



Annual Report 2013-2014

www.fragilex.org.au Ph: 1300 394 636 ABN:18 655 264 477

Who are we?

The Fragile X Association of Australia Inc (FXAA) is a national not-for-profit, member-based organisation that provides support for children and adults with Fragile X-associated disorders and their families.

Established in 1989, the Association aims to:

- Improve the health and wellbeing of those affected by Fragile X Syndrome (FXS)
- Promote early detection of FXS by educating health and other professionals about how FXS presents
- Support research into the prevention and treatment of FXS
- Promote acceptance and integration of people with FXS into the community.



We achieve these aims by:

1. Providing multi-disciplinary clinics that support individuals and families with Fragile X, offering access to: diagnosis and assessment, counselling, speech therapy, occupational therapy, and other therapies.
2. Providing other educational and support interventions to promote the detection, relief, treatment and prevention of Fragile X Syndrome. This includes promoting awareness and lobbying government.

What is Fragile X?

Fragile X Syndrome (FXS) is the leading inherited cause of intellectual disability and occurs when there has been expansion or lengthening of a gene on the X chromosome. When the gene lengthens, it switches off production of a protein vital for normal brain development and other functions. Individuals with FXS present in a wide range of different ways but most will have a combination of the following features:

- **Developmental features** – intellectual disability; learning difficulties; especially with maths; delayed speech and language; problems grasping abstract concepts.
- **Behavioural features** – social anxiety; aggression; reduced eye contact; withdrawal from social interaction; rocking, hand flapping and self-talk.
- **Physical features** – some children may present with distinct physical features such as a long, narrow face; large protruding ears or high forehead; low muscle tone and loose joints; poor fine and gross motor skills.

The Fragile X gene can be passed onto males and females and may be passed down through generations. The prevalence of FX in Australia is estimated at 1 in 4000 for boys and between 1 in 5000-8000 for girls, with one severely affected child being born each week. It is also estimated that there are 20 carriers of the affected gene born each week.

Two FX-associated Disorders (FXDs) can develop in adult carriers:

- **FXPOI (Fragile X-associated Premature Ovarian Insufficiency)** – affects approximately 25% of female carriers and is characterized by early menopause. Female carriers can also have problems with social anxiety, depression and difficulty with abstract concepts such as mathematics.
- **FXTAS (Fragile X-associated Tremor Ataxia Syndrome)** – a progressive neurological condition that occurs in nearly 50% of male carriers and between 5-20% of female carriers. It manifests as Parkinson-like symptoms including intention tremor, ataxia and cognitive decline.

Contents

President's Report	Page 3
Story: Groovy Mood Food	Page 4
The 2013-2014 Board	Page 5
Our Team in the Office	Page 6
Our Community	Pages 7-8
Highlights from Across the Year	Pages 9-14
FXAA Scientific and Research Committee	Pages 15-16
Looking to the Future- Our Areas of Focus	Pages 17-19
Financial Overview	Page 20
Treasurer's Report	Page 21
Financial Statements	Pages 22-33



President's Report

Our Annual Report provides a great opportunity to reflect on and celebrate the year that was—a year filled with many highlights and successes, but also challenges along the way.

Seminars and assessment clinics held in Adelaide, Brisbane and Sydney were a highlight. We were fortunate to have international experts Professors Randi and Paul Hagerman and Louise Gane leading the workshops and clinics, and the involvement of Australian experts. A grant from the Tasmanian Community Fund allowed us to hold a FX Training Day & Assessment Clinic in Launceston, conducted by Dr Jonathan Cohen and the Fragile X Alliance team.

Through these events we have had the privilege of connecting with over 400 people and deepening their understanding of Fragile X - families, health professionals, teachers, carers and disability support service providers.

Fragile X-specific assessment clinics funded by the Association continued to be a core service provided to members. 21 clinic places were provided through Dr Natalie Silove at Westmead Hospital in Sydney and the Fragile X Alliance clinic in Melbourne. Adult clinic places were provided through Dr Jane Law at the Developmental Disability Service in Ryde, funded through Medicare. Our continuing hope is that clinics/experts will be developed in all states and territories to offer services tailored to FX clients. While NSW, Queensland and Victoria have clinics while other states lag behind.

We have all been working together on our two greatest challenges—lack of awareness of FX-associated disorders, and fundraising.

A specific donation from a generous member family has allowed us to commence a targeted and ongoing initiative to generate a high degree of understanding within the medical community of Fragile X- associated disorders: Fragile X Syndrome, Fragile X-associated Premature Ovarian Insufficiency (FXPOI) and Fragile X-associated Tremor Ataxia Syndrome (FXTAS). We look forward to reporting on this over the coming year.

Like many not-for-profit organisations we are hampered by two interrelated factors: the challenge of securing sustainable funding and the small size of our membership base.

Our goal is to secure a wider base of funding streams. We are very grateful to our members who tirelessly advocate for Fragile X and who raise money through various fundraising events. Members in Queensland, Victoria, South Australia, Victoria and WA have been very active in organising family support functions, in fundraising and in maintaining discussion groups. Board members Candice Stingel and Jeremy Sweeney in particular have worked hard to raise awareness and secure support. Over time, our Endowment Fund will provide a steady source of income (through the interest that it generates) to help cover the day-to-day running of the Association.

I would like to expressly thank the members and supporters who have made donations over the past year, both to the Association and our Endowment Fund.

A further goal is to see our membership base grow to a size that better reflects the estimated 90,000 people in Australia affected by FX-associated disorders.

None of our work is done in isolation. Our members, their families and supporters, medical professionals, community organisations, and businesses are important as champions of the work of the Association and in giving a voice to the Fragile X community. I want to take this opportunity to thank our members and supporters and ask that you continue to partner with us into the future. We could not do it without you.

On behalf of the Board and the team in our office, it is the Association's great pleasure and privilege to provide a listening ear, practical support and a doorway to the greater Fragile X Community. We look forward to continuing to do so through the coming year.

Your President,
Robyn Iredale

The Story of Groovy Mood Food

By Liza Roberts, mum of Zachary Roberts

It all started with a passion- a passion for cooking and eating ice cream and a passion for entertaining. Join these together and Groovy Mood Food is born.

Zachary Roberts was completing his final years of high school and one day said "mum I want to have my own company". Well this was the start. So I asked Zachary, "what sort of company?" I left him alone to think for a while and then he came back to me with some ideas and drawings.

Zachary drew a blueprint of a gelato company, with lots of stick figure customers walking up to a shop with dollar bills in their hands and walking off happy with an ice cream in their stick hand. From this idea we talked, dreamed, shared ideas, started making gelato and talking to others about it.

We had help from Carers QLD, through a transition program which supported Zachary with his very own ice cream machine, laptop and a little money towards cooking utensils. We had assistance from Many Rivers, regarding the business side and how to get started.

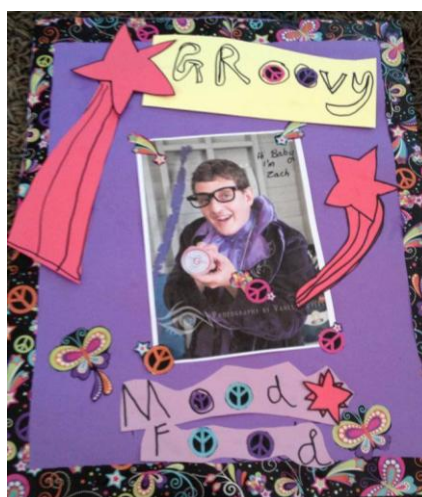
We tested our products on everyone who would try them, and set up a facebook page. I had to complete a food handler's qualification, apply for food licences and negotiate commercial kitchen space.

