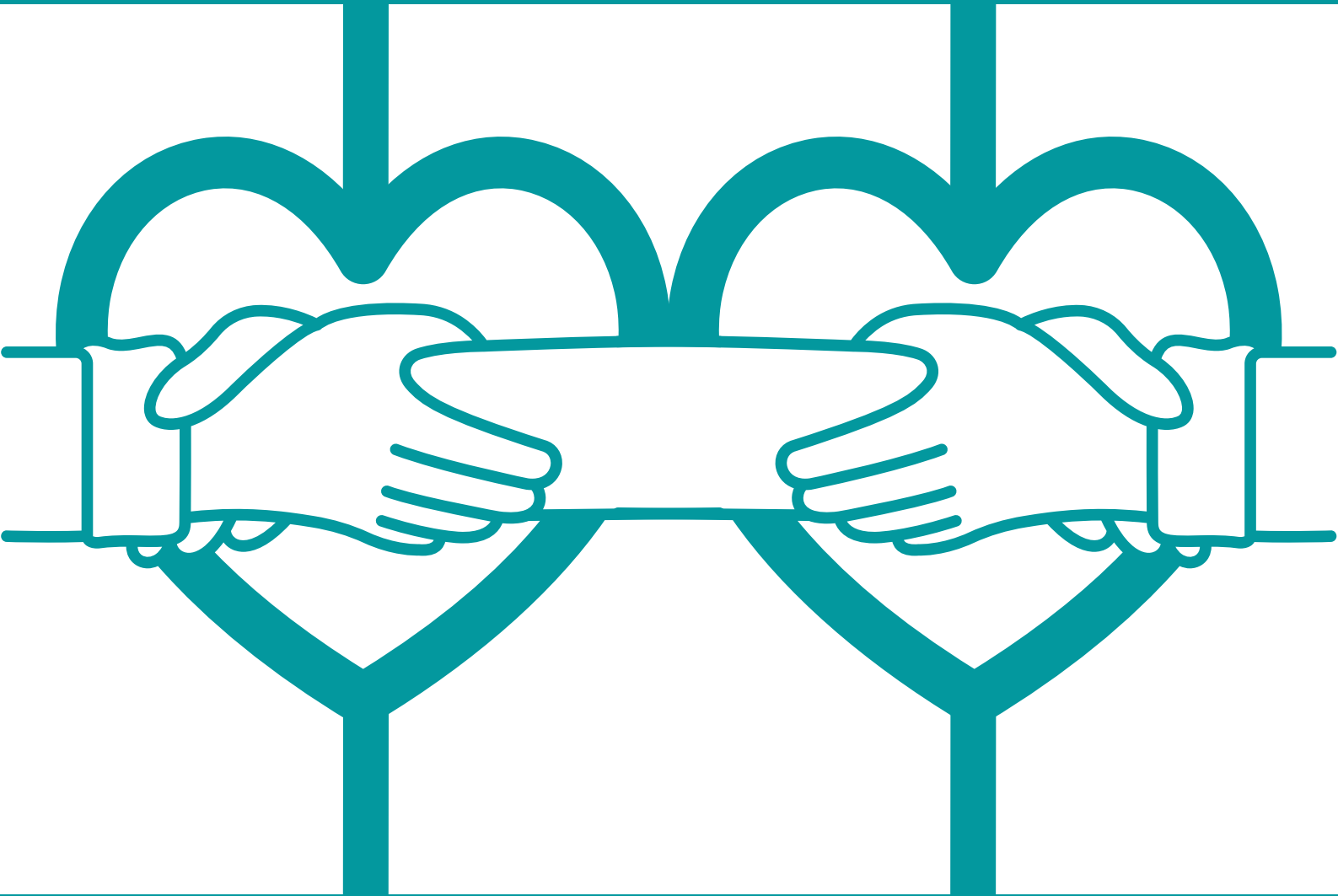


ADSG Yearly Review

Supporting and Connecting



A look back at 2022





Who are we?

We provide information and support for Australians who have Dystonia, their family members, carers and parents of children with Dystonia. More details here: [About ADSG](#) 

It was another busy year of providing support, connecting and raising Dystonia awareness. There were very few in person meet ups but it was great to see group members engaging online! Group membership has increased by 21%.

