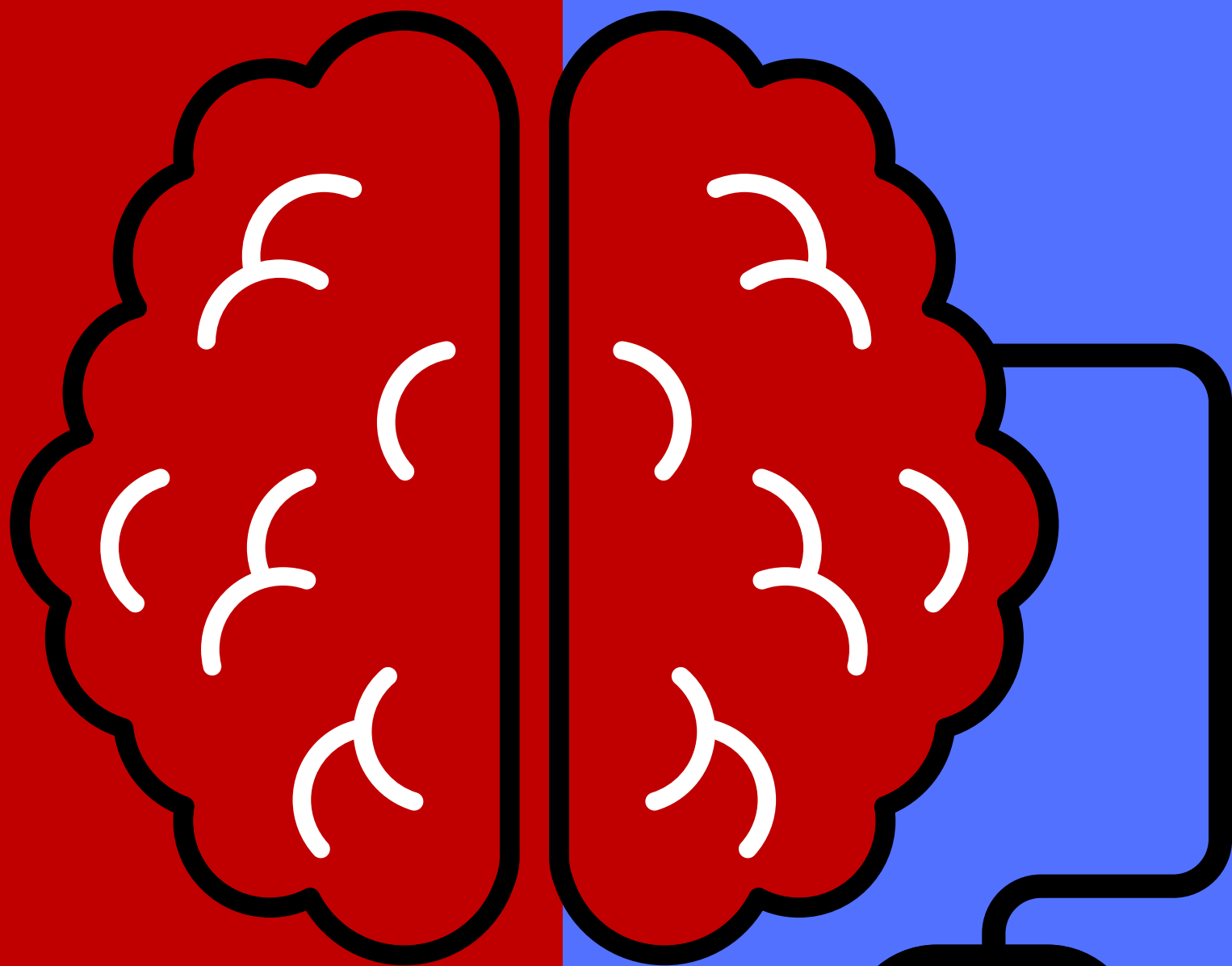


Australian Dystonia Support Group



**Yearly
Review**

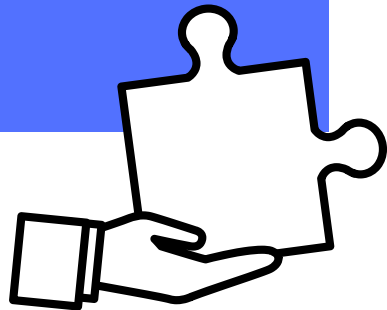
2020

A Challenging Year

It was a difficult year due to the COVID-19 pandemic but despite this we provided support to individuals and responded to enquiries. We still communicated with our contacts, networks and researchers. We thank those we collaborated with for their support.

There were many daily requests to join our group and numbers increased by 10%.

Join our group



We provide information and support for Australians who have Dystonia, their family members, carers and parents of children with Dystonia. It is free to join.

 [Join Now](#)

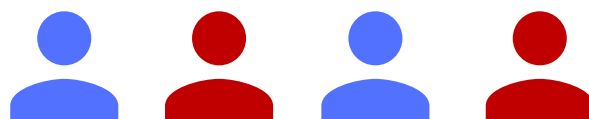


Gatherings and Events

Due to COVID-19 it affected us meeting at venues but we were able to connect with individuals online as well as share plenty Dystonia related events and webinars.

In September 2020, we had another Dystonia Awareness Month.

It was great to see lots of helpful involvement by our Members.



[Read this yearly review for more!](#)

Dystonia Awareness Month 2020



