



# Axios

support empower inform

**SUMMER 2024**

# Contents

1. Welcome
2. Infocus with Michelle
3. Chromodiveristy
4. AXYS Raffle
5. AXYS Picnic re-cap
6. Tips & Snips
7. Good Reads
8. What's On
9. Invitation to you





Welcome

Happy New Year


We trust the festive season was pleasant for you and your loved ones. We hope you enjoyed a well-deserved break.

2023 has been a whirlwind for all, and here at AXYS Australia, we achieved many great works. We welcomed new board members and said goodbye to others, we embraced new members into the AXYS community and assisted many through our various communication platforms. Behind the scenes, we continued to work in collaboration with organisations to educate ourselves and keep up to date with the latest news and research.

We hope you enjoy this Summer edition of the newsletter, and we thank you for your ongoing support. We can't wait to bring you new and exciting things in 2024.

**AXYS Board**





*Im Focus*

**MICHELLE**

**Can you tell us about your journey with X and Y variants?**

I received my son Hudson's who is now 2yrs old diagnosis in utero. I attended my gynaecologist for my scheduled appointment without even thinking I was receiving the results from my genetic testing. Hudson is my 4th child (3rd son) and there is no family history of any genetic conditions. I remember my gynaecologist leading with well you are having a boy to which I interjected "I didn't want to know the sex of the baby" and it was at that point he continued 'well unfortunately I have to inform you that your genetic testing results have shown that your baby has a genetic condition that is specific to males only. Your son has Klinefelter Syndrome.'

**What were your initial thoughts and fears at diagnosis and have they changed since?**

I was initially advised by my gynaecologist that he may not be sporty and my other children are all extremely sporty and I held a fear of judgment and initially kept the diagnosis to our immediate family, from about 6 months, I told my parents and our close friends, we now treat it a bit like an Asthma diagnosis, anyone caring from Hudson, doctors etc we make a point to tell, otherwise if it comes relevant and infertility and penis size were probably my concerns right up until birth.

I had been told by the endocrinologist that there was a small chance that he would be born with a micro penis and if he was he would have testosterone injections as an infant and the unknown created uncertainty I currently have no fears surrounding XXY for Hudson.

**What is the support that you have found most helpful?**

While pregnant I was connected to both men with Klinefelter Syndrome and mothers of sons with Klinefelter. Speaking with the males with Klinefelter was probably the greatest help, to connect via social media and chat with people with Klinefelter Syndrome and have honest conversations with them about their childhood and current lives, what amazing humans to give their time to comfort a stranger in her time of need.

If you are someone with Klinefelter reading this and would like to be a part of our lived experience support team for those newly diagnosed and expecting parents please reach out via email:

[support@axys.org.au](mailto:support@axys.org.au)



# Chromodiversity

AXYS and the My XXY-Chromodiversity™ Foundation have been working together to raise awareness, change lives and unlock futures – Elliot the founder of this foundation has recently presented the following posters at International health conferences.

## From Deficit to Difference

De-pathologizing the language of genetics

Australian Genomics | CHROMODIVERSITY™ It's in our DNA

Tiffany Boughtwood, Australian Genomics & Elliot Polak, MyXXY

**"For a long time, I believed everything was my fault. It crushed me."**  
R. Baldock, Data Analyst, Extra Y

**"95% of my life has been spent not knowing. It was like getting into a boxing ring with as your opponent the invisible man."**  
P. Street, Diagnosed XXY at the age of 63

**"Health care workers do not treat you like a person. They treat you like an it."**  
Chromodiverse person w/ Intellectual Disability

**"A premature death that could have been avoided in so many ways."**  
G. Glissman, Healthcare Exec. & Parent of a late diagnosed Extra X son who killed himself

**"It was a big part of our marriage falling apart. The stress and anxiety while we were figuring out what the was going on."**  
Parent of a child w/ Trisomy X

**"There has never been a better time in history to be diagnosed with a common genetic difference such as an Extra X or Y chromosome (1/400 live births)."**

So why is it that diagnosis is still almost always considered bad news? And at a time of surging prenatal diagnosis, what can we do about it?

