



September 2022 NEWSLETTER

Welcome everyone,

We have had an exciting year with some significant changes and many opportunities to link in with our XYY families and the community. February 13th 2022 marked our 4th year of being an Association.

The AGM held in September 2021 saw the election of a new Secretary, Kylie Clark-Parry and Treasurer, Kristy Wilkins.

Ken Gilkes continues to support our association maintaining our website and providing IT support. Our additional committee member Emily Wordsworth provides valuable support as a Business Analyst within QLD health and understanding the overlaps specifically to 47XYY and 47XXY (Klinefelters).

Our biggest news is our partnership with the Lions Club of Mandurah Inc. We have become a club branch of theirs and are now known as the Mandurah XYY Syndrome Club Branch. The opportunities and support that come with being a Lions Club Branch are invaluable and we are so very grateful to the Lions Club of Mandurah Inc. and especially to Peter Lamb for his guidance and support.

The Lions Club of Mandurah Inc. has a big heart to make a difference within the community and this is what, we as XYY Syndrome Association of Australia Inc. stand for too!

Right from the start we have felt that we have been heard and that the Lions understood there is a true need for our cause and from that moment we have had this feeling carry on throughout our ongoing working relationship.

They have the skills, knowledge, heart and understanding that we need help to grow our association while supporting males diagnosed with XYY within our community.

We have a long journey ahead and every helping hand is truly appreciated. TOGETHER we are making a difference for the future of XYY Syndrome.

On the 12th July 2022 we had the honour of being invited to attend the 51st Annual Changeover dinner for the Lions Club of Mandurah Inc. We took this opportunity to thank the Lions Club of Mandurah Inc. for their invaluable support and commitment to our cause. Jack, one of our XYY boys (15 years) proudly presented the President, Barry Simms with a certificate of appreciation. It was a wonderful opportunity for the Lions members to meet first hand a young boy with XYY Syndrome and in turn for Jack to understand what clubs and opportunities the world has to offer.



Jack and Amber



Our Team: L to R - Kylie, Kerry, Jack, Barry and Amber



Research, Education and Networking

Perth Children's Hospital – Telethon Kids Institute

12th October 2021, Peter Lamb (former Secretary, currently 1st year Director for the Lions Club of Mandurah Inc.) arranged a visit to

[PCC Telethon Kids Institute](#)

Here we met with Professor Terrance Johns of the Paediatric Cancer Research and Head of Telethon Kids Cancer Centre. He gave us an insight into what is required to conduct formal research and inspired us to continue towards our goal of having a future foundation for XYY.



Achievement award nomination

2021 – WA Regional Achievement and Community Awards – nominated for Woolworths Community Group of the Year Award



The lack of information and understanding of XYY Syndrome by the wider community has had a great impact on the mental health of our XYY males and their families. The feeling of being isolated and not understood has been one of the hardest truths that these boys and men (and their families), face every day.

XYY Syndrome Association of Australia Inc. is continuing to reach those who are feeling isolated, haven't been heard or do not know where to find information about the condition.

'Get on Board' has been our overall project since the inception of the XYY Syndrome Association of Australia Inc. was established. The project was designed to create a positive and supportive platform for all XYY males, their families and carers, to be heard. By creating these platforms, we are bridging the gap by sharing lived experiences and offering support. In return we have gained the trust of these families to share their needs and concerns, inspiring us to continue to do what we do!

By creating positive awareness and early intervention for XYY Syndrome within the education system, we are not only helping males diagnosed with XYY, but we are also supporting the growth for better understanding of this condition. Having these types of supports in place we can help minimise the risk of failing those who need more support while trying to gain an education.

The next step is to create a Care Plan Package for newly diagnosed boys and men, medical specialists and early childhood educators giving them a better understanding of the condition and enabling them to adequately support these families.



Networking within the Community

Monday 23rd August 2021

IPL Radio interview – Amber Gilkes, Chairperson

What an amazing opportunity to be interviewed on
“IPL Radio” at their Rockingham studios
[Click Here for a Stream of the Interview](#)



Saturday 9th October 2021

Mental Health Awareness week

Support by the City of Mandurah at Lakelands Shopping Centre.
We held an Information stall to raise awareness about XYX Syndrome.

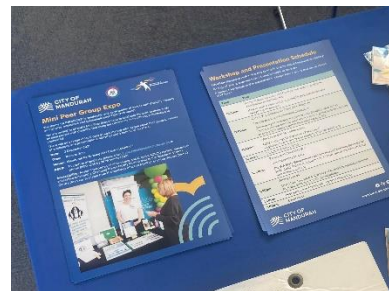


2nd December 2021

Mandurah Performing Arts Centre – Mini Peer Group Expo

Guest speaker Amber Gilkes

We were invited to share our experiences setting up an association within our local community and talk about our challenges, successes and everything in-between. Amber focused on the difficulties around setting up a ‘not for profit’ association for a rare genetic condition that’s not understood, the barriers around XYX and the purpose and importance of creating awareness for this condition.





Fundraising

August 2021 – Grill'd – Local Matters

[Grill'd Mandurah](#) supported us with a 'local matters jar' during the month of August 2021 and we came in third for the month raising \$100. They also allowed us the opportunity to set up an information stand within the restaurant and connect directly with the community.



November 2021 - Lions Club Christmas Cakes

What a wonderful month we had connecting with the community, nothing like some yummy Lions cake to bring us together! The Lions Club of Mandurah Inc. supplied us with Lions cakes to sell and raffle to help raise funds to support the awareness for XYX Syndrome.

