



# Yearly Review

2023



**Australian Dystonia Support Group**

[www.australiandystoniasupportgroup.wordpress.com](http://www.australiandystoniasupportgroup.wordpress.com)

## Join Our Group

**No membership or joining fee**

**We provide information and support for  
Australians who have Dystonia, their family  
members, carers and parents of  
children with Dystonia** 

# Australian Dystonia Support Group

Support and information to Australians who have Dystonia, their family members, carers and parents of children with Dystonia



## Who are we?

We are a national volunteer based support group that provides support and information to Australians who have Dystonia. We also welcome family members, carers and the parents of children with Dystonia. Our role is to also work together with organisations, networks and researchers to raise more awareness in the community.

## Is there a joining or membership fee?

There is no membership or joining fee. Members include those who have Idiopathic (Primary) and Acquired (Secondary) Dystonia.

## What support do we provide?

- A closed online support group for members to share their experiences and connecting with others who live with similar challenges
- Sharing of support gatherings, Dystonia information sessions or seminars
- Dystonia information and updates by other networks and contacts
- Communication with researchers in relation to Dystonia clinical trials to share with members
- Flyers, posters and other publications for members and the community
- Education about Dystonia and a yearly Dystonia Awareness Month
- Necessary feedback to networks and contacts to help them understand what is important to people with Dystonia and their families

## Are we funded?

We have no funding support and our website, social media pages, publications and other administration work is done on a volunteer basis. Publications are printed by the Admin Team or Members at their own expense. Members volunteer their time to organise support gatherings, information sessions or seminars.

# Online Review

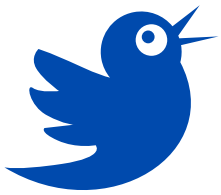
## Australian Dystonia Support Group



Website Views  
**10K**  
UP 31.5%



Facebook Page  
**Reach 43.6K**  
DOWN 19.5%



Twitter Followers  
**UP 2.8%**



Facebook Page  
**Likes 2.7K**

**Group  
Membership  
Increased  
by 10%**



### Top Website Pages/Posts

- [Movement Disorder Specialists \(Page\)](#) ↗
- [What is Dystonia \(Page\)](#) ↗
- [Dystonia Awareness Month \(Page\)](#) ↗
- [Dystonia Treatments \(Page\)](#) ↗
- [Rare Disease Day – Did you know there are rare forms of Dystonia? \(Post\)](#) ↗
- [ADSG 10 YEAR Journey and Memories \(Post\)](#) ↗

### Top Website Referrers

Google Search/Facebook  
Brain Foundation/Healthdirect



[Find us on Twitter](#)

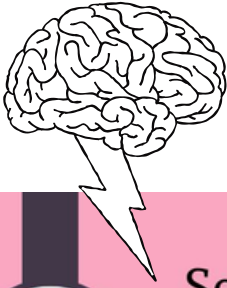
### Popular Facebook Posts

- [Dystonia Awareness Month | Make It Known](#) ↗
- [How to Make a Hot Chocolate with Dystonic Tremor](#) ↗
- [Brain Awareness Week | Dystonia is not well known](#) ↗

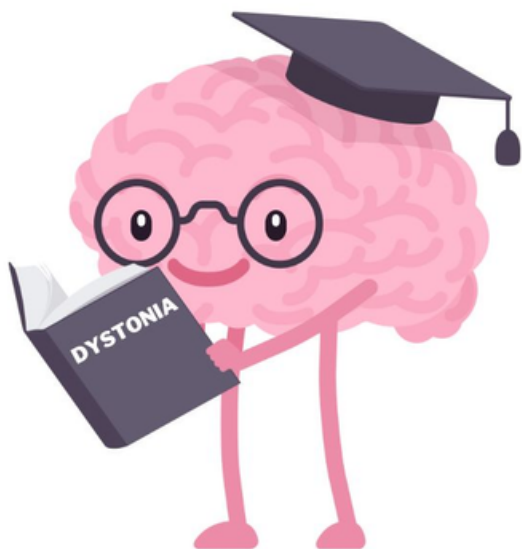
Find us on  
**Facebook**



# Dystonia Awareness Month 2023



A Good Book Will Keep Your Brain Distracted



## Facebook Posts

**7.2K** People Reached

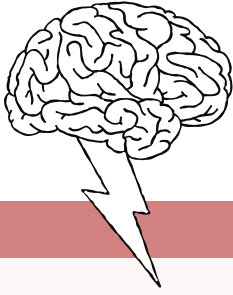
**3.1K** Popular Post

We composed Dystonia resources to share including a social media kit, posters and a bookmark.

