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support empower inform

SPRING 2023

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Welcome

Welcome! We are so glad you are here! Thank you for taking the time to read our newsletter. Managing a diagnosis and thinking about the future can be an emotional and challenging time. This newsletter is about supporting you. We hope to provide you with some helpful information, links to resources, and ongoing research and grants but most importantly a great way to connect and share with others. No matter where you are in your journey, we hope the information provided here will Support, Empower, and Inform you and allow you to approach the future with a little more confidence.

By Spreading the Word, we will raise awareness and continue to provide education to families and carers, please free to pass the newsletter around.

AXYS Board



Introduction



WHO WE ARE

AXYS Australia is a not-for-profit organisation run by volunteers who have a direct link to someone with an X & Y chromosome variation. We are individuals, parents, families, health professionals, and allies who are continuously working hard to support, empower and inform.

AXYS helps support individuals and families living with X & Y sex chromosome variants in particular; Klinefelter Syndrome/XXY, XYY, XXX, XXYY, XXXY, XXXXY, and associated variants.

We are here to increase awareness and to inform the health and education sectors and the broader community on what these X and Y sex chromosome variants are the impact it has on individuals and families and how they can better support, guide, and implement appropriate tools and treatment plans. We aim to ensure that everyone living with an X & Y chromosome variant has the opportunity to reach their fullest potential and live a happy life with minimal impacts from possible health-related issues.

About Us



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.



Meet the Board



Chloe Hanna

CHLOE LIVES IN THE COUNTRY OUTSIDE OF MELBOURNE WITH HER FAMILY AND GARDEN. SHE IS A CLINICAL COORDINATOR WORKING IN MELBOURNE, WITH A FOCUS ON SUPPORTING INDIVIDUALS WITH VARIATIONS IN THEIR REPRODUCTIVE DEVELOPMENT AND THEIR FAMILIES. SHE HAS A BACKGROUND IN GENETIC COUNSELING.

CHLOE'S KEY INTEREST IS TO ENHANCE THE MULTIDISCIPLINARY APPROACH TO CARE FOR FAMILIES, AS WELL AS DEVELOPING LINKS BETWEEN INDIVIDUALS, PEER SUPPORT NETWORKS, HEALTH CARE GROUPS AND THE BROADER COMMUNITY TO ENABLE A MORE HOLISTIC AND TRANSPARENT SYSTEM! SHE HAS A LOT TO LEARN AND IS GRATEFUL TO BE GIVEN THE OPPORTUNITY TO BE A PART OF AXYS.



Richard Bradley

RICHARD HAS LIVED EXPERIENCE OF XXY JOINING THE AXYS BOARD TO PROVIDE PEER SUPPORT, AND EDUCATION TO THE WIDER COMMUNITY AND HEALTH PROFESSIONALS.

RICHARD IS A PHD RESEARCH STUDENT INTERESTED IN THE INTERSECT BETWEEN DISABILITY AND THE ICF. EXAMINING HOW PROTOTYPICAL AND PSYCHOPATHOLOGICAL SYMPTOMOLOGY NUANCES COULD BE IDENTIFIED THROUGH INDIVIDUAL FUNCTIONING AND AN INDIVIDUAL'S SUBJECTIVE EXPERIENCE.

RICHARD LIVES IN REGIONAL NSW WITH HIS PARTNER AND STEPSON. WHEN HE'S NOT CONDUCTING RESEARCH, HE ENJOYS SKYDIVING AND THE THRILL OF PURE ADRENALINE FUELLED WEIGHTLESSNESS.

Meet the Board



Luisa Amati

LUISA RECENTLY JOINED THE AXYS AUSTRALIA BOARD. SHE LIVES IN THE WESTERN SUBURBS OF MELBOURNE WITH HER PARTNER AND TWO CHILDREN. IN 2016, HER SON WAS DIAGNOSED PRENATALLY WITH KLINEFELTER'S SYNDROME AND SINCE THEN SHE HAS BEEN ON A PERSONAL JOURNEY TO LEARN MORE ABOUT HIS DIAGNOSIS AND HOW HE CAN BE SUPPORTED THROUGH LIFE. SHE HOPES TO SHARE WITH YOU HER REAL-LIFE EXPERIENCES, AND WHAT SHE HAS LEARNED, AND IN TURN HELP OTHERS.