Suddenly it was starting to gain momentum, and we got support from family and friends, and even total strangers. This spurred me on to look for work experience opportunities for Zachary in the hospitality field, and after some introductions, lots of questions and small steps, Zachary completed work experience and has moved on to some casual work with a nearby takeaway with a wonderful boss Laurelle.

Zachary is involved in all aspects of his business from designing the logo, posters and marketing materials. He negotiates sales to retailers and has negotiated with three businesses to sell his products on a regular basis. He promotes his business with an Austin Powers inspired character, which he takes to expos and hopefully soon markets. He is learning money skills and is starting to be able to add up products when selling. He has learnt to use the business bank card and has remembered the PIN number. He can make sorbets with minimal support now and has actually lessened his sensory issues with eggs a little.

We are getting busier and may need extra employees to assist with production if we keep growing like this, and summer is still around the corner. For someone who has been labelled as "not job ready," and exited out of the job service provider system, I have hope that Zach and our family are making a difference, albeit small, with one gelato at a time.

<https://www.facebook.com/pages/Groovy-mood-food>



The 2013-2014 Board of Fragile X Association of Australia



Robyn Iredale, President (NSW)

Adjunct A/Professor at ANU, Canberra.

Robyn is a FXS Carrier and parent of two FXS adults, with eight other family members affected by FXS.



Bruce Donald AM, Treasurer (NSW)

Lawyer, Sydney.

Bruce is a parent of two FXS young women, with seven other members of his wife's extended family affected.



Tim Turpin, Secretary (NSW)

Adjunct Professor at University of Western Sydney, Sydney.

Tim is a step-parent of two FXS adults.



Simone Zaia, Board Member (NSW)

Social Worker and Case Manager, Sydney.

Simone is a FXS carrier, with several family members affected by FXS.



Professor Kim Cornish, Board Member (VIC)

Dean, Faculty of Psychological Sciences, Monash University, Melbourne.

Professor Cornish has a long history of research into FXS, and is known internationally for her work.



Cathy Love, Board Member (VIC)

Consultant Occupational Therapist, Melbourne.

Cathy is a member of the Better Start Reference Group.



Jeremy Sweeney, Board Member (WA)

Community Services Worker, Perth.

Jeremy son has FXS.



Shelley McRae, Board Member (QLD)

Biochemist, Brisbane.

Shelley's son has FXS and several family members are affected by FXS.



Candy Stingel, Board Member (QLD)

Parent, Brisbane.

Candy is an FXS carrier. Two of Candy's children have FXS and several family members are affected by FXS.

Our team in the office



Wendy Bruce, Executive Officer

Wendy is responsible for managing the general running of the Association, with particular responsibility in managing compliance, seeking grant funding opportunities, writing the quarterly FX Info newsletter, providing support to members organising fundraising events and overseeing the communication of current information and news to the FX community through our various social media channels.



Joan MacDonald, Project Officer

Joan's background is in project management, possessing both marketing and IT degrees. Before joining FXAA, Joan worked with a NSW charity for people with intellectual disability. Joan coordinates assessment clinics, organises workshops and seminars, coordinates our website content and oversees the communication of current information and news to the FX community through our various social media channels.



Janie Roberts, Counsellor

Janie has a Masters in Counselling and Psychotherapy and has worked as a counsellor at Carers NSW, Weave Women and Childrens Centre and the Rape Crisis Centre. Janie is also a clinical member of Counsellors and Psychotherapists Association of New South Wales Inc (CAPA) and Psychotherapy and Counselling Federation of Australia (PACFA). Janie's focus is on encouraging families, couples, siblings and individuals from the FX community to contact her for face-to-face support (in the Sydney area), or for phone-based counselling support.



Liz Russell, Accountant

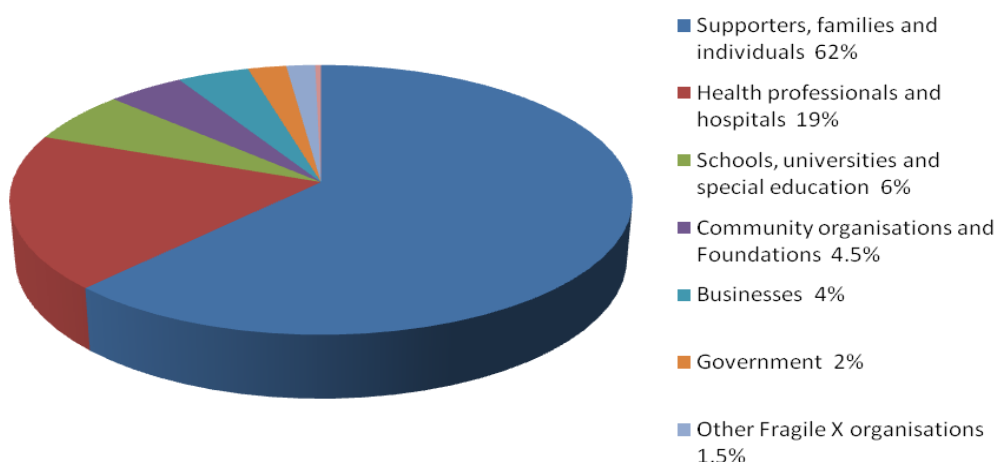
Liz is a qualified accountant. She prepares the Association's financial statements, processes donations and membership fees and coordinates the Association's financial compliance.

Our Community

The important work of the Association cannot be done in isolation. We work in partnership with a wide range of individuals and entities to ensure our effectiveness and to strengthen our voice for the Fragile X community.

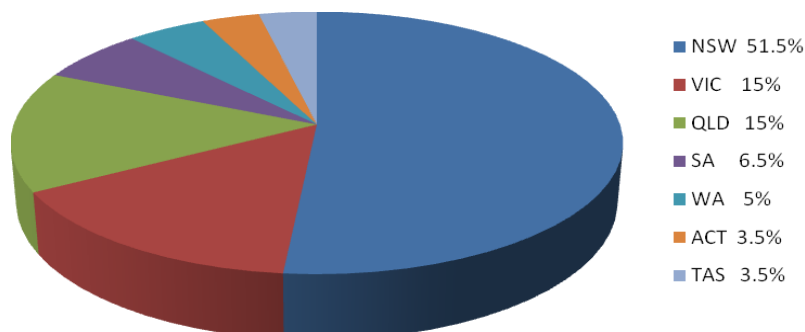
Our contacts database

We regularly connect with approximately 1770 people on our database, from individuals and families with Fragile X that need our support, to professionals who keep us up to date with the latest research and testing and to financial supporters. The Association would not be as effective without their support.