During the Dystonia Awareness Month some of our members provided their lovely photos and Dystonia quotes or verses for our awareness posters and images. Please share our awareness items as it helps the community learn about Dystonia. Many thanks to all who participated and shared our awareness posts!

13.7K

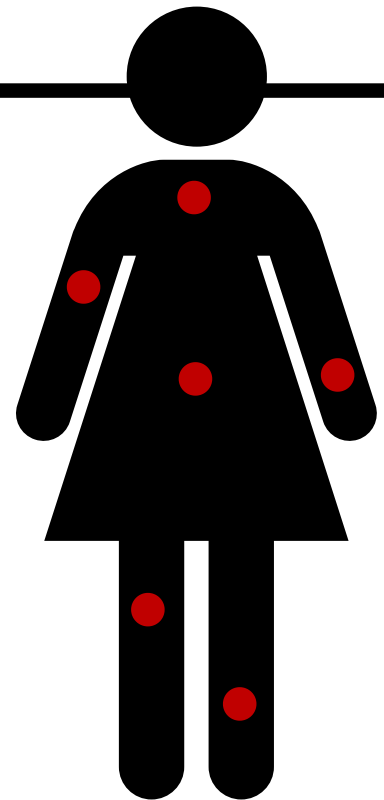
People reached via Facebook

5.1K

Awareness Posters reached

4.3K

Most Popular Image reached



>>> [Share our Dystonia awareness posters](#)

>>> [Visit our Dystonia Awareness Page for tips](#)

Online Review

Our Website



Site Views
11,457

Highest Referrers

[Google search](#)

[Facebook](#)

[Twitter](#)

[Australia](#)

[Dysphonia Network](#)



**Popular
pages/posts**

[Movement Disorder
Specialists](#)

[Dystonia Awareness
Month](#)

[What is Dystonia](#)

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

[Dystonia and pain
research Survey](#)



Find us on
Facebook

Our Facebook Community Page



2,416



Likes 9% Up



Page Reached

77,917 People

Popular Posts

[Rare Disease Day 2020](#)

[September is Dystonia](#)

[Awareness Month](#)

[What is Dystonia?](#)

[ADSG Dystonia](#)

[Awareness Month](#)

[Poster 1](#)

[Dystonia Muscles and
Struggles](#)

Our Twitter Page

29% Visits Up



[@AusDystoniaSG](#)

Health Information Online

There has been a high use of the internet and information provided online due to the COVID-19 Pandemic.