**"Early intervention is the absolute key."**  
A. Deutsch, Nurse, Parent of 3 Extra X boys

**"We're not a disorder. We're not a syndrome. We're people."**  
T. Whittington, Social Entrepr., Extra X / Intersex

**"Your child is a person first, not a medical condition."**  
J. Samuel, Author, Parent of a girl with Down's

**"After diagnosis you are still the same person as before."**  
A. Jonker, Pres. Klinefelter Association

**"You're enough, just as you are."**  
B. Vestrum, Consultant, Extra X

**"Embrace difference, celebrate strengths!"**  
J. Langenhoff, Trisomy X & Turner's (Mosaic)

**"5 minutes of just listening and validating someone's experience is the best gift a doctor can give."**  
Prof. L. Bloom, Pres. The Ehlers-Danlos Society

### An issue we need to tackle NOW

Year	1 in 400	1 in 200
Year 1	1000	10,000
Year 2	1200	12,000
Year 3	< 2000	22,000

**Myths and misconceptions result in unnecessary trauma for families. Language matters.**

**We believe it is urgent to change the way we consider, support and talk about genetic diversity.**

**Shifts heading: from abnormality triggers unnecessary fear for others around the world**

**Positive diagnosis can result in empowerment to explore, self-acceptance, and self-advocacy**

None or total  "I feel often you are not..."  
Low intelligence  "Global cognitive skills same as average"  
Psychopath or serial killer  "No evidence of correlation"  
Lacking sentence  "Rare mutation & prevention from age 1"

**Flipping the script from "tragic genetic abnormality" to "common genetic variation"**

Abnormality	Strength	Difference
**** A3B-enzyme	**** Actor and poet	**** Deaf
**	** Well-informed, supported and in-control	** Difference

**An equal opportunity to a fulfilling life**

**CREATE BETTER FUTURES**  
Our podcast about genetic diversity

**Aberration / Abnormality**  
**Deficit / Disorder / Disease**  
**Flaw / Fault**  
**Mutation / Mistake**  
**Patient / Problem**  
**Syndrome**  
**Deficiencies & Impairment**

**Alteration / Blueprint**  
**Difference**  
**Feature**  
**Modification**  
**Person**  
**Variation**  
**Needs & Strengths**

By Australian Genomics & My XXY | Chromodiversity™ Foundation  
Contacts: T.boughtwood@australiangenomics.org.au & elliot@myxy.org

## CLOSING THE GAP BETWEEN GENETIC SCREENING AND COORDINATED CARE

### A Unified Approach to Support Clinics & Families

**Surging prenatal diagnosis. Termination rate: 44% to 85%\***

**Missed window of opportunity for early age prevention of predictable risk**

DETERIORATING FRACTURES**	VENOUS THROMBOSIS**	METABOLIC SYNDROME**
3-10x more likely for XXY, XYY	12x < 30yo more likely for XXY, XYY high impact on QoL**	46% XYY data
75% across all 4 SCAs	50-60% across all 4 SCAs	15-30% across all 4 SCAs
ANXIETY**	DEPRESSION**	POOR QUALITY OF LIFE**
20-30% across all 4 SCAs	70% XYY data	75% XXY and XYY data

Early diagnosis of relatively common genetic differences such as X&Y Sex Chromosome Aneuploidies (SCAs: 1 in 400 live births) is set to explode by an order of magnitude in the next 5 years, with tens of thousands of new families each year facing unmet needs.

Low healthcare provider awareness and lack of appropriate early age care is likely to result in unsustainable cost to health, educational and social systems.

**Urgent need for coordinated care - at scale**

**A telehealth platform to unlock the power of unified data**

Shaped by outstanding research and advocacy

NIMH | AXYS | eXtraordinary Kids | Melbourne Klinefelter Society | University of Queensland | WPP | SCIENCEAFFINITY | National Institute of Mental Health | Murdoch children's research institute | Universiteit Leiden | OmnicomGroup | Stanford MEDICINE

© 2023 My XXY | Chromodiversity™ Foundation. All rights reserved. Not for profit. Contact: elliot@myxy.org

[Click to Download](#)

[Click to Download](#)

Raffle



Play For Purpose is a 100% not-for-profit, is a fully national charity raffle that helps good Australian causes to raise funds and enable them to continue to do important work in our communities.