Membership

Our membership base includes 230 members from across Australia. This represents approximately 1100 family members and individuals affected by Fragile X. The state breakdown is as follows:

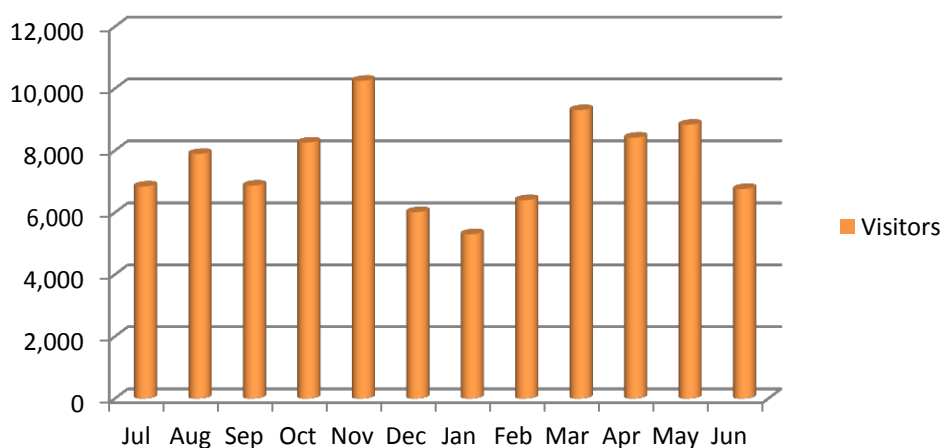


fragilex.org.au

Between 1 July 2013 and 30 June 2014 we had 91,160 unique visitors to our website.

Unique website visitors

1 July 2013-30 June 2014



The peak of activity seen in October and November is a result of workshops held during this time period.

Social media reach

As of 30 June 2014 our public Facebook page had 838 likes and there were 1,700 visits between 1 July 2013 and 30 June 2014.

Our private Facebook discussion groups for state members also continue to grow and connect the Fragile X community, providing a forum for discussion and sharing of ideas.

Events and other contacts

Across the year the Association was able to connect with and support individuals and families through the following channels:

- The Association funded FXS seminars in Adelaide, Brisbane and Sydney, each attended by around **100 people**.
- **21 assessment clinic places** were funded for children of members and adults.
- Our counselling service is provided at no charge to members and is a valued and essential service. Our Counsellor Janie Roberts has around **1,000 contacts** with members each year, including up to **500 counselling sessions** a year.



Highlights from across the year

Fragile X Awareness Day, 22 July 2013

Fragile X Awareness day is an ideal opportunity for us to strengthen community awareness of Fragile X across Australia.

It was great to see the acknowledgement and support of the **Hon. Andrew Powell MP**, member for Glass House in Queensland. He proudly wore an orange ribbon on Fragile X Awareness Day!



*The Hon. Andrew Powell MP,
member for Glass House, QLD.*

Our Treasurer, **Bruce Donald AM**, also did his part in shining the spotlight on Fragile X. He made a presentation to **Robin Williams' Radio National Science Show**. The full transcript of this interview can found on our website.

Annual Christmas card competition

Each year Fragile X Christmas cards are made available for sale to members and to the general community. This is another way is to raise awareness of Fragile X.

Congratulations to the 2013 Christmas Card Design winners! These talented artists can be seen here wearing their prize-winning designs on custom-made t-shirts!



Miriam Kelleher aged 7, from Melbourne



Luciana Romanski aged 8, from Sydney

Fragile X seminars in Adelaide, Brisbane and Sydney

During the month of September we delivered three Fragile X Family & Community Days held in Adelaide, Brisbane and Sydney. All three were well-attended and successful in meeting the set outcomes.

We were very fortunate to have the expertise and insights of our keynote speakers **Professor Randi Hagerman**, **Professor Paul Hagerman** and **Ms Louise Gane** from the M.I.N.D. Institute in the US.



Adelaide: Tim Turpin (FXAA), Louise Christie, Professor Randi Hagerman, Professor Paul Hagerman, Robyn Iredale (FXAA), Dr Jonathan Cohen (Fragile X Alliance), Michael Cohen

At each workshop Randi provided an overview of Fragile X Syndrome and spoke about the US approach to management of FXS. Paul shared the latest research on FXTAS, and interventions for FXS and FXTAS. Louise presented insights into genetic counselling and the issues related to the diagnosis and management of Fragile X across families. Other expert speakers included Dr Jonathon Cohen, Marcia Williamsz, Dr Michelle Wong, Professor Sylvia Metcalfe, Dr Jozef Gecz, Louise Christie, Marta Arpone, Dr Jan Liebelt, Dr Gregory O'Brien, Astra King.

Family & Community Workshop in Launceston, October 2013



Dr Jonathon Cohen, Mrs Lynn Mason, Tasmanian Community Fund, Wendy Bruce.

Thanks to the generous grant from the **Tasmanian Community Fund**, the Association was able to host a one-day Fragile X Workshop and assessment clinic in Launceston in October 2013. **Mrs Lynn Mason**, the Chair of the Fund, officially opened the Workshop and welcomed participants.

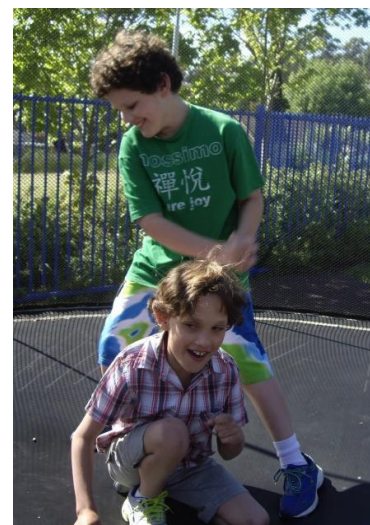
Dr Jonathan Cohen and the team of therapists from Fragile X Alliance in Melbourne, ran the Workshop for an

audience of around 100 people, which included families and carers, educators, health professionals and disability service providers.

The Workshop covered a wide range of management strategies relevant to developmental disabilities and autism spectrum disorders.

Alongside the Workshop, the Fragile X Alliance team also ran assessment clinics for several families in Launceston. Much positive feedback was received.

Many thanks to **St Giles** in Launceston for kindly making their Vos House Respite Centre available to the Association for the clinics at no charge.



Brothers Harry and Tommy enjoying their time at the Clinic.

AGM September 2013

The 2013 Fragile X Association Annual General Meeting was held on Saturday 7 September.

The meeting marked a new season for the Board, with several Board members retiring and a new Board being elected for 2014. President **John O'Connor** thanked the Board members and acknowledged their effort and commitment to the Association over the past year. In particular he thanked retiring Board members **John Kelleher**, **Will Delaat**, **Dr Mike Field**, and **Dr Honey Heussler**. He also thanked **Doug Rodgers** for his extensive commitment to the Association over many years.



It was also an opportunity to award Life Membership of the Association of Australia, to **John and Christine Kelleher**, honouring the extensive and longstanding contribution they have made over many years. We are grateful for the amazing contribution they have made to the Association and the wider Fragile X community.

10th Annual Manly Wharf Bridge to Beach ocean paddling race, Sydney, 23 February 2014

We were delighted to be asked to be the official charity partner for the 10th Annual Bridge to Beach ocean paddling race. This marked a milestone for the Association, as it was the first time we had partnered with an event of this nature.



Organised by **OceanPaddler**, the event not only provided an awareness-raising platform for Fragile X but we also raised \$7,000, providing much-needed funds for the continuing work of the Association!

A great day was had by all, with fantastic weather enjoyed by the 420 competitors, who paddled 11kms from Blues Point to Manly Wharf.

