-rights

Research Links



Research Papers

Journal of Neurology, Neurosurgery and Psychiatry - [Risk of spread in adult-onset isolated focal dystonia: a prospective international cohort study](#)

Elsevier - [Whole genome sequencing for the genetic diagnosis of heterogenous dystonia phenotypes](#)

Frontiers in Neurology - [Physical Activity, Sedentary Behavior, and Barriers to Exercise in People Living With Dystonia](#)

Trials Running

Movement Disorder Research Project – [Participants needed!](#)

Visit our [Dystonia Research](#) Page to participate in other trials.

Have you seen this Survey? Dystonia - Rare or not?



<https://surveys.dystonia-europe.org/survey/public/RAREORNOT>

Cochrane Crowd Colloquium Challenge 2019

Hariklia, our admin was one of the top three screeners!

It was a 48 hour marathon challenge screening citations to identify randomized controlled trials (RCTS). She undertook this challenge while coping with the symptoms of Dystonia. She received a prize pack for her achievement which included a Cochrane Crowd T-shirt, Test Treatments book signed by two of the authors and badges. Click link to post about the Challenge and Hariklia's thoughts! Link here: [2019 Chile Challenge Winners!](#)



As a Cochrane Citizen Scientist I help to identify or classify quality research to support informed decision-making about healthcare treatments.

Research helps to understand Dystonia better and aim for new treatments or a cure

Donate

