

THE CONNECTED ISSUE

THE CTDNA NEWSLETTER CONNECTING PEOPLE AND THE ISSUES,
ON ALL THINGS CONNECTIVE TISSUES.

What's inside this issue:

- OUR FIRST 12 MONTH WRAP-UP
- COMMUNITY ENGAGEMENT TO DATE
- 2025 UPCOMING EVENTS
- HOW TO GET INVOLVED



Click image to follow CTDNA on instagram



Nikki Anderson, CTDNA Community Member with lived experience of Stickler Syndrome



Sue and Janna at Parliament House Canberra, RDD 2024

THE YEAR THAT WAS.

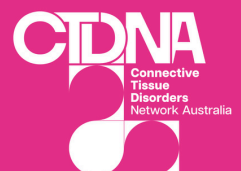
12 MONTHS IN A 'START-UP' NOT-FOR-PROFIT.

Where we've been, who we've spoken to, and where we're headed.

Well, the first year of Connective Tissue Disorders Network Australia (CTDNA) has come to a close. 12 months has passed since the organisation was incorporated and granted 'charity status' by the Australian Charity and Not-for-profit Commission (ACNC), and Deductible Gift Recipient (DGR) by the Australian Tax Office in early 2024. It can be said without a shadow of a doubt, that despite so much being achieved, it is clear there is much work to be done.

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The first year, with Sue Hutley as Chair, and Janna Linke and Michelle Hamer as founding Directors, who respectively hold the roles of clinical lead and lived experience advisory lead have seen all aspects and avenues of pursuit for CTDNA in this formative time given the individual due diligence they each required.

The first order of business after incorporation was to become a member of Rare Voices Australia, the Ehlers-Danlos Society, Global Alliance and Health Consumers NSW. Next up was establishing partner organisation arrangements with the Australian POTS Foundation, The Australasian Mastocytosis Society, Emerge Australia, Chronic Pain Australia and Ehlers-Danlos Syndromes New Zealand.

We thank a national legal firm who provide pro-bono legal services, Digital Surfer, our website developer and EEA Advisory for their pro-bono accounting services. Our initial donors, included Krysten, Sue-Ellen, Bryony and Mia - 'The Girls' who chose CTDNA as their charity to support in honour of their sister, Rhianna who lost her battle with vascular Ehlers-Danlos syndrome (vEDS), in January 2021.

CTDNA Directors Sue and Janna at the Ehlers-Danlos Society Global Learning Conference in Brisbane with Sherri Marshall & Jo Hargreaves (patient support group leaders) and Kelly McQuinlan, EDS New Zealand

We are very grateful for all the donations that have been made to CTDNA over the course of our first year.

Further important highlights included; starting the year back in February 2024 with the annual Rare Voices Australia Rare Disease Day event at Parliament House in Canberra - attended by both Sue and Janna.

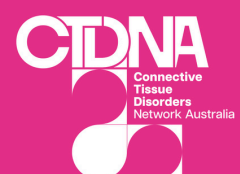
Janna then attended the Australian POTS Foundation Conference in March. Over the ensuing 12 months meetings with several State and Federal Members of Parliament from around the county followed. These meetings were undertaken by Sue, Janna and Michelle and included conversations in person and virtually.

CTDNA Directors were invited to participate in consumer stakeholder discussions to develop best practice, up-to-date condition pages on heritable connective tissue disorders (HCTD) with Rare Voices Australia for the Rare Voices Australia portal. Co-design sessions for this were held in 2024 with representatives from the Ehlers-Danlos, Marfan and Stickler syndrome communities in attendance. These pages will be available in 2025.



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Towards the three quarter mark of CTDNAs first year, Janna attended the Genetic Alliance Australia Rare Disease Forum at NSW Parliament House. This was the first time in which CTDNA was an invited exhibitor and working member patient advocacy organisation of the Rare Disease Community.

November saw Janna back in Canberra for another parliamentary event, this time hosted by Chronic Pain Australia (CPA), and Michelle attended the launch of the Gender Equity in Medicine Hub launch in Melbourne.



Sue Hutley (in red) speaking on a panel at the 2024 Rare Voices Australia - Rare Disease Summit in Brisbane.

We have engaged with the National Health and Medical Research Council on HCTDs, and public hospital genetics teams. Even getting a shoutout from Mr Alan Singh, Executive Director, Research Quality and Advice at NHMRC who mentioned our engagement with them during a Parliamentary Friends of ME/CFS meeting in Canberra on November 18th. Our mission, and advocacy efforts of 2024 to raise awareness of HCTD taking effect. (Meeting recording linked [here](#) and CTDNA mention timestamp @ ~ 32 minutes).



Winning submission from The EDS Society GLC Zebra's Got Talent Competition by Community member Evelyn Froend

Sue was an invited delegate speaker at the Rare Voices Australia National Rare Disease Summit in Brisbane in November.