We are grateful to **OceanPaddler**, in Manly, NSW for partnering with Fragile X Association. Congratulations also go to our fundraising winners: **Luke Ratcliff, Pete Tillett, and Team Fat Paddler!**



The Annual Fragile X Association Achievement Awards

The Annual Fragile X Association Achievement Awards celebrate perseverance and successes of our members. The Awards are intended to provide inspiration and encouragement to those nominated and to other families.

The Achievers for 2013, some young and some not-so young, have each achieved wonderfully in their own arena, and are an inspiration.



Sporting Achievement:
Matthew Phillips



Art Achievement:
Tom Mikkelsen



Participation
Achievement:
Patrick Rasmussen



School Achievement:
Miriam Kelleher



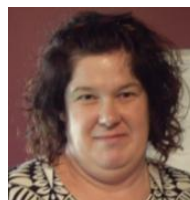
Achieving Independence:
Dion Butler



Sustained Achievement:
Chris Parkes



Family Support
Achievement:
Lynn Brewin



Community
Achievement:
Narelle Robertson

Member Fundraising and Awareness Events

We are always so grateful for the support of our members and the great efforts they go to in raising awareness of FX and much-needed funds to support the work of the Association. Here are just some of the many fundraising events that occurred over the year.

HBF Run for a Reason, Perth

Association member **Shante Sweeney** was joined by members **Kaye** and **Sue** to participate in the HBF Run for a Reason in Perth on 25 May 2014. They raised almost \$2,000.



City to Surf, Sydney, August 2013

Congratulations to mother-daughter team **Cynthia Roberts** and **Amy Simpson** who ran in the City to Surf to raise awareness of Fragile X, raising over \$3000 from their efforts. As you can [read in their story, right](#), this was a tangible way they could acknowledge the challenges Cynthia's son Dan faces every day.



The Sydney Morning Herald Half Marathon, Sydney, May 2014

The Sydney Morning Herald halfmarathon

The Sydney Morning Herald Half Marathon attracts more than 10,000 participants each May. Congratulations to **Michelle Cullen** who ran the 21.1 km distance race on Sunday 18 May 2014.

Michelle said: *"It was a great morning and a fantastic experience! I managed to run the half marathon in 2 hours and 6 minutes. Also, I raised \$5,760.50 for the Fragile X Association, which I was also so happy about!!!"*

Bridge to Brisbane, September 2013



Board Member **Candy Stingel** along with **Nyleta McRae** organised a team for the Bridge to Brisbane in September 2013. It was a fantastic day with two families walking and running together and raising over \$2,000!

Calling themselves the 'Orange Army', the team dressed proudly in orange singlets with the FXAA logo, awareness ribbons and arm bands. The plan is to make this a huge event, increasing the size of the 'Orange Army' annually.

Cynthia and Dan's story

The challenge to run 14k is nothing compared to the challenges my son Daniel experiences every day. Daniel has fragile X syndrome. Day to day for Dan, and our family, this means: Dan has an IQ of 50 – a mental age of 4- 5.....he is 18.

Dan has finished school but will never work. He attends a community participation programme Monday to Friday. Dan can recite lots of lines from movies and TV programs: "Sticky tape, we have sticky tape, lots of sticky tape at our house" (Bananas in Pyjamas); "I'm so in love" (Sleeping Beauty – but recited when giving mum a hug....Thank you Mr Disney!).

But Dan communicates in just single words – "juice" "toast" "Ipad" or gesturing. Dan can't write his own name but is a whiz on the Ipad. At 18 Dan will never drive a car. He can ride a bike with training wheels, but can't use the brakes so I have to run next to him. He takes great delight in telling me "run" and peddling as fast as he can (City to Surf training, thanks to Dan).

Dan has trouble concentrating, exhibits features of ADHD and suffers from epilepsy. He takes 5 different medications everyday...14 tablets in all. Dan can be overwhelmed with input. If he can't express this, it can come out physically...hitting and biting. He sometimes has drawn blood.

At 18 he still has occasional toileting accidents. His sisters have had to grow up sooner than their years would normally demand, taking on a shared parenting role. But without a doubt, Dan has made us all better people. We are more tolerant and patient.

When I tell Dan I am the luckiest mum in the world, there is no greater truth.



Alicia with Barry Linke, General Manager Grange Golf Club

Golf Club Raffle

We are always inspired by the love our member families show for their family members with Fragile X. **Alicia** is a year 12 student in Adelaide. Alicia's brother has FXS and she wanted to do something to support him. A keen golf player, Alicia organised a raffle at the Grange Golf Club where she is a member and an employee. Alicia secured the generous support of the Club, which donated 4 of the 5 prizes. Selling 400 tickets, Alicia raised an impressive \$740 and raised awareness of FXS around her school, local businesses as well as friends and family.

BBQ at Bunnings in Brisbane

Every little bit counts in terms of fundraising and we are grateful for the creativity and drive our members show when it comes to fundraising. Thanks to **Candy, Deb and team** for their efforts with the Bunnings BBQ fundraisers!



10th Anniversary Card Day at Dural: \$45,000 raised over 10 years !

For the past 10 years **Mrs Trish Piper** and **Mrs Barbie Barratt** have hosted an annual Card Day event for Fragile X Association, at Dural in Sydney. Initially hosted in Trish's home, the event soon became so successful it outgrew their home and moved to the Dural Country Club.

Over recent years, with the generous support of both the Galston Community Bank branch of the Bendigo Bank and the Dural Country Club, the event has gone from strength to strength raising around \$45,000 for Fragile X Association.

This year around 80 ladies gathered for the 10th Anniversary Card Day, playing bridge, canasta, euchre or mah-jong.

Particular thanks to Galston and District Community Bank Branch of Bendigo Bank and the manager **Mr Bernie Triebe**. Supporters of the event donated raffle and door prizes. We are grateful to sponsors Waterford Wedgwood Dalton, Bunnings in Dural, and Corban & Blair. Thanks also goes to **Mrs Ruth Shirriff**, an award-winning quilter, who donated a magnificent bed quilt and to **Galston Community Bank** who donated \$1500 in support.

A huge thank you to Trish, Barbie and their husbands for a magnificent effort over 10 years.



Mrs Trish Piper



Mrs Barbie Barratt



FXAA President Robyn Iredale and Bernie Triebe

FXAA Scientific and Research Committee

The Scientific and Research Committee serves to provide the Association with professional advice about scientific and clinical matters concerning Fragile X.

Through the past year the Committee comprised two Board members and ten co-opted specialists. The Committee met quarterly, and provided technical input into a range of issues with which the Association is engaged. Through 2013/14 this enabled the Association to:

- compile a database of recent Australian scientific papers and current research projects
- finalise a set of Fragile X 'Fact Sheets'
- finalise a glossary of commonly used FX technical terms
- gather advice on current developments in FX screening and testing procedures.

Committee members have also regularly provided the Association with summary research reports for the FX Info Newsletter as well as longer technical papers for the Association's website.

NATSEM Project on Modelling the Lifetime Social and Economic Cost of Fragile X

The Association continued to provide input to this ARC funded project undertaken by Professor Laurie Brown and Ms Vel McKeachie (PhD student). This project is now in the final year of completion. The first stage of the project modelled the direct costs to families for the upbringing of a child with pre- and full mutation FXS to age 25 years. A report from this stage of the study is now available at www.fragilex.org.au.