**A BIG thanks to all who shared our posts!**

**Visit Our DAW Post** [↗](#)

# Movement Disorders Day 2023



## Dystonia at a Glance

### Movement Disorder



#### Relates to the Brain

Causes muscle spasms  
or uncontrollable  
movements



#### Different forms

Affects various body  
areas such as the eyes,  
throat, neck and legs



#### Can affect daily life

Symptoms include  
pain, tremors and  
awkward postures



#### It's not well known

Occurs any age and  
can take 4-6 years  
for a diagnosis

We promote this  
yearly event to raise  
further awareness of  
movement disorders  
especially Dystonia as  
it can be difficult to  
diagnose, treat and  
understand.

[About Dystonia ↗](#)

[Dystonia Life  
Experiences ↗](#)

[WMDD Resources ↗](#)

[View Our  
WMDD Post ↗](#)

**SHARE**



# Brain Awareness Week



## AWARENESS OF BRAIN CONDITIONS

#BRAINAWARENESSWEEK

13-19 MARCH 2023



#DYSTONIA

[www.australiandystoniasupportgroup.wordpress.com](http://www.australiandystoniasupportgroup.wordpress.com)

[BAW Dystonia Resources Kit ↗](#)

[Our BAW Website Post ↗](#)

[Brain Foundation BAW Page ↗](#)

In March, we partnered with the Brain Foundation to promote this event. We shared resources, a Dystonia Story plus a video with an overview of Dystonia and related research.

We would like to thank the Brain Foundation for raising awareness and their ongoing collaboration

# Other Notable Events

## World Voice Day 2023

**Laryngeal Dystonia or Spasmodic Dysphonia is also known as a voice disorder and affects the muscles of the larynx (voice box).**



**World Voice  
Day**

**Your Voice  
Matters ↗**

## Rare Disease Day 2023



**Dystonia is not  
well known and  
often remains  
undiagnosed.  
Rare forms of  
Dystonia ↗**

**Visit Our Website for Upcoming Events ↗**

# Resources and Links



## Information and Articles



**Artificial Intelligence Tool Predicts Which Patients with Dystonia Respond to Botox Treatment with 96 Percent Accuracy** ↗

**Model systems for understanding dystonia pathogenesis** ↗

**Dystonia Dialogue Newsletters (DMRF)** ↗

**Rapid-onset dystonia-parkinsonism (GARD)** ↗

**Functional movement disorders: Neurophysiology, diagnosis and treatment** ↗

**Research funding to improve the lives of people with dystonia (Perron Institute)** ↗

**Seven ways flexibility empowers and supports those with chronic illnesses (Brain Foundation)** ↗

**Medications and Lifestyle Changes Can Help People Cope with Dystonia** ↗

**You Are Not Alone - Stories of Persons with Dystonia** ↗

**Dystonia: Alleviating Maneuvers / Sensory Tricks** ↗

**How do people with Cervical Dystonia manage their condition? | Survey Results!** ↗

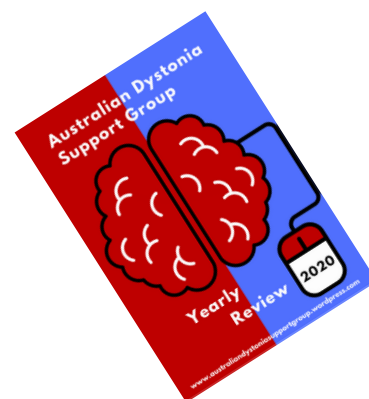
**Visit Our  
News Page**



**Dystonia Leaflet**

**Unlocking Minds and Opening Doors** ↗

**Visit our website for prior reviews** ↗





# Resources and Links



## Updates For Noting

We would like to thank Queensland Government Department for kindly including Dystonia to their Health Conditions Directory. It will help patients find support. View here: [Health Conditions Directory](#) ↗

Sadly Blepharospasm Australia has closed down. Their website may stay online as a reference source for information. Scroll on our webpage for a Health Professionals list: [Other Directories](#) ↗



## Medicine Updates

**1300 MEDICINE  
Service** ↗

### 60 days' supply of PBS-listed medicines

People living with a chronic condition will be able to buy 60 days' supply of PBS listed medicines of the cost of a single prescription. The price changes are happening in 3 stages over 12 months and will be complete by 1 September 2024.