Join Our Group
No Membership Fee
No Joining Fee



The Queensland Government Department is currently working towards including Dystonia to their [Health Conditions Directory](#) and healthdirect has kindly included a [Dystonia page](#) to their website. This will help the public easily find support relating to Dystonia especially since it's not well known. We have seen an increase of people finding us through these type of networks. We would like to thank them and other Networks for their support. **Keep an eye out for Dystonia awareness resources during 2023!**

Online Review

Australian Dystonia Support Group Website



Website Views
7.6K



Highest Referrers
Google Search
Facebook/Twitter
healthdirect

Popular Pages/Posts

[Movement Disorder Specialists \(Page\)](#) ↗

[What is Dystonia \(Page\)](#) ↗

[Dystonia Research \(Page\)](#) ↗

[Can't Hold my Head Up Story \(Page\)](#) ↗

[Dystonia Awareness Month](#) ↗ and [Slideshow \(Post\)](#) ↗



Our Facebook Community Page



2.7K Likes
Up 3.8%



Page Reach
54.2K Up 2.6%



Popular Posts

[Dystonia Awareness Fast Facts Slideshow](#) ↗

[Rare Disease Day](#) ↗ & [World Voice Day](#) ↗

[Dystonia Awareness Image 1](#) ↗ & [Image 2](#) ↗

 Find us on
Facebook

Our Twitter Page



Followers
Up 0.7%

Follow us on Twitter



Dystonia Awareness Month 2022



Facebook Posts

8.6K

People Reached

3.2K

Popular Post

[View Slide](#)




Awareness increased in 2022!

We composed a Dystonia Fast Facts Slideshow and images kit for the Awareness Month (Sep). Global materials or posts were shared also. Thanks to all who participated.

[Visit our Dystonia Awareness Month Page](#) 

Key Upcoming Events

Rare Disease Day | 28 February 2023 

Brain Awareness Month | 13-19 March 2023 

World Voice Day | 16 April 2023 

More on the Events Page



Brain Awareness Week

Brain Foundation Event

**13 - 17
March
2023**



Brain 
Awareness Week

**Dystonia Information
Dystonia Speaker
Patient Dystonia Story**

**Learn more about Brain Health
Awareness of Brain Conditions**

[Brain Awareness Week 2023](#) 

More here: [ADSG Events](#) 

www.australiandystoniasupportgroup.wordpress.com

Resources and Links

Information and Articles

Dystonia Dialogue Newsletters (DMRF) [↗](#)

DMRF Canada Newsletters/Dystonia Canada Report) [↗](#)

World Movement Disorders Day - Increasing understanding of Dystonia [↗](#)

StatPearls Publishing Continuing Education

- **Laryngeal Botulinum Toxin Injection** [↗](#)
- **Benign Essential Blepharospasm** [↗](#)
- **Tartive Dystonia (TD)** [↗](#)

Dystonia: What Is It, Causes, Treatment and More (Osmosis Elsevier) [↗](#)

Anchor/ health reporter shares her story with voice disorders (KTBS News) [↗](#)

Dystonia: Frequently asked questions (Dystonia UK) [↗](#)

Dystonia - More than a Movement Disorder Resources (DMRF Canada) [↗](#)

Dystonia 16 (DYT16) - MedlinePlus [↗](#)

[Visit our News Page](#) 

UPDATES

Medicare Benefits Schedule

[Genetic testing for the diagnosis of early-onset or familial neuromuscular disorders](#) [↗](#)

MSAC supported the creation of new Medicare Benefits Schedule items for the genetic testing of certain patients with neuromuscular disorders (NMDs). Initially the application included a Neuropathy panel which listed specific genes. THAP1 & TOR1A (Dystonia related) were also listed. The panel will only run a certain number of genes and those selected will be in line with clinical characteristics & clinically relevant. Please discuss the Neuropathy Panel or tests with your doctor if you would like to know more. Visit our website for links to Genetic Services and other information. [Links Page](#) [↗](#)

Resources and Links

UPDATES

TGA Consultations

Update: Repurposing of Prescription Medicines Consultation

Feedback was provided in regards to repurposing of medicines that may help to reduce the barriers in extending an indication for an existing medicine such as Botulinum Toxin. There was a follow up consultation during 2022 and the Australian Government Department is now using the feedback to shape regulatory reforms and policy. To view the outcome details visit the TGA consultation webpage. Link: [Repurposing of Prescription Medicines](#) ↗

Paracetamol Proposed Amendments

An independent review of Paracetamol examined the incidence of serious injury and death from intentional paracetamol overdose. There was a public consultation on the recommendations including possible options to amend the Poisons Standard. Details & updates here: [TGA Consultation Page](#) ↗

For Noting

Transition of Quality Use of Medicines programs

A range of Quality Use of Medicines (QUM) functions are transitioning to the Australian Commission on Safety and Quality in Health Care. This includes NPS Medicinewise and Choosing Wisely Australia. Updates here: [Transition of Quality Use of Medicines programs](#) ↗

Complete a Survey!