Do you know how to identify or find trusted health content?

Click image on the right to view tips and advice to help you assess health information online.

Safer Internet Day

This awareness Campaign will be running 9 February 2021. New resources will be launched. Visit the website for further information and tips to help keep safe online.

→ [Safer Internet Day 2021](#)



Have you seen our Dystonia Information webpage?



Keep a look out!

ADSG had the opportunity to provide feedback for a planned Cervical Dystonia Booklet so keep a look out for this!



FACTS OR FICTION?

Online

→ Quality health and wellbeing content online can help you make informed decisions.

→ In what formats is health information available online?
Text, images, audio, videos, animations, tools and apps.

78%
of Australians say they looked for health information online in the past year.

→ How can you consume it?
Via computers, laptops, tablets, mobile phones and social media.

→ Why do people use the internet to seek health advice?
They have limited time, want a second opinion, or they might be looking for information for family or friends.

When looking for trusted health information online, ask yourself these questions...

Can you trust it?

Who wrote it?

- What are the qualifications of the writers?
- Who publishes the content?

TIP → Check the 'About us' page.
TIP → Look for .gov or .edu sites.

Is it right for you?

Is it clear?

- Is the information easy to find and understand?
- Are images or video used to help explain the text?

TIP → Browse the site or use any available search features.

Compare different sources

Is it up to date?

- When was it written?
- When was it last reviewed?

TIP → Look for this information at the bottom of each page.

Is your privacy respected?

- Is there a privacy policy on the site?
- If the site collects personal information, is it secure and private?
- What will your personal information be used for?

TIP → Look for a 'Privacy statement' or 'Privacy policy'.

Think for yourself

Is it accurate?

- Is the information based on research?
- Are information sources provided?

TIP → Look for HoNCode certification – a global standard for quality and transparent health information online.



TIP → Look for references at the end of the page.

Look for clues about the quality of information

Is it balanced?

- Are risks and benefits explained?
- Is the website selling something?
- Is there advertising on the site?

TIP → Commercial interests can mean the information is biased.

TIP → Beware of testimonials - they often make untested claims.

What to do?



If in doubt, call healthdirect on

1800 022 222

to speak with a registered nurse 24/7

Remember, your doctor is the best person to make a diagnosis and answer questions about your health.

Self-care



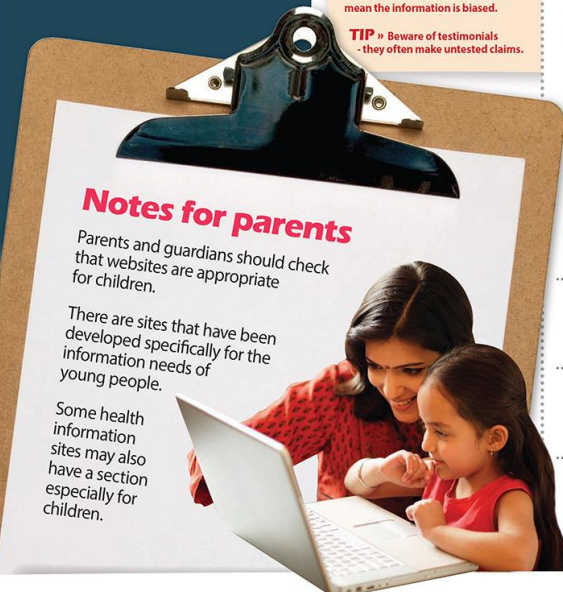
Visit a pharmacy



See your doctor



Call triple zero (000)



Notes for parents

Parents and guardians should check that websites are appropriate for children.

There are sites that have been developed specifically for the information needs of young people.

Some health information sites may also have a section especially for children.