WHILST HER FAMILY IS HER FULL-TIME PASSION, SHE ALSO ENJOYS COOKING, READING, AND TRAVELING.



Michelle Wilson

MICHELLE IS A MOTHER OF FOUR, THE YOUNGEST OF THE TRIBE, HUDSON BEING DIAGNOSED WITH KLINEFELTER SYNDROME VIA NIPT TESTING. MICHELLE AND HER FAMILY LIVE IN SYDNEY AND RUN THEIR OWN FAMILY BUSINESS.

WITH THE BIRTH OF HER SON AND HIS DIAGNOSIS, MICHELLE BECAME PASSIONATE ABOUT SEEKING FURTHER KNOWLEDGE ON KLINEFELTER'S AND UNDERSTANDS FIRSTHAND HOW A DIAGNOSIS CAN CHANGE A PATH.

JOINING THE AXYS AUSTRALIA BOARD MICHELLE HOPES, TO ASSIST NOT ONLY HER SON BUT HIS PEERS, NEWLY DIAGNOSED FAMILIES, AND THE BOYS AND MEN THAT WALK THIS PATH BEFORE HIM TO BE SEEN, TO BE HEARD, TO HAVE ACCESS TO A COMMUNITY THAT SUPPORTS THEM AND FURTHER EDUCATE THE ALLIED HEALTH PROVIDERS OUR COMMUNITY RELIES ON THROUGH THE WONDERFUL CONNECTIONS, WEALTH OF KNOWLEDGE AND AMAZING INDIVIDUALS WITHIN AXYS AUSTRALIA AND THEIR COMMUNITY.

We Celebrate



IF YOU EVER HAVE REACHED OUT TO THE AXYS AUSTRALIA GROUP, CHANCES ARE YOU HAVE HEARD OF ANITA. ANITA JOINED THE AXYS AUSTRALIA BOARD IN 2017 (NEED TO CONFIRM) AND OVER THE PAST SIX YEARS HAS WORKED AS A VOLUNTEER TO HELP AND SUPPORT MANY PEOPLE IN VARIOUS PHASES OF THEIR JOURNEY. SHE HAS PLAYED AN INTEGRAL PART IN THE ONGOING RUNNING AND SUPPORT OF AXYS AUSTRALIA.

ANITA HAS ORGANISED INFORMATIVE AND DIVERSE AXYS CONFERENCES AND PROVIDED A SENSITIVE AND FRIENDLY SPACE FOR PEOPLE TO COME TOGETHER. ANITA HAS SHARED HER STORY AND AWARENESS FOR X & Y SPECTRUM VARIATIONS NATIONALLY AND INTERNATIONALLY.

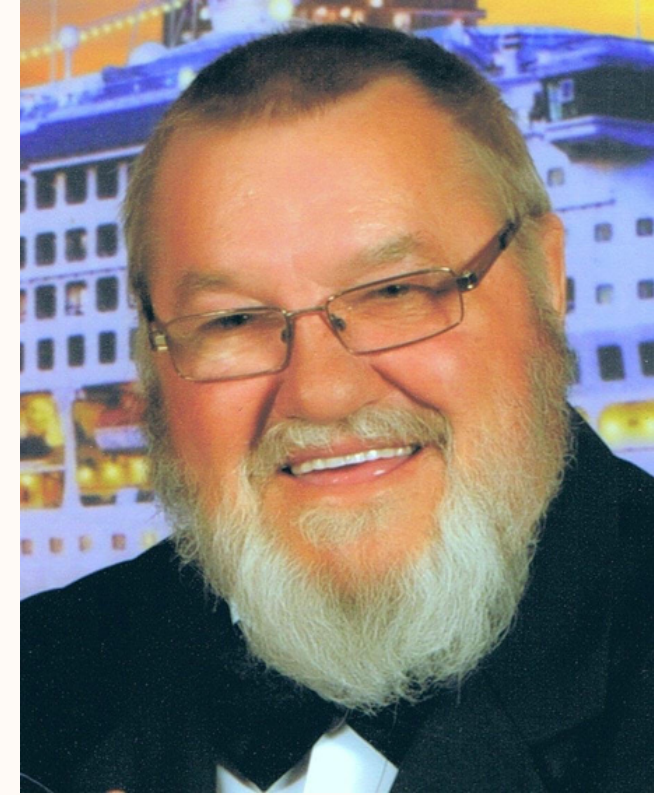
LAST MONTH (PENDING NEWSLETTER DATE) ANITA DECIDED TO RESIGN AS A BOARD MEMBER OF THE GROUP.

