

## Section 1: INTRODUCTION AND SUMMARY

## introduction

### Background

Australia has a vibrant health charity sector and the National Patient Organisation Network (NPON) was convened to support the sector and strengthen its impact through collaboration.

This report draws on data collected from the 2019 and 2022 Australian Information Statement where charities respond to questions about finances and operations over a 12 month period. It also draws on a survey conducted by CCDR that collects information about the activities of member organisations, and the importance and accessibility of care and treatment for the communities they serve, as part of the health system.

### **Data from the 2022 Australian Information Statement (Australian Charities and Not-for-Profit Commission)**

Data were extracted for charities that are NPON

members. There were 84 organisations with data in 2019 and 87 organisations with data in 2022 (<https://www.acnc.gov.au/for-charities/annual-information-statement>).

Data from the Australian Information Statement is presented in sections 2 to 5 and cover details about the charity, income, expenditure and employment.

### **Data from the 2024 CCDR NPON questionnaire**

There were 83 organisations that responded to the questionnaire. Data from the questionnaire are presented in sections 6 to 14 and covers advocacy activities, support services, healthcare professionals, NDIS application support, information and education, clinical trials and research, palliative care, pain management, programs and outreach to specific communities, and the importance and accessibility of care and treatment.

## Summary

What do NPON organisations do with a combined \$200 million income, 700 full time equivalent employment, and 3,000 volunteers?

### SUPPORT SERVICES

- 73% peer-to-peer support
- 57% support groups (face-to-face)
- 51% support groups (telephone)
- 44% helplines
- 19% financial aid
- 11% telehealth nurse structured services
- 4% transport
- 1% legal aid



### ADVOCACY

- 63% are active in patient rights advocacy
- 59% are active in health system/service change advocacy
- 53% participate in policy and Senate Inquiries
- 48% deliver PBAC/MSAC submissions & access
- 48% aids access to clinical trials
- 45% deliver research funding



### INFORMATION

- 96% online information
- 80% research updates
- 77% written information (hard copies)
- 73% webinars
- 67% patient information days or conferences
- 60% clinical updates
- 21% apps



### NDIS SUPPORT

- 28% online information tailored to community
- 20% written information tailored to community
- 16% a helpline
- 7% a telephone structured service



### CLINICAL TRIALS

- 68% direct patients to clinical trials
- 52% clinical trial co-design, connect patients with CT
- 22% fund clinical trials
- 15% manage a clinical registry



### RESEARCH

- 63% research co-design, connect patients
- 40% fund research
- 30% conduct research
- 27% develop national research strategy



### PROFESSIONAL EDUCATION

- 78% information for professionals
- 65% presentations on request
- 59% webinars to professionals
- 57% written information for professionals
- 52% conferences to professionals



### PAIN MANAGEMENT

- 37% information about pain management
- 28% carer support for pain management
- 25% advocacy or policy for pain management
- 19% referral to pain management specialists
- 13% support or education for health professionals



### PALLIATIVE CARE

- 28% carer support for palliative care
- 24% information about palliative care
- 23% advocacy or policy for palliative care
- 16% support or education for health professionals
- 13% referral to palliative care services



Most NPON member organisations are small charities with an income of less than \$250,000

## About NPON members

Data was extracted from the 2019 and 2022 Annual Information Statement Data from the Australian Charities and Not-for-profits commission (ACNC) (available from <https://data.gov.au>).

In 2019 and in 2022, most NPON members were small charities.

In 2019 the most common main activities were civic health service delivery, health service deliveries and education. The most common secondary activities were research, social services education and health service delivery.

In 2019 the most common main beneficiaries were people with chronic illness, the general community

in Australia and people with disabilities. The most common secondary beneficiaries were families, people with disabilities, the general community in Australia, people with chronic illness and children and youth aged 6 to 25.

In 2019 most charities were located in New South Wales, Victoria or Queensland and these are the states that charities most commonly operated in.

In 2019, fundraising most commonly occurred in New South Wales, followed by Victoria, South Australia and online. In 2022 fundraising was most commonly online followed by New South Wales, Victoria, and South Australia.

## Total revenue

Data was extracted from the 2019 and 2022 Annual Information Statement Data from the Australian Charities and Not-for-profits commission (ACNC) (available from <https://data.gov.au>).