The final stage of the study is scheduled for completion in 2015. It will provide modelled estimates of indirect and intangible costs including the impact of FXS on the employment opportunities and the costs of adult caring. Once the analysis includes these indirect and intangible costs it would be anticipated that the estimated costs of raising a child and then caring for and supporting an adult with FX would be even higher than those already reported.

Scientific and Research Committee members through 2013/14

Board Members:

Dr Tim Turpin (Chair)	Adjunct Professor, School of Business, University of Western Sydney.
Dr Robyn Iredale	Adjunct Fellow, Australian National University, Canberra.

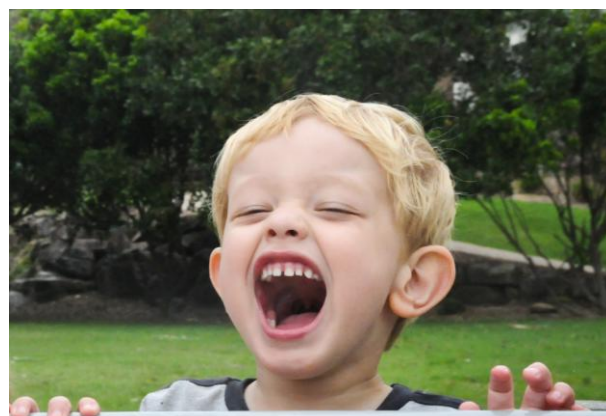
Co-opted Members:

Dr David Amor	Victorian Clinical Genetics Services, Royal Children's Hospital, Melbourne.
Dr Alison Archibald	Paediatrics, Royal Children's Hospital, Melbourne.
Dr Jonathan Cohen	Medical Director, Fragile X Alliance Clinic and Adjunct Senior Research Fellow, CDDHV, Monash University, Melbourne.
Professor Kim Cornish	Head of School, Deputy Dean of the Sub-Faculty of Biomedical and Psychological Sciences, Monash University.

Dr David Godler	Senior Research Fellow, Cyto-molecular Diagnostics Research, Murdoch Children's Research Institute, Royal Children's Hospital, Melbourne.
Dr Honey Heussler	Developmental Paediatrician, Mater Health Services, Mater Children's Hospital, South Brisbane.
Dr Matthew Hunter	Department of Paediatrics, Faculty of Medicine, Nursing and Health Sciences, Monash University, Melbourne.
Dr Danuta Loesch	School of Psychological Science, La Trobe University, Melbourne.
Professor Sylvia Metcalfe	Group Leader, Genetics Education and Health Research, Murdoch Children's Research Institute and Professor in Medical Genetics, Department of Paediatrics, The University of Melbourne.
Dr Tracey Williams	Macquarie University, Sydney.

Looking to the future - our areas of focus

As the Fragile X Association looks to the future and its ongoing sustainability, it will focus on five key areas to ensure it continues to provide essential support and a distinct voice for the Fragile X Community.



1. Family Support and Services

Supporting families in the Fragile X community is core to what we do as an Association. One key objective for the future will be to provide a Fragile X workshop and mobile clinic in each capital city over the next 3 years. We will actively seek grant funding to achieve this.

We will also continue to provide access to the following support services:

- **Counselling-** Counselling offers empathetic listening, a non-judgmental attitude, a safe place to vent, and an opportunity to consider new insights and perspectives. The counselling provided is free and confidential.
- **Adult Clinics in Sydney-** We currently provide three FXS Adult Clinics in Sydney each year with Dr Jane Law. The clinic is a joint venture of the Association and the NSW Developmental Disability Health Unit and held at the Royal Rehabilitation Centre in Ryde. The adult clinics are available for individuals aged 17 years and older, and open to people from any state if they are willing to travel. The initial appointment is a full medical examination with Dr Law, who has extensive experience of Fragile X. Participants receive advice regarding medications and relevant services that can be accessed. If necessary, referrals can also be made to other specialists.
- **Children's Clinics in Sydney-** The Association funds children's assessment clinics three times a year in Sydney, with two children's places available at each clinic. The clinic is run from the Children's Hospital in Westmead, coordinated by Dr Natalie Silove. There is a fantastic team of experts involved, including a speech therapist, occupational therapist, psychologist and a genetic counsellor.
- **Adult and Children's Clinics, Fragile X Alliance, Melbourne-** The Fragile X Alliance in Melbourne, headed by Dr Jonathan Cohen, also offers specialist multi-disciplinary Assessment Clinics for both adults and children. The Association funds the Fragile X clinics provided by Dr Cohen and his team. The clinics provide medical evaluation and assessment, psychological evaluation and treatment, speech and language evaluation and therapy, occupational evaluation and therapy, educational strategies, optometry, audiometry, genetic counselling and support.

2. Raising Awareness in the medical community

A key communications initiative is to continue actively raising awareness of Fragile X-associated disorders.

A major focus from mid 2014 has been the targeting of health professionals. This important

initiative has been very generously sponsored by a private donor and commenced in June this past year. Our goal is to improve understanding of Fragile X in the medical community, strengthening assessment and diagnosis.

3. Fundraising

A sustainable income is vital for the Association's future. We are a small organisation with only four part-time staff providing support and services to families nationally, on a budget of approximately \$270,000. Our Board members are all volunteers.

We need to constantly address our funding base. To date we have not been able to convince government to assist us with funding our basic operations as it moves more towards funding disabled people individually rather than support organisations. Foundation and corporate philanthropic organisations are also reluctant to fund office and running costs.

The Board will continue to actively seek grant funding to provide workshops and clinics, and continues to lobby government for funding of current and future services.

4. Growing our membership base

The annual membership fee has been kept low to encourage families to join and share the information and support we provide. We intend to keep that fee low and to work hard to attract new members. It is estimated that 90,000 people in Australia are affected by FX-associated disorders. Through our awareness program and our other activities we hope to increase that membership significantly to reflect the broader FX community.

At the same time we will continue to encourage our current members to support the Association financially and in other ways, through their networks of family and friends, professional acquaintances and community organisations.

5. National Disability Insurance Scheme (NDIS)

The Association has begun exploring the possibility of becoming a registered service provider under the National Disability Insurance Agency (NDIA). The National Disability Insurance Scheme (NDIS) will require individuals to develop their own support plans.

The next few years represent a transition phase to the NDIS and it is essential that the Association becomes active in helping people to negotiate the transition – to be “NDIS ready.” Most of our members and the FX community generally know and understand little about the NDIS. As Dr Jonathan Cohen states in a letter of June 2014:

‘The current NDIA mechanisms that help individuals improve self-advocacy skills through WEBINARS are entirely inappropriate for people with an intellectual disability or social anxiety and depression. Potentially this is a very serious situation and the Association is trying to be proactive in ensuring it does not eventuate’.

The complex processes involved in negotiating or managing mainstream individualised packages

and successful transition to NDIS are simply beyond the capacity of most FXS individuals and individuals who have an intellectual disability. These families need support to succeed. The Association could develop a support service that would enable FX people and those with an intellectual disability generally to fully access and utilise their entitlements under the NDIS.

Why are specific support services required for FXS and others with intellectually disability?