They are operated by the 50-50 Foundation, an award-winning ACNC is a registered charity that has run over 1,000 charity raffles in support of more than 500 charities and sporting clubs since 2012, raising over \$7.8 million for good causes. Play for Purpose is run quarterly, so don't miss out, get your tickets now!

 **PLAY FOR  
PURPOSE**  
*The Sports & Charity Raffle*

[playforpurpose.com.au/axys-aust](https://playforpurpose.com.au/axys-aust)



# Picnic in the Park



On Sunday 3rd December we held the AXYS Picnic in the Park – Victoria. We welcomed back some regulars and meet new families who joined us through the year. This was a wonderful opportunity to converse and connect with many in our community.

The weather was lovely, and the children of varying ages all played. Don't forget the delicious sausage sizzle!

Thank you to all who joined us and assisted in preparing this day. Stay tuned in 2024 for events in your State and Territory.





If you need some simple yet effective calming strategy start 2024, consider the following and let us know how you go.

The strategies below aim to help you and your kids regulate when overwhelmed and challenged with sensory overload:

### **Music**

Gentle music is widely regarded for its soothing properties, allowing the brain to fall back into a gentle pattern.

### **Other sounds**

Waterfalls, soft drumming, nature sounds – all can be found on YouTube to help soothe bodies.

### **Lighting**

Soft lighting – think darkened rooms, with blinds/or cardboard cut-outs on the window. Some soft fairy lights or a beautifully shaded night lamp to help soothe visual over-stimulation.

### **Mindful**

Colouring is a simple yet effective way to work on one task that will slow the busyness of the day.

### **Connect with Nature**

Go for a walk, create a treasure hunt, and collect different objects you find or play a game of ISpy.





Tips & Snips  
cont....

This time of year can present a range of complex emotions and environments for kids and adults. Things like changing routines, catching up with family and friends (or not catching up) and managing summer weather can impact us in different ways.

Like the X & Y chromosome variation spectrum, the ways that we all manage our mental health and well being is a spectrum.

Practicing grounding techniques (thanks DeStressMonday.org for the picture) can help to distract from negative thoughts. Some people also use breathing techniques, although I prefer grounding exercises.

# The 5-4-3-2-1 Grounding Technique

Ease your state of mind in stressful moments.



Acknowledge **5** things that you can see around you.



Acknowledge **4** things that you can touch around you.



Acknowledge **3** things that you can hear around you.



Acknowledge **2** things that you can smell around you.