NPON members received revenue from the government, donations and bequests, goods and services, and interest. In 2019 the total revenue for NPON members ranged from \$0 to \$40,123,178

(median=\$203,060; IQR = 1,309,706), and in total 84 member charities had a combined revenue of \$174,225,904.

In 2022 the total revenue for NPON members ranged from 0 to 52,577,000 (median=\$238,609; IQR=\$1,094,001), and in total 87 member charities had a combined revenue of \$213,762,418.

In 2019 84 NPON members had a combined income of \$174,225,904.

In 2022 87 NPON members had a combined income of \$213,762,418.

## Total expenses

Data was extracted from the 2019 and 2022 Annual Information Statement Data from the Australian Charities and Not-for-profits commission (ACNC) (available from <https://data.gov.au>).

NPON members had expenses from employees, interest, and grants and donations both within and outside Australia.

In 2019 82 NPON organisations had total expenses ranging from \$1988 to \$39677000 (median =

\$210,918.50; IQR = \$1,207,956.25), and in total 84 member charities had combined expenses of \$16,5701,905.

In 2022 86 NPON organisations had total expenses ranging from \$762 to \$52,233,000 (median = \$211,233.50; IQR = \$1,249,855), and in total 87 member charities had combined expenses of \$211,183,329.

In 2019, 84 NPON member charities had combined expenses of \$16,5701,905.

In 2022, 87 NPON member charities had combined expenses of \$211,183,329.

## Employees

### Staff overview

Data was extracted from the 2019 and 2022 Annual Information Statement Data from the Australian Charities and Not-for-profits commission (ACNC) (available from <https://data.gov.au>).

In 2019, NPON member organisations employed a total of 454 full time staff 377 part time staff, 55 casual staff, a total full time equivalent of 681.97

staff. In addition, they had a total of 3996 volunteers.

In 2022, NPON member organisations employed a total of 505 full time staff 529 part time staff, 83 casual staff, a total full time equivalent of 767.47 staff. In addition, they had a total of 2892 volunteers.

<b>2019 Staff in NPON member organisations</b> <ul style="list-style-type: none"> <li>• Full time: 454</li> <li>• Part time: 377</li> <li>• Casual: 55</li> <li>• Full time equivalent: 681.97</li> <li>• Volunteers: 3996</li> </ul>	<b>2022 Staff in NPON member organisations</b> <ul style="list-style-type: none"> <li>• Full time: 505</li> <li>• Part time: 529</li> <li>• Casual: 83</li> <li>• Full time equivalent: 767.47</li> <li>• Volunteers:2892</li> </ul>
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**NPON advocacy activities**

Data was collected from NPON members in 2024 about advocacy activities/services that organisation is involved with or would like to initiate in the future.

Over 60% of NPON organisations advocate for patient rights, and nearly 60% are involved in health symptom or service change. Approximately half of the organisations deliver PBAC or MSAC submissions & access, aids access to clinical trials, and offer research funding.

NPON organisations described the amount of interaction with the PBAC or other government feedback opportunities. In general, following submission there was very little feedback. Approximately 59% of organisations never or rarely received detailed information on how patient representation was used. About 60% sometimes or rarely received detailed information on the impact of patient representation. Approximately half of the organisations were never invited to provide additional clarifications after the submission period

is closed, and 62% of organisations never or rarely were informed of any new policies, guidelines or reports that patient representation contributed to.

**NPON organisations comments about advocacy activities**

*As a very small organisation with limited funding (funds raised by our own efforts - no government support) there is a clear limit to what we can achieve in any of these areas. What matters most is the extent to which we can partner with alliances/groups/organisations (incl APON) who can ensure that our shared concerns are raised. To the extent that there is something very specific to Fragile X, such as carrier screening, testing then we ensure we prepare something targetted that is within the capacity of one of our Board members to write.*

*It would be great to do this, or deliver this but... this would require resources and funds*