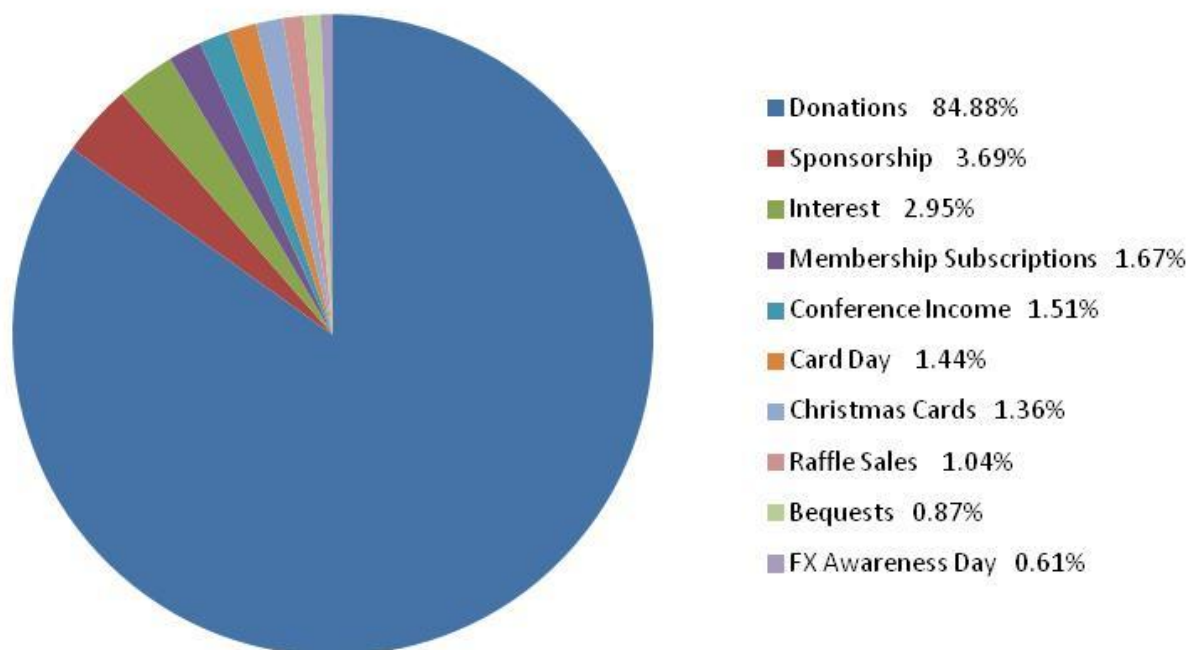
The nature of Fragile X syndrome and its associated disorders and other forms of intellectual disability is that there is no single pattern or profile of support needs. Each impacted individual has unique needs and requires a tailored mix of services and supports to function optimally and to reach their full potential - no model decision support plan fits all. Each package therefore must be planned, negotiated and tailored to successfully meet the specific needs of the individual.



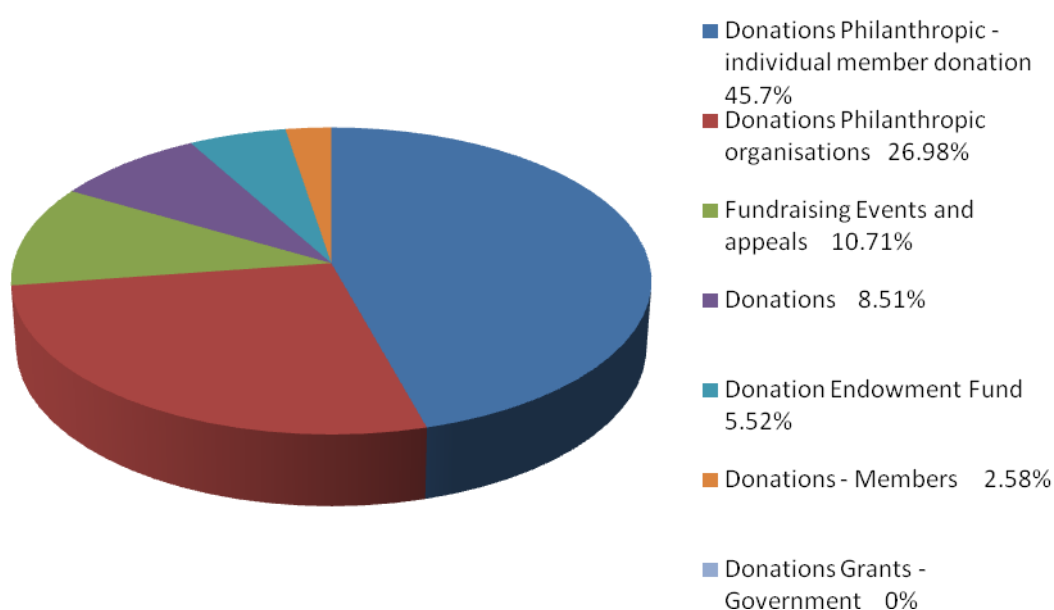
Financial Overview

The Association continues to be challenged by sustainable income in the face of ongoing costs. Our total income can be broken down as follows:

TOTAL INCOME



DONATIONS BREAKDOWN





Treasurer's report

During my first year as Treasurer I have reported through the Association's newsletters on the funding challenge faced by us as a small organisation and the need for members to endeavour to contribute where they can.

The annual accounts are a success story, again showing how member contributions and impressive efforts large and small have kept us viable and effective. However the accounts do reflect the decisions taken by the Board and the Executive Committee to make use of reserves to fund the full range of activities undertaken, resulting in a deficit for the year.

Nevertheless, at year's end we have adequate resources and expected revenues to be satisfied we are well placed to continue our activities at the same general financial level.

Members should note that the accounts present expenditure on a cost centre basis allocating staff costs to our main activity areas of support services, clinics, workshops and general administration. This provides a useful measure of how we apply our funds.

During the year we have achieved good value in renewing our premises costs and have begun a review of insurance costs to ensure they are the best achievable for necessary risk cover. A moderate increase in fundraising costs relates to use of donation portals and merchant charges as we expand fund raising systems.

The Association's Endowment Fund has grown by about \$25,000 during the year and while still in its infancy, does provide a financial base for our stability as an organisation. Over time we will endeavour to grow this Fund substantially.

Our core viability however over the last three years has been the result of the generosity of the Cunningham family who remain committed to the organisation, for which we are deeply grateful.

Significant grants were also gratefully received in this financial year from The Milton Foundation, ANZ Trustees, a private family foundation and Novartis.

The Board also wishes to acknowledge the dedicated fundraising efforts of many of our members, their families and friends, over the past year.

Our staff accountant Liz Russell is to be commended for her work and we sincerely thank our auditor and Mr Brian Tierney for his pro bono professional audit.

I commend the accounts to the Members.

A handwritten signature in dark ink, appearing to read 'Bruce Donald'. The signature is fluid and cursive.

Bruce Donald
Treasurer



ManserTierney&Johnston
Chartered Accountants

**FRAGILE X ASSOCIATION
OF AUSTRALIA INC
ABN 18 655 264 477**

**FINANCIAL STATEMENTS
30 JUNE 2014**

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

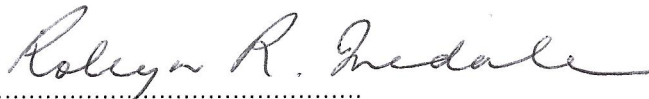
STATEMENT BY MEMBERS OF THE BOARD

The Board has determined that the association is not a reporting entity and that these special purpose financial statements should be prepared in accordance with the accounting policies outlined in Note 1 to the financial statements.