Our supporting business for this event – Sandy's Cakes without her help we could not have had such an incredible response from our local community. Sandy donated her time to decorate 5 Lions cakes and they looked amazing, these cakes were raffled off at the Lakelands Shopping Centre.

Lakelands Shopping Centre is also a huge support to our cause, giving us space to connect with the community and we can't thank them enough for their help.





Support

Grants

We received approval for the [ConnectGroups](#) 2022 [Give it Forward](#) Grant which helped us purchase a yearly subscription for a “Pro zoom” account for the association.

The zoom account gives us the ability to connect, engage and network with the wider community, while creating opportunities to attend online training and join webinars.

Fundraising and Donations

Donation Boxes continue to be generously accepted by local businesses in the Lakelands Community.

[Lakers News](#) has been an ongoing supporter for the past 2 years, continuously having one of our donation boxes on their counter. Many thanks to Abel Carlos Peixoto Martins from Lakers News.

Donations 2021-2022

- Lions Club of Mandurah Inc.
- [Lakers News](#) Lakelands Shopping Centre - Donation Tin
- [Mandurah Muscateers](#) – provided a new Laptop and IT support for our administration.
- Member donations

Raffles

- Lions Cakes
- Bendigo Bank

Current raffle - Lions Club of Mandurah Inc. [Bendigo](#) Bank Raffle - all proceeds from ticket sales will go directly to XYX association.

Sponsorship and Partnership

Lions Club International

[The Lions Club of Mandurah Inc.](#) has shown incredible support to our team and our cause.

Peter Lamb attending our committee meetings and advising us where needed, Rob Garratt training for Xero-Accounting program, Operation support, they always answer our calls/emails when we reach out for support, no matter where they are.

[CG Digital Services](#) Ken Gilkes has given our cause ongoing support from building, designing and maintaining our website, without his support we would not have the website we have today. Ken has volunteered many years of his time to keep us up and running.

[Wealth Visory](#) Aaron Colley, from the day we shared our cause with him he offered to help by supporting us with funding an accounting program – Xero, to look after all our accounting needs and keep our finances on track.

[ConnectGroups](#) continues to offer us grants when needed and training for our committee, they are always one call away to help us grow and develop to be the best “Not for profit” that we can be.



Our current team



Amber - Chairperson

Amber Gilkes is the Founder and Chairperson of XYY Syndrome Association of Australia Inc. She is a mother of two boys, aged 9 and 12. After her eldest son was diagnosed with XYY Syndrome at the age of four, she devoted her time to advocating for boys and men with XYY Syndrome, with the goal of providing information, support and positive awareness for this rare condition.

The skills Amber has gained through life experience and living with a male with XYY Syndrome has provided her with opportunities to understand and advocate for this condition.

Amber has a Certificate IV in Training & Assessment, a Diploma in Community Services and Children's Services. She has over 15 year's experience working and managing child care centres.



Kerry - Deputy Chairperson

I am a serving Police Officer with the WA Police Force with more than 30 year's experience, having joined as a Police Cadet in 1990. I am also a mother of two teenagers, Kate 17 and Jack 15 (XYY).

From the moment I met our Chairperson Amber in late 2016, I knew that one day I would stand beside her sharing information and creating more awareness about XYY Syndrome, to help create a safe and equitable future for our boys. I am passionate about helping other XYY families and creating a better understanding of XYY Syndrome within the community, especially in the educational environment.



Kylie - Secretary

The XYY Association has been a lifeline for me and my family since my son's diagnosis. Without this amazing group of people our journey would have looked so different; finding understanding and acceptance has been life changing and lifesaving. My background is in HR Management in the Armed Forces, so I believe there are a few skills that can be utilised to assist the association. The association has given us so much as a family and in return to show my appreciation, I've offered my skills on the committee.

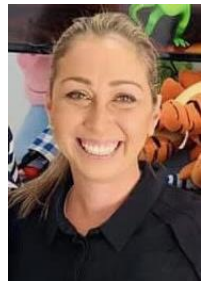
Our current team



Kristy - Treasurer

Hi I'm Kristy, I'm the treasurer of the XYY Association. I have a husband and 2 boys aged 12 and 8 we also have 2 dogs 2 cats 8 chickens and 4 ducks I've lived in Mandurah my whole life and wouldn't live anywhere else.

I enjoy helping others and doing craft activity's, I'm also a scout leader for the Mandurah scout group I run as a volunteer our high school canteen two days a week and am the treasurer/secretary for the Ravenswood sanctuary model boat club.



Emily - Committee member

I am a parent to a son, who has 47XXY, or Klinefelter Syndrome. Even though the differences in chromosomal duplication, there is an overlap of symptoms of both diagnoses, therefore can contribute to specific knowledge areas of these overlaps. In a professional capacity as a Business Analyst, I enjoy providing advice and recommendations from an organisational perspective and giving back to the community.

Useful resources

[What is XYY Syndrome, The Diagnosis, Common Traits and Comorbidity.](#)

Written by XYY Syndrome Association of Australia Inc. - February 2021

[Educational Handout](#)

Written by XYY Syndrome Association of Australia Inc. - August 2018



Book - Jack and his extra 'Y' by Arlie COLVIN

This is an excellent book to share with teachers, classmates, friends and family to help explain some common struggles and characteristics of the XYY male.

A copy of this book can be found via [Amazon](#) or [eBay](#)



Connecting to XYY Syndrome Association of Australia Inc.



Member Benefits, Sponsorships and Partnerships

<https://xyyaustralia.org/member-benefits/>

<https://xyyaustralia.org/membership-form/>

Our Mission Statement

<https://xyyaustralia.org/mission/>