WE HAVE BEEN EXTREMELY FORTUNATE TO HAVE ANITA AS A MEMBER OF THE BOARD AND SHE WILL BE MISSED DEARLY. THANKS TO HER HARD WORK, DILIGENCE, AND COMMITMENT WE HAVE BEEN ABLE TO CONTINUE TO SUPPORT INDIVIDUALS AND FAMILIES.

WHILST IT IS TIME FOR HER TO HAND OVER THE BATON, WE KNOW THAT THE STEPPING STONES ANITA CREATED OVER THE LAST SIX YEARS HAVE PAVED THE WAY FOR MANY AND WE LOOK FORWARD TO THE DAY WHEN WE CAN FOLLOW HER EXAMPLE IN HELPING OTHERS FEEL SUPPORTED.

BEST REGARDS ANITA!

We Remember



GEOFF SILCOCK DEDICATED AN ENORMOUS AMOUNT OF TIME TO SUPPORTING OTHERS, INCREASING AWARENESS, AND FORMING GREAT CONNECTIONS WITH INDIVIDUALS AND FAMILIES, HIS DREAM WAS TO CHANGE THE WORLD AND HELP EVERYONE WITH KLINEFELTER SYNDROME/XXY. GEOFF WAS THE CORNERSTONE TO ENSURING OUR MEMBERS CAUGHT UP REGULARLY AND HAD 1:1 SUPPORT THROUGH MANY PHONE AND IN-PERSON DISCUSSIONS.

GEOFF SHARING HIS LIVED EXPERIENCE OF HAVING A LATE DIAGNOSIS OF XXY WAS INVALUABLE TO SO MANY PEOPLE, HE CONTINUALLY DEDICATED YEARS TO AXYS AUSTRALIA AS A MEMBER AND AS A DIRECTOR. HE LIT UP A ROOM WITH HIS VIBRANT SMILE AND PUT EVERYONE AT EASE WITH HIS GREAT SENSE OF HUMOR, HE WAS A MUCH LOVED AND UNIQUE MAN, AND DESPITE ALL HE DID FOR OTHERS HE NEVER ONCE SOUGHT ANY ACCOLADES OR RECOGNITION FOR HELPING SO MANY PEOPLE.

AXYS IS TRULY GRATEFUL FOR EVERYTHING GEOFF DID AND FEELS LUCKY TO HAVE KNOWN AND WORKED SO CLOSELY WITH HIM. WE ARE THINKING OF ROBYN AND THEIR FAMILY.



Projects

BUILDING AXYS AWARENESS.

HEALTH EDUCATION

This Month AXYS was invited to provide training to University of Melbourne Master's of Genetic Counselling students. New board member Michelle spoke about her experience of receiving an NIPT diagnosis and the medical pathway she has experienced. This was an opportunity to raise awareness of AXYS' work supporting members and advocating for better peer support, resources, and information for families learning about sex chromosome variation diagnoses.

GRANTS AND STRENGTHENING NETWORKS

AXYS HAS PARTNERED WITH TWO NATIONAL HEALTH RESEARCH GRANT APPLICATIONS TO IMPROVE THE MODEL OF CARE FOR INDIVIDUALS AND THEIR FAMILIES WITH VARIATIONS IN THEIR SEX CHARACTERISTICS, INCLUDING SEX CHROMOSOME VARIATIONS. THESE PARTNERSHIPS INVOLVE AXYS BOARD MEMBERS AND THE AXYS COMMUNITY IN CO-DESIGNING THE RESEARCH PROCESS TO ADVOCATE FOR A GREATER UNDERSTANDING OF THE PRIORITIES OF THE AXYS COMMUNITY.