We have tremendous gratitude for the community we represent; Australians living with or impacted by genetic, heritable and / or rare connective tissue disorders. We thank each and every one of you that has liked, commented and shared our social media posts, emailed us to connect, completed one of our surveys or shared some of your experience on life with HCTD with us. We've even had a few community members with lived experience who have joined some of our meetings with MPs to confidentially share their stories.

[Read CPA 2024 National Pain Report here](#)

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We will continue our stakeholder engagement and community outreach activities throughout 2025 - realising that the power of our collective effort is strengthened exponentially by sharing the lived voice, community is at the core of all our activities and work.

Media snippets

CTDNA secured media mentions during 2024, these included; multiple [radio](#) and podcast interviews with Director, Michelle Hamer [here](#) and [here](#). And, local Sydney news items with Janna Linke [here](#).

Governance

Organisation subcommittees were established and inaugural meetings held for our [SMAC](#), [LEAP](#) and [FFaRM](#). These committees help ensure the governance requirements and goals of the organisation are maintained and met, as outlined in the CTDNA Constitution.

Ambassadors

We engaged our first Ambassadors, [The Jones Family](#), who are impacted daily by vEDS, the HCTD that Bradley, Hunter and Issac live with.



The first CTDNA Ambassadors, 'The Jones Family' who have lived experience of vEDS



CTDNA's newest Ambassador; Anu Francis

And can bring some words of hope from our newest ambassador [Anu Francis](#) - Australian Paralympian Triathlete, who we are so pleased to be able to announce in the first edition of our newsletter;

"I hope that as a CTDNA Ambassador I can help improve the lives of others living with heritable connective tissue disorders by sharing my story and using my platform as a Paralympian living with Ehlers-Danlos syndrome to increase awareness and understanding of these conditions. Together I am hopeful that we can improve care, support, education and research to create a brighter future where we can all reach our full potential and achieve our dreams, whatever they may be!"

Thank you, Anu. We and the CTDNA HCTD Community look forward to working with you, knowing you will excel in this role!

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Volunteers

Several volunteers have supported the CTDNA Board of Directors in the development and implementation of policy, strategic fundraising plans and generally with establishing a company that is rooted in ethical decision making. Reaching us to onboard plenty of additional volunteer help in early 2025. *If you've reached out, we will be in touch asap!

Government submissions

We provided a submission for the Victorian Women's Pain Inquiry, and prepared a NSW pre-budget submission in late 2024. More submissions will be targeted and responded to as we increase our operational capacity throughout 2025.

Research connections established

During 2024 CTDNA received a number of requests to support Australian research projects related to heritable connective tissue disorders and patient cohorts. Some of these will take time to progress, and will be led through our SMAC with consultation from our LEAP.

A number of Australian [clinical trial and registry links](#) were added to the CTDNA website.

2025 and beyond

Finally, most recently, Janna and Sue both attended the epic 3 days Global Learning Conference held by the Ehlers-Danlos Society in Brisbane in early February. This was a great opportunity for CTDNA to really be showcased and expand our reach into the community we represent. The increased engagement that has followed the exposure we were given has been wonderful to see.

Janna spoke on a number of panels at the conference on issues close to her heart, including; effective community engagement in patient advocacy, and the unmet needs of those with EDS in Australia (the same unmet needs, that are common across most HCTDs).

On February 11 Sue again attended the Rare Voices Australia Rare Disease Day Event at Parliament House Canberra - rounding things out for our first year summary newsletter!



Sue with RVA Director, [Roxane Marcelle-Shaw](#) who lives with EDS and David Mayne of Partner organisation TAMs - RDD Canberra 2025

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2025 Community engagement

- Flyers; request a bundle be sent out to you for distribution in your network to raise the profile of CTDNA and HCTDs by emailing hello@ctdna.org.au
- Share your story [here](#) (as much or as little as you like).
- Learn how you might be able to volunteer with CTDNA [here](#).



Click to open a PDF of the CTDNA flyer

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Wider Community News

- Check out the current open surveys on the Ehlers-Danlos Society website [here](#) to see if there is something you can get involved in.
- Check out the open surveys currently being run by the Australian POTs Foundation [here](#) to see if you can get involved.
- The Kids Research Institute Australia and UWA are conducting a research project, around; Supporting sport participation of young people with chronic conditions, exploring the experiences and perspectives of young people with chronic health conditions, their families, and sport providers regarding sport participation. To find out more information or get involved click [here](#). The principal investigator, Hamsini Sivaramakrishnan, can be contacted via email hamsini.sivaramakrishnan@thekids.org.au.
- Make a submission and have your voice heard as part of the government's Consultation on changes to the Disability Standards for Education 2005. Closes Feb 28! Click [here](#).

Until next time, signing off – The CTDNA Founding Directors
Sue Hutley, Janna Linke & Michelle Hamer

UNSUBSCRIBE