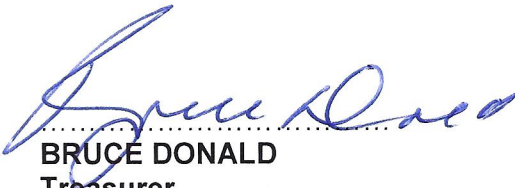
In the opinion of the Board the attached financial statements comprising the Balance Sheet, Income and Expenditure Statement and Notes to the Financial Statements:

1. present a true and fair view of the financial position of Fragile X Association of Australia Inc as at 30 June 2014 and its performance for the year ended on that date in accordance with the accounting policies described in Note 1 to the financial statements and the requirements of the Associations Incorporation Act 2009 (NSW); and
2. at the date of this statement, there are reasonable grounds to believe that Fragile X Association of Australia Inc will be able to pay its debts as and when they fall due.

This statement is made in accordance with a resolution of the Board and is signed for and on behalf of the Board by:



ROBYN IREDALE
President



BRUCE DONALD
Treasurer

Dated this 4th day of September, 2014.



ManserTierney&Johnston
Chartered Accountants

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF
FRAGILE X ASSOCIATION OF AUSTRALIA INC

Report on the Financial Statements

We have audited the accompanying financial statements, being special purpose financial statements, of Fragile X Association of Australia Inc (the association), which comprises the balance sheet as at 30 June 2014, the income and expenditure statement for the year then ended, notes comprising a summary of significant accounting policies and other explanatory information and the statement by members of the Board.

Board's Responsibility for the Financial Statements

The Board of Fragile X Association of Australia Inc is responsible for the preparation and fair presentation of the financial statements and has determined that the basis of preparation described in Note 1 is appropriate to meet the requirements of the Associations Incorporation Act 2009 (NSW) and is appropriate to meet the needs of the members. The Board's responsibility also includes such internal control as the Board determines is necessary to enable the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditor's Responsibility

Our responsibility is to express an opinion on the financial statements based on our audit. We have conducted our audit in accordance with Australian Auditing Standards. Those standards require that we comply with relevant ethical requirements relating to audit engagements and plan and perform the audit to obtain reasonable assurance whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the association's preparation and fair presentation of the financial statements, in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the association's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates made by the Board, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion

.../2



ManserTierney&Johnston
Chartered Accountants

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF
FRAGILE X ASSOCIATION OF AUSTRALIA INC

Opinion

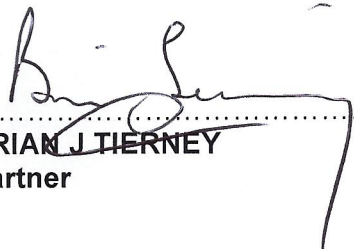
In our opinion, the financial statements presents fairly, in all material respects, the financial position of Fragile X Association of Australia Inc as at 30 June 2014 and of its financial performance for the year then ended in accordance with the accounting policies described in Note 1 to the financial statements, and the requirements of the Associations Incorporation Act 2009 (NSW).

Basis of Accounting and Restriction on Distribution

Without modifying our opinion, we draw attention to Note 1 to the financial statements, which describes the basis of accounting. The financial statements have been prepared to assist Fragile X Association of Australia Inc to meet the requirements of the Associations Incorporation Act 2009 (NSW). As a result, the financial statements may not be suitable for another purpose.

Signed at Wahroonga this 4th day of September 2014

MANSER TIERNEY & JOHNSTON
Chartered Accountants


.....
BRIAN J TIERNEY
Partner

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

BALANCE SHEET
AS AT 30 JUNE 2014

	Note	2014	2013
CURRENT ASSETS			
Cash on hand			
At Bank		100,656	63,388
Bank Guarantee		6,875	9,625
Endowment Fund	8	159,133	134,736
Petty Cash		52	101
Term Deposits		<u>-</u>	<u>85,789</u>
		<u>266,716</u>	<u>293,639</u>
Accounts receivable and other debtors			
Accounts Receivable		4,342	14,160
GST Refundable		<u>7,906</u>	<u>8,184</u>
		<u>12,248</u>	<u>22,344</u>
TOTAL CURRENT ASSETS		<u>278,964</u>	<u>315,983</u>
NON-CURRENT ASSETS			
Property, plant and equipment			
Office Equipment - At Cost		20,273	19,609
<u>Less: Accumulated Depreciation</u>		<u>(9,283)</u>	<u>(6,446)</u>
TOTAL NON-CURRENT ASSETS		<u>10,990</u>	<u>13,163</u>
TOTAL ASSETS		<u>289,954</u>	<u>329,146</u>
CURRENT LIABILITIES			
Accounts payable and other payables			
Accounts Payable		8,440	6,072
Income Received in Advance		4,125	-
Payroll Liabilities		1,667	2,980
Other Liabilities		<u>42</u>	<u>-</u>
TOTAL CURRENT LIABILITIES		<u>14,274</u>	<u>9,052</u>
TOTAL LIABILITIES		<u>14,274</u>	<u>9,052</u>
NET ASSETS		<u>\$275,680</u>	<u>\$320,094</u>
MEMBERS' FUNDS			
Opening Balance		320,094	273,950
<u>Add: Surplus/(Deficit) for the Year</u>		<u>(44,414)</u>	<u>46,144</u>
TOTAL MEMBERS' FUNDS		<u>\$275,680</u>	<u>\$320,094</u>

The accompanying notes form part of these financial statements.

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

INCOME AND EXPENDITURE STATEMENT
FOR THE YEAR ENDED 30 JUNE 2014

	2014	2013
INCOME		
Gross Proceeds From Fundraising Appeals		
Bequests	2,345	34,000
Card Day	3,898	6,689
Christmas Cards	3,669	2,142
Conference Income	4,075	-
Donations	229,759	254,878
FXAA Awareness Day	1,646	702
Raffle Sales	2,808	-
Sponsorships	9,990	-
Other	<u>-</u>	<u>4,943</u>
	<u>258,190</u>	<u>303,354</u>
Other		
Interest	7,984	9,570
Subscriptions	<u>4,525</u>	<u>5,450</u>
	<u>12,509</u>	<u>15,020</u>
Total Income (carried forward)	<u>270,699</u>	<u>318,374</u>

The accompanying notes form part of these financial statements.

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

INCOME AND EXPENDITURE STATEMENT
FOR THE YEAR ENDED 30 JUNE 2014

	2014	2013
Total Income (brought forward)	<u>270,699</u>	<u>318,374</u>
Less:		
EXPENDITURE		
Total Costs Of Fundraising Appeals		
Christmas Cards	3,334	1,070
Card Day	2,450	1,830
Other	<u>5,724</u>	<u>802</u>
	<u>11,508</u>	<u>3,702</u>
Total Costs Of Providing Services		
Support Services and FX Awareness	66,129	66,635
Clinics and Counselling	72,750	55,199
National Newsletter Printing	4,185	6,520
Research Funding	<u>-</u>	<u>6,000</u>
	<u>143,064</u>	<u>134,354</u>
Other		
Bank Fees and Charges	1,044	511
Board and AGM Expenses	589	2,364
Workshops and Seminars	37,419	1,609
Consultants	559	21,213
Depreciation	2,836	2,662
General Administration - Employment Costs	55,687	47,619
Insurance	5,995	5,625
Office Expenses	4,631	3,860
Office Rent	37,041	38,396
Postage	3,341	2,142
Stationery	1,900	1,008
Subscriptions	923	-
Sundries	2,388	991
Telephone	<u>6,188</u>	<u>6,174</u>
	<u>160,541</u>	<u>134,174</u>
Total Expenditure	<u>315,113</u>	<u>272,230</u>
SURPLUS/(DEFICIT) FOR THE YEAR	<u><u>\$(44,414)</u></u>	<u><u>\$46,144</u></u>

The accompanying notes form part of these financial statements.