References

You might find our sources for these tips helpful for further reading:

- Healthy web surfing - www.nlm.nih.gov/medlineplus/healthywebsurfing.html
- Tutorial: Evaluating health information - www.nlm.nih.gov/medlineplus/evaluatinghealthinformation.html
- Content quality guidelines - www.healthfinder.gov/aboutus/content_guidelines.aspx
- Staying safe online - www.nhs.uk/aboutNHSChoices/aboutnhschoices/staying-safe-online/Pages/find-health-information-online.aspx
- Health On the Net Foundation - www.hon.ch/HONcode/Conduct.html
- All IW, 2016 - <https://www.aihw.gov.au/getmedia/4e937c11-0c00-4693-ab00-67cd09b1f30c/aihw-aus-222.pdf>

healthdirect
Australia

HEALTHDIRECT AUSTRALIA is funded by the Governments of Australia.

Information courtesy of Healthdirect. You will need to seek permission to use infographic. Source Link: [Health information online](#)

Information and Articles

Healthline - [Supporting a loved one with Chronic Illness](#)

Brain Foundation - [Dystonia](#)

DMRF Dystonia - [Frequently Asked Questions \(RDCRN\)](#) - [Is it Tremor or Dystonia?](#)

DMRF - [Dystonia Dialogue Winter 2020 Newsletter](#)

Drop the Jargon Day - [Dystonia Infographics](#)

DMRF Canada Newsletter - [Dystonia Canada Report Fall 2020](#)

Dystonia Coalition - [Database Uncovers Characteristics of Upper Limb Dystonia](#)

More in our Quarterly Reviews!

>>> [ADSG Quarterly Review October 2020](#)

>>> [ADSG Quarterly Review July 2020](#)

>>> [ADSG Quarterly Review April 2020](#)

Webinars, Videos and Podcasts

DMRF Canada mydystonia&l Series - [Dystonia What's New with Dr Janis Miyasaki](#)

DMRF Canda mydystonia&l Series - [Treating Dystonia: What I've Learned So Far with Dr. Fasano](#)

DMRF Canada - [Understanding Cervical Dystonia with Dr Rizek](#)

Neuromatch.ioTalk - [DystoniaNet With Dr Davide Valeriani from Massachusetts Eye and Ear](#)

ERN-RND - [Paroxysmal dyskinesias: update on clinical and genetic features](#)

Dystonia Europe - [Classification of Dystonia](#)

NSDA - [Helpful Voice Techniques for Managing High Vocal Demands](#)

Parkinson & Movement Disorder Alliance - [Pathophysiology of Parkinson's and dystonia](#)

Dystonia Europe - [Neuromodulation treatment for Dystonia](#)

BEBRF - [Take Control of Your BEB](#)

BEBRF Podcast Part 1 & 2 - [I can't stop blinking and what the hell is Blepharospasm?](#)

Dystonia Europe - [Positive Twist podcast about dystonia](#)



→ [Visit our Recent News page for updates](#)

Upcoming Events

[Rare Disease Day](#) - 28 February 2021

[Swallowing Awareness Day](#) - 18 March 2021

[Brain Awareness Week](#) - 15-21 March 2021



→ [Visit our Events page](#)

For Noting

Botulinum Toxin for Focal Dystonia

The [MBS review Taskforce](#) recommended Botulinum Toxin for Focal Dystonia to be added to the MBS. The [Australian Register of Therapeutic Goods \(ARTG\)](#) doesn't include therapeutic use of Botulinum toxin (BoNT) type A for this indication. [PBAC](#) and [MSAC](#) can only consider an application if Focal Dystonia is included on the ARTG record for BoNT A. If this happens we will provide an update.

Patient Focused Medicines Development Project



A survey was launched to understand patients' or the general public's thoughts around Patient or Consumer Information Leaflets. Based on the feedback received, recommendations will be made to help increase health literacy, the understanding of products and access to relevant info. We will provide an update when the information is available.