More details here: <https://www.60dayscripts.com.au>

**Medicine  
Shortage Reports  
Database** ↗

### Changes to Paracetamol

On 3 May 2023, the TGA announced the final decision to amend the scheduling of paracetamol in the Poisons Standard. From 1 February 2025 there will be new restrictions on paracetamol. More details here:

<https://www.tga.gov.au/news/media-releases/tga-makes-final-decision-reduce-paracetamol-pack-sizes>

**New resource on our website!**

**Dystonia Medical Alert Wallet/Purse Card** ↗

# Resources and Links



## Webinars and Podcasts



- Dystonia Animated Episode 3 | Sam's Surgery Story (YouTube)** ↗
- Dystonia: Diagnosis and Phenomenology (Podcast)** ↗
- Beyond “torsion”: non-motor features of Dystonia (Podcast)** ↗
- Genetic landscape of Dystonia (Podcast)** ↗
- Unraveling the neural routes of Dystonia (Podcast)** ↗
- Current and future approaches to treatment of Dystonia (Podcast)** ↗
- Managing Dry Eye (BEBRF Webinar)** ↗
- Dystonia Matters Podcasts: Tajana's & Beccy's Story** ↗
- Botulinum Treatment Options for Spasmodic Dysphonia (Webinar)** ↗
- Laryngeal Vibration Can Reduce Voice Symptoms of Laryngeal Dystonia: New Findings and Part II - Additional Q&A (Webinar)** ↗
- Quantitative Measures for Adductor Laryngeal Dystonia & Overview of rTMS as a Possible Intervention (Webinar)** ↗
- Swimming with Dystonia (DMRF Webinar)** ↗
- Neurorehabilitation approaches for Dystonia Care Management (Webinar)** ↗
- Patient Webinar on DBS (Dystonia Europe)** ↗
- Laryngeal Dystonia: Exploring Brain Circuits in Pursuit of a Personalized Approach (Webinar)** ↗
- Think Neuro Mini: What is Dystonia? (Podcast)** ↗
- Advancements in Dystonia Treatments | Congress 2023 (Podcast)** ↗
- Reach Out, Reach All Webinars Series Three** ↗
- Dysphonia International: Ask the Experts: Q&A Session (Webinar)** ↗
- Task-specific brain oscillatory activity in laryngeal dystonia (Podcast)** ↗
- Think Neuro Mini: What is Deep Brain Stimulation (DBS)? (Podcast)** ↗
- Focus on Voice Research (Webinar)** ↗
- Rare Research Report: November 2023 (Dystonia Coalition Podcasts)** ↗
- Mindfulness for People with Voice Disorders: Research and Resources (Webinar)** ↗

# Research Links



**Deep brain stimulation in dystonia: factors contributing to variability in outcome in short and long term follow-up** ↗

**Use of Botulinum Toxin in Spasmodic Dysphonia: A Review of Recent Studies** ↗

**Does Ultrasound Guidance Improve the Effectiveness of Neurotoxin Injections in Patients with Cervical Dystonia?** ↗

**Disorders of Movement due to Acquired and Traumatic Brain Injury** ↗

**Isolated Cervical Dystonia: Diagnosis and Classification** ↗

**Treatment of Tardive Dystonia: A review** ↗

**Genetic Links to Episodic Movement Disorders: Current Insights** ↗

**Anatomical categorization of isolated non-focal dystonia: novel and existing patterns using a data-driven approach** ↗

**New developments in diagnostics and treatment of adult-onset focal Dystonia** ↗

**Spinal dystonia and other spinal movement disorders** ↗

**Bradykinesia and Dystonia** ↗

**Non-motor symptoms in dystonia: from diagnosis to treatment** ↗

**Function and dysfunction of the dystonia network: an exploration of neural circuits that underlie the acquired and isolated dystonias** ↗



## Get Involved in Research

**Trial (NSW): MRI guided focused ultrasound (MRgFUS) - For Focal Hand Dystonia/Writer's Cramp/Musician's Dystonia** ↗

**Trial (VIC): Research using MRI and Brain Stimulation (For CD)** ↗

**Donate to Dystonia Research or Cause**