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2014

Note 1 – Summary of Significant Accounting Policies

The financial statements are special purpose financial statements prepared in order to satisfy the financial reporting requirements of the Associations Incorporation Act 2009 (NSW). The committee has determined that the association is not a reporting entity.

The financial statements have been prepared on an accruals basis and are based on historic costs and do not take into account changing money values, or except where specifically stated, current valuations of non-current assets.

The following significant accounting policies, which are consistent with the previous period unless otherwise stated, have been adopted in the preparation of these financial statements.

a) Property, Plant and Equipment

Property, plant and equipment are carried at cost, independent or committees' valuation. All assets, excluding freehold land and buildings, are depreciated over their useful lives to the association from the time the asset is held ready for use.

b) Impairment of Assets

At the end of each reporting period, the entity reviews the carrying amounts of its tangible and intangible assets to determine whether there is any indication that those assets have been impaired. If such an indication exists, an impairment test is carried out on the asset by comparing the recoverable amount of the asset, being the higher of the asset's fair value less costs to sell and value in use, to the asset's carrying amount. Any excess of the asset's carrying amount over its recoverable amount is recognised in the income and expenditure statement.

c) Employee Provisions

Provision is made for the association's liability for employee benefits arising from services rendered by employees to the end of the reporting period. Employee provisions have been measured at the amounts expected to be paid when the liability is settled.

d) Provisions

Provisions are recognised when the association has a legal or constructive obligation, as a result of past events, for which it is probable that an outflow of economic benefits will result and that outflow can be reliably measured. Provisions are measured at the best estimate of the amounts required to settle the obligation at the end of the reporting period.

e) Cash on Hand

Cash on hand includes cash on hand, deposits held at call with banks, and other short-term highly liquid investments with original maturities of three months or less.

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2014

Note 1 – Summary of Significant Accounting Policies (cont'd)

f) Accounts Receivable and Other Debtors

Accounts receivable and other debtors include amounts due from members as well as amounts receivable from donors. Receivables expected to be collected within 12 months of the end of the reporting period are classified as current assets. All other receivables are classified as non-current assets.

g) Revenue and Other Income

Revenue is measured at the fair value of the consideration received or receivable.

Interest revenue is recognised using the effective interest rate method.

Grant and donation income is recognised when the entity obtains control over the funds which is generally at the time of receipt.

All revenue is stated net of the amount of goods and services tax (GST).

h) Goods and Services Tax (GST)

Revenues, expenses and assets are recognised net of the amount of GST, except where the amount of GST incurred is not recoverable from the Australian Tax Office (ATO). Receivables and payables are stated inclusive of the amount of GST receivable or payable. The amount of GST recoverable from, or payable to, the ATO is included with other receivables in the Balance Sheet.

i) Financial Assets

Investments in financial assets are initially recognised at cost, which includes transaction costs and are subsequently measured at fair value which is equivalent to their market bid price at the end of the reporting period. Movements in fair value are recognised through an equity reserve.

j) Account Payable and Other Payables

Accounts payable and other payables represent the liability outstanding at the end of the reporting period for goods and services received by the association during the reporting period that remain unpaid. The balance is recognised as a current liability with the amounts normally paid within 30 days of recognition of the liability.

k) Comparative Figures

Where required by Accounting Standards, comparative figures have been adjusted to conform with changes in presentation for the current financial year.

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2014

Note 2 - Information on Material Matters

During the year the Association received \$50,000 as the income of few annual grants from a benevolent institution to fund the Association's operations. The Association received \$93,000 from a private benefactor family.

Note 3 - Application of appeal monies

During the year the Association received net income of \$258,190 from fundraising appeals, \$3,185 from the investment of appeal monies and \$4,525 from membership fees.

An amount of \$143,064 was spent on the provision of services (including \$72,750 for clinics and counselling, \$4,185 for newsletters and \$66,129 for other awareness and support). We spent \$120,286 on rent, insurance, administration and office expenses. We spent \$37,419 on conferences and seminars.

Note 4 - Information on traders

The Association did not use traders in carrying out fundraising appeals.

Note 5 - Fundraising appeals conducted during the period

Appeals conducted were:

- Soliciting of donations
- Sale of Christmas cards
- Card playing day in March 2014
- Fun runs
- Fragile X Awareness day events
- Garden open day

Note 6 - Analysis of monetary figures

Ratios	\$	%
Total cost of fundraising/ Gross income from fundraising	11,508/258,190	4.5 (1.2% last year)
Net surplus from fundraising/ Gross income from fundraising	246,682/258,190	95.5 (98.8% last year)
Total costs of services/ Total expenditure	143,064/315,113	45.4 (49.4% last year)
Total costs of services/ Total income received	143,064/270,699	52.8 (42.2% last year)

Note 7 - Commitments

No material commitments were entered into by the association during the year.

FRAGILE X ASSOCIATION OF AUSTRALIA INC
ABN 18 655 264 477

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 30 JUNE 2014

	Note	2014	2013
Note 8 - Endowment Fund			
Balance Sheet - as at 30 June			
CURRENT ASSETS			
Cash and cash equivalents			
At Bank		2,156	54,736
Term Deposit - Due 16 October 2014 at 3.10%		<u>156,977</u>	<u>80,000</u>
TOTAL CURRENT ASSETS		<u>159,133</u>	<u>134,736</u>
NET ASSETS		<u><u>\$159,133</u></u>	<u><u>\$134,736</u></u>
EQUITY			
Opening Balance		134,736	90,000
Transfer to Capital		19,585	-
Add: Income for the Year	9	<u>4,812</u>	<u>44,736</u>
TOTAL EQUITY		<u><u>\$159,133</u></u>	<u><u>\$134,736</u></u>

Note 9 - Endowment Fund
Income & Expenditure Statement - for the year ended 30 June

INCOME		
Bequest as residuary beneficiary of deceased estate	2,345	34,000
Donations	17,242	7,400
Interest	<u>4,810</u>	<u>3,336</u>
	24,397	44,736
Less:		
Transfer to Capital	<u>19,585</u>	<u>-</u>
INCOME FOR THE YEAR	<u><u>\$ 4,812</u></u>	<u><u>\$ 44,736</u></u>



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Become a member

Join the association to receive current information and research.

Workplace Giving

Introduce Fragile X Association to your workplace giving program .

Fundraising

Organise an Awareness Event .

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Find out how your organisation can support the Association.

CONTACT US:

Our website: www.fragilex.org.au

Email: support@fragilex.org.au

Ph: 1300 394 636

Address: PO Box 109, Manly, NSW 2095