WE HAVE ALSO PARTNERED WITH THE MELBOURNE CHILDREN'S RESEARCH INSTITUTE IN A RESEARCH GRANT APPLICATION TO IMPROVE DIAGNOSIS RATES AND SUPPORT FOR PEOPLE WHO ARE NEWLY DIAGNOSED, FROM PRENATAL TO ADULTHOOD. THESE ARE FANTASTIC OPPORTUNITIES FOR AXYS AND OUR MEMBERS TO ADVOCATE FOR THE HEALTH AND PSYCHOSOCIAL SUPPORT NEEDS OF OUR COMMUNITY.

Tips & Snippets



THE NATIONAL DISABILITY INSURANCE SCHEME (NDIS) IS THE NEW WAY OF PROVIDING FUNDING SUPPORT FOR AUSTRALIANS WITH DISABILITY, THEIR FAMILIES, AND CARERS. ONCE YOUR CHILD HAS BEEN APPROVED BY NDIS ACCESS THE NEXT STEP DEPENDS ON YOUR CHILD'S AGE; FOR CHILDREN AGED 0 - 6, YOUR EARLY CHILDHOOD PARTNER WILL USE THE INFORMATION YOU PROVIDED (GOALS, ASSESSMENT, COMMUNITY ENGAGEMENT ETC.) TO CREATE YOUR NDIS PLAN. 7 YEARS AND OVER, YOU'LL MEET WITH YOUR NDIA VIA VIDEO OR LOCAL AREA CO-ORDINATOR TO DISCUSS YOUR ONGOING PLAN.

FOR FURTHER INFORMATION GO TO WWW.AXYS.ORG.AU/NDIS

What's On

SUMMER IS HERE!

AXYS PICNIC IN THE PARK! JOIN US FOR A CASUAL CATCH-UP. A GREAT OPPORTUNITY TO MEET NEW PEOPLE OR CATCH UP WITH SOME OLD FRIENDS.

**SAUSAGE SIZZLE AND GAMES PROVIDED.
BRING SOME SNACKS AND A PICNIC BLANKET!**

**WHERE: ROYAL PARK PLAYGROUND (NEXT TO RCH)
PARKVILLE, VICTORIA**

DATE: SUNDAY 3RD DECEMBER 2023

TIME: 11AM ONWARDS

**LOOK OUT FOR THE BLUE AND YELLOW BALLOONS TO
FIND US!**



What's On

**ASSOCIATION FOR CHILDREN
WITH A DISABILITY**

A THREE-PART WORKSHOP FOR
FAMILIES OF TEENS AGED 13+
WITH DISABILITIES.

DATE AND TIME

**TUE, 17 OCT 2023 10:00 AM - 12:00 PM
ONLINE**

REGISTER

WWW.EVENTBRITE.COM.AU/E/TEENS-AND-BEYOND

CELEBRATE NATIONAL CARERS WEEK

**NATIONAL CARERS WEEK, FROM 15 TO 21 OCTOBER
2023, IS A TIME FOR ALL AUSTRALIANS TO
RECOGNISE AND CELEBRATE THE IMPORTANT
CONTRIBUTIONS THE 2.65 MILLION UNPAID CARERS
MAKE TO THEIR FAMILIES AND OUR COMMUNITY.**



MELBOURNE DISABILITY EXPO

**MELBOURNE CONVENTION CENTRE
FRIDAY 17TH & SATURDAY 18TH NOVEMBER
WWW.MELBOURNEDISABILITYEXPO.COM.AU**



Invitation

Volunteer

AXYS community feedback is that our members highly desire social opportunities to connect with each other. AXYS strives to make this a reality for our community Members. We are seeking passionate, empathetic, committed and excited volunteers to assist us in creating a fun-filled supportive environment at our community events. Volunteers make a difference. If you are interested please email us at contact@axys.org.au

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

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

Share your Story

We would love to hear your personal stories.

Write to us at support@axys.org.u

A large, soft-edged watercolor splash in shades of yellow and gold, centered on a white background. The splash has a textured, painterly appearance with varying tones of yellow and gold.

*Thank
you*

A cluster of abstract brush strokes in blue and yellow, located in the top-left corner of the image. The strokes are of various sizes and orientations, creating a dynamic, artistic feel.A cluster of abstract brush strokes in blue and yellow, located in the bottom-right corner of the image. The strokes are of various sizes and orientations, mirroring the ones in the top-left corner.