The Department of Health and Human Services Victoria (DHHS) - Clinical Information Sharing system (CIS)

DHHS plans to introduce a system enabling clinicians to access the complete health records of patients held across the Victorian public hospital network and external health providers. This is without offering consumers an opt-out option and without any requirement to obtain prior informed consent. Additionally, consumers will not receive notification of when their data has been accessed, or for what reason. Two consultation forums was hosted by the [Health Issues Centre \(HIC\)](#) and discussions included the right to opt for or against participation, the right to withhold consent to access and the right to curate what information the records should hold and the accuracy of that information. A full report of these forums was provided to DHHS with recommendations that plans to amend legislation be put on hold until the principles outlined in the report have been adopted as the basis for further system planning. If you have concerns about this you can reach out to [HIC](#). Click link to view the report.

→ [Will sharing improve caring? A Clinical Information Sharing System - The Consumer Perspective](#)

WA Health Genomics Strategy 2021 - Have an interest in Genomics in WA?



Complete a survey by 31 January 2021 on the strategy which includes the goals and initiatives. Click link for more information.

→ [WA Health Genomics Strategy 2021](#)

Hot Topic - Botulinum Toxin and Aftercare

Care information after having Botulinum Toxin injections is a common topic. We have advocated for suitable info to be available for the community. If there are updates we will provide them.

Please speak to your doctor or click the following links to read the Consumer Information Leaflets for info.

→ [Allergan \(Botox\)](#)

→ [Ipsen \(Dysport\)](#)

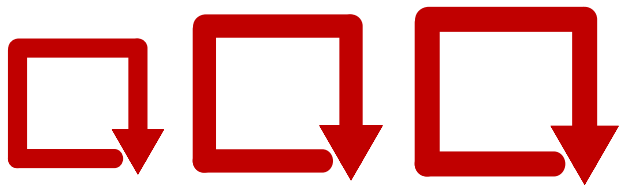
→ [Merz \(Xeomin\)](#)



Research Links

Research Papers

- [Review Article - Effectiveness of Electrical Stimulation among patients with Voice Disorders Dystonia](#)
- [Mac Keith Press \(Developmental Medicine & Child Neurology.\) Diagnostic approach to paediatric movement disorders](#)
- [Review Article Neurorehabilitation in dystonia a holistic perspective](#)



[View our AD SG quarterly and yearly reviews for more links to Dystonia research articles or papers](#)

COVID-19 Information

There is a large amount of COVID-19 information or research online. Click link provided to direct you to 7 tips to help you identify if the information is reliable. Link: [Top tips for navigating the infodemic](#)



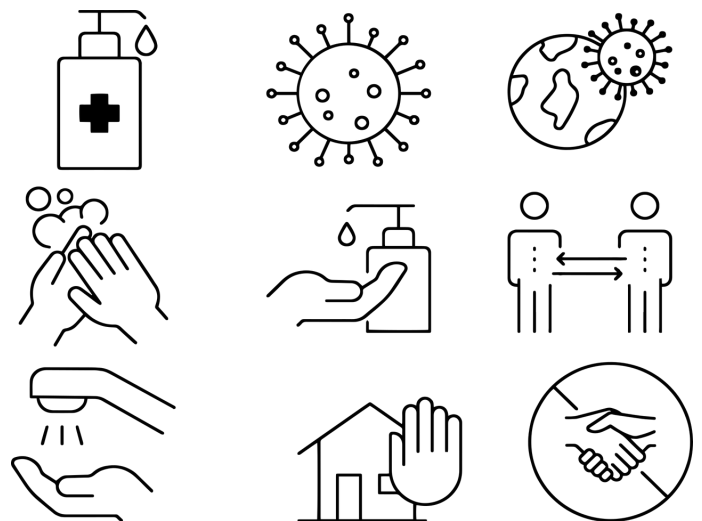
[Visit our Dystonia Research Page for more!](#)

Trials Running Now

- [Participate in a Tele-yoga Study for adults with Cervical Dystonia](#)
- [Visit our website for more current trials!](#)



Give Now
Make a Difference



Other COVID-19 Links

- [Coronavirus and dystonia](#)
- [Covid-19 Vaccinations](#)