National Safety and Quality Primary and Community Healthcare Standards Guide for Healthcare Services (Draft) ↗

Resources and Links

Top tips for finding good health information online

Good health information can help you make informed decisions. There are things you can do to find good health information online and judge whether it is right for you.

Look for information that is relevant to you

- Does it answer your questions?
- Is it Australian?
- Does it connect you to local services?

Look for trusted sources

- Is it written by an expert, or expert organisation?
- Is there evidence for the information?
- Is the information current, and up-to-date?

If you connect with people online, remember other people's experiences may not be typical and might be different to yours

Check the information with your healthcare professional

Ask for help if you need it to find health information online or judge its quality

Look out for warning signs

- Does it try to sell you something?
- Does it create a sense of fear or panic?
- Does it only give you one choice or option?
- Does it rely on just one case or experience?

Look for information you can understand

- Does it use simple words?
- Does it explain difficult ideas?

AUGUST 2021



AUSTRALIAN COMMISSION
ON SAFETY AND QUALITY IN HEALTH CARE

Scan the QR code for more information
or visit safetyandquality.gov.au/good-health-information



Top tips for finding good health information online: Reproduced with permission and developed by the Australian Commission on Safety and Quality in Health Care (ACSQHC) - Sydney (August 2021)

Resources and Links



Webinars and Podcasts

Dysphonia International Webinar

- [Advances in Spasmodic Dysphonia Research](#)
- [Q&A Session Part II](#)

Botulinum Treatment Options for Spasmodic Dysphonia Webinar (Dysphonia International) [Symposium 2022 \(BEBRF Foundation\)](#)

Treatable dystonias and dystonia in inborn errors of metabolism (ERN-RND Webinar)

Mindfulness Practices for Health and Well-Being (Dystonia of San Diego Webinar)

Reach Out, Reach All Webinars (Dytonia UK)

- [Your Questions Answered with Dr Tom Gilbertson Part 2](#)
- [Your questions answered - Sleep and Dystonia](#)
- [Your questions answered - Mental Health and Dystonia](#)

Ask the Expert: Q&A Session on Spasmodic Dysphonia and Related Voice Conditions (Dysphonia International)

Beyond Dystonia: Are We Detecting and Managing Non-Motor Symptoms Properly? (DMRF Canada)

Dystonia: Diagnosis, Phenomenology, Etiology and update on treatment Webinar (UCSF)

Transforming Lives with DBS: a PD, ET and Dystonia Patient Perspective (PMD Alliance) Webinar

Dysphonia International Webinar

- [A Tour of Voice Disorders with a Focus on Spasmodic Dysphonia](#)
- [Part II: Q&A](#)

Botulinum Neurotoxin Injections for Dystonia Considerations for Best Results (DMRF Webinar)

Dystonia Coalition 10th Annual Meeting - Therapeutic needs in Dystonia

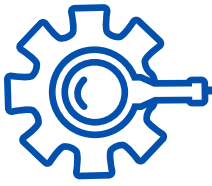


Podcasts

Artist and Dystonia advocate Sheri Grube Story

Runner's Dystonia Featuring Kara Goucher

Research Links



Get Involved in Research

Current Clinical Trials/Studies

Take a Survey! Diet and Dystonia

The main goal of this research is to examine how diet affects dystonia, and if so how dystonia specialists could address these problems. Click button to direct you to survey.

[Diet and Dystonia](#)



Research Involvement

Find out as much as possible about the trial. Discuss questions with your doctor and the research team.

[Questions to Ask](#)

MRI guided focused ultrasound (MRgFUS) Trial

It is a clinical trial assessing the role of MRI guided focused ultrasound (MRgFUS) in individuals aged over 18 with an established diagnosis of focal hand dystonia, either writer's cramp or musician's dystonia, who have failed or poorly tolerated medications and/or botulinum toxin therapy. Click button to direct you to the trial.

[MrgFUS Trial](#)



MRI and Brain Stimulation Study

Investigating whether brain stimulation can reduce cervical dystonia symptoms. Click button to direct you to the study.

[Seeking Patients](#)



[More trials](#)

[Donate To Dystonia Research or Cause](#)