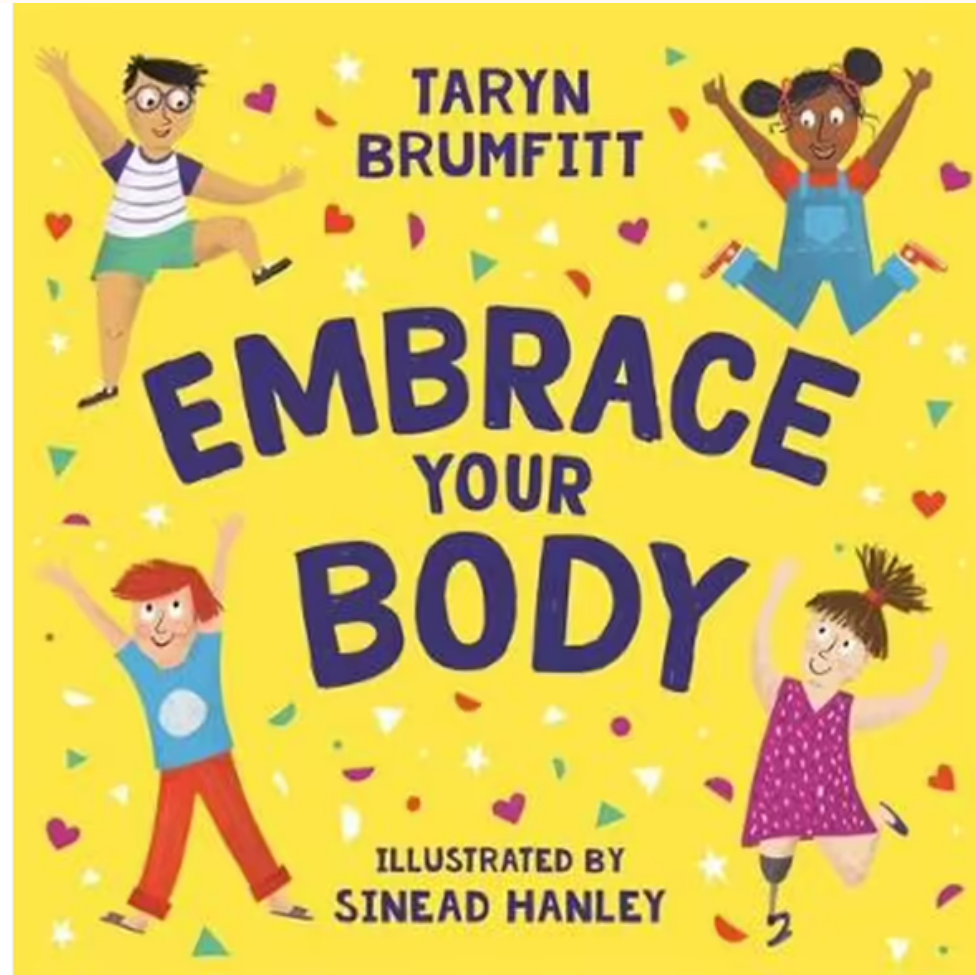
Acknowledge **1** thing that you can taste around you.

#DeStressMonday

DeStressMonday.org

DESTRESS  
MONDAY

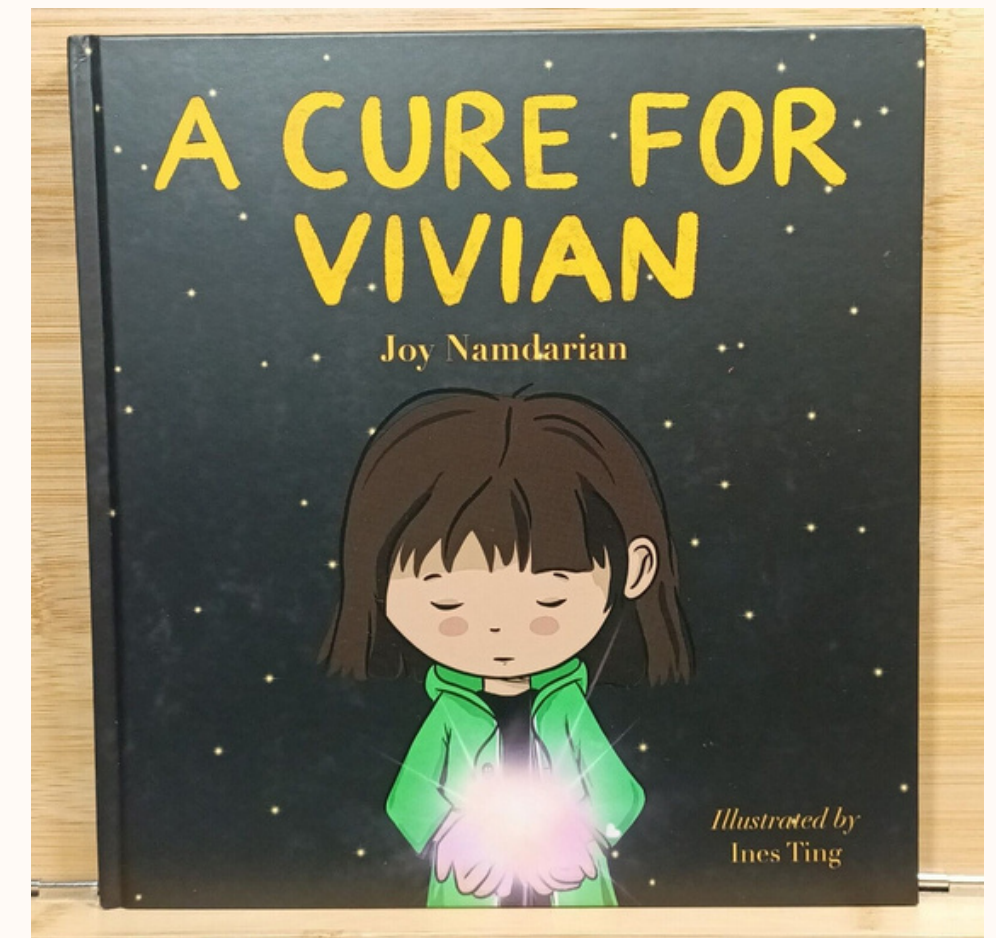
# Good Reads



## EMBRACE YOUR BODY

Taryn Brumfitt is determined to inspire everyBODY to celebrate their body, regardless of size, colour, ethnicity, gender or ability. This picture book encourages everyone to love who they are, inside and out.

[bodyimage movement.com](http://bodyimage movement.com)



A little girl called Evelyn goes in search of a cure for her baby sister, Vivian, who has an unknown illness. Evelyn encounters three mysterious creatures who each give her a golden magical gift. A heart-warming story with a beautiful message. [namdarbooks.com.au](http://namdarbooks.com.au)



What's On



**A FREE ONLINE FOUR-WEEK PROGRAM FOR CARERS  
BY CARERS VICTORIA COMMENCING IN FEBRUARY  
2024.**

REGISTRATIONS NOW OPEN  
MORNING, AFTERNOON, AND EVENING GROUPS  
AVAILABLE INCLUDING GROUPS FOR LGBTQIA+,  
BEREAVED AND MALE CARERS.

PEOPLE WHO PROVIDE CARE FOR A LOVED ONE  
OFTEN EXPERIENCE LONELINESS AND CAN FEEL  
ISOLATED. THE CHALLENGES OF COVID-19 HAVE  
ONLY MADE THIS MORE DIFFICULT. IF THIS SOUNDS  
FAMILIAR, THIS PROGRAM MAY BE RIGHT FOR YOU.

FIND OUT MORE

FOR MORE INFORMATION PLEASE EMAIL  
[INTOUCH@CARERSVICTORIA.ORG.AU](mailto:INTOUCH@CARERSVICTORIA.ORG.AU)



sourcekids  
**DISABILITY  
EXPO**

**EXHIBIT**

ADELAIDE 2-3 March 2024  
SYDNEY 16-17 March 2024  
MELBOURNE 5-6 July 2024  
BRISBANE 3-4 August 2024  
PERTH 26-27 October 2024



*Invitation*

## **DONATE**

AUSTRALIAN X AND Y SPECTRUM SUPPORT WELCOMES ANY DONATIONS TO ASSIST US IN SUPPORTING OUR MEMBERS NATIONWIDE. WE GREATLY APPRECIATE YOU CONSIDERING DONATING TO OUR CAUSE. DONATIONS ABOVE \$2 ARE TAX DEDUCTIBLE. HEAD TO THE WEBSITE FOR MORE INFORMATION. [WWW.AXYS.ORG.AU](http://WWW.AXYS.ORG.AU)

## **REACH OUT**

WE ARE HERE TO HELP AND SUPPORT YOU!

HELP AND ENQUIRY LINE: 0412 038 142 EMAIL:  
CONTACT@AXYS.ORG.AU WEBSITE: [WWW.AXYS.ORG.AU](http://WWW.AXYS.ORG.AU)

## ***Share your Story***

We would love to hear your personal stories.

Write to us at [support@axys.org.au](mailto:support@axys.org.au)





*Thank  
you*

AXYS Australia is run by volunteers who dedicate their own time to ensure we can further increase awareness, support, and empower others. We have a vast array of skill sets in which we work together to achieve great positive change for individuals living with an X & Y chromosome variant.