<b>NPON advocacy activities</b> <ul style="list-style-type: none"> <li>• 62.65% are active in patient rights advocacy</li> <li>• 59.04% are active in health system/service change advocacy</li> <li>• 53.01% participate in policy and Senate Inquiries</li> <li>• 48.19% deliver PBAC/MSAC submissions &amp; access</li> <li>• 48.19% aids access to clinical trials</li> <li>• 45.78% deliver research funding</li> </ul>	<b>Submissions or representing patients in government feedback</b> <ul style="list-style-type: none"> <li>• 59% never or rarely received information on how patient representation was used</li> <li>• 60% sometimes or rarely received information on the impact of patient representation</li> <li>• 48% were never invited to provide additional clarifications after the submission period is closed</li> <li>• 62% never or rarely were informed of any new policies, guidelines or reports that patient representation contributed to</li> </ul>
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## NPON support services

Data was collected from NPON members in 2024 about support services that the organisation is involved with or would like to initiate in the future.

The most common services offered, and that were offered by more than half of the organisations are peer-to-peer support, support groups (face-to-face), and support groups (telephone). Other services offered include, helplines, financial aid, telehealth nurse structured services, transport and legal aid

Self-care interventions are tools which support self-care. Self-care interventions include evidence-based, quality drugs, vitamins & minerals, lotions

and creams, devices, diagnostics and/or digital products (including apps) which can be provided fully or partially outside of formal health services and can be used with or without health worker. The majority of organisations engaged in self care interventions either by informing patients of self care opportunities, reviewing the evidence/literature related to self-care opportunities, and referring patients to self-care opportunities.

The top five self care interventions listed by NPON organisations were evidence-based quality drugs, digital products (including apps), diagnostics, devices, and lotions and creams.

### NPON support services

- 73% offer peer-to-peer support
- 57% offer support groups (face-to-face)
- 51% offer support groups (telephone)
- 44% offer helplines
- 19% offer financial aid
- 11% offer telehealth nurse structured services
- 4% offer transport
- 1% offer legal aid

### Self care interventions

- 61% offer inform patients of self-care opportunities
- 36% offer review the evidence/literature related to self-care opportunities
- 28% offer refer patients to self-care opportunities

### Self care interventions important to community

- 62% Evidence-based quality drugs
- 42% Digital products (including apps)
- 41% Diagnostics
- 39% Devices
- 25% Lotions and creams

## Employment of healthcare professionals

Data was collected from NPON members in 2024 about employment of healthcare professionals in the organisation. .

The majority of organisations (n=49, 71.01%) do not employ healthcare professionals, for those that do, approximately half work in non-clinical services, and approximately a third of nurses deliver clinical services.

### Healthcare professional employment

- 71% do not employ any healthcare professionals
- 16% employ registered nurses
- 9% employ counsellors
- 6% employ an occupational therapist
- 3% employ a medical doctor
- 3% employ a physiotherapist
- 1% employ a genetic counsellor
- 1% employ a psychologist
- 53% of healthcare professionals work in non-clinical services
- 36% of nurses deliver clinical services

## NPON NDIS support services

Data was collected from NPON members in 2024 about any NDIS support or information that they offer.

There were 5 organisations (7.25%) that offered a structured telephone service, 11 organisations (15.94%) that offered a helpline for NDIS, 19 organisations (27.54%) that offered online information and 14 organisations (20.29%) that offered written information.

### NPON organisations comments about NDIS support services

*Dysphonia not currently recognised for NDIS purposes*

*I would love this for our community - but this would be really difficult for me to put together. I don't have the knowhow or expertise in the area.*

*Our NDIS service is used to guide the NF Community through this often-complex process. We write support letters explaining NF, as it can cause invisible but significant disabilities. Our NDIS workload has increased recently. We are dealing with families who are distraught and struggling to access services. They're only able to access these essential services, like speech and physiotherapy, due to NDIS funding, an increasing number of families are having their access denied.*

*We provide the above by paying a 3rd party provider. We pay for families to have time with an external provider to discuss their applications,*

#### NDIS support services

- 7% offer a telephone structured service
- 16% offer a helpline
- 28% offer online information tailored to their community
- 20% offer written information tailored to their community

## NPON information and education services

Data was collected from NPON members in 2024 about information provided for patients and education provided for healthcare professionals.

Almost all the organisations offered online information for patients, and most organisations offered research update, written information (hard copies), webinars, patient information days or conferences, and clinical updates. A few organisations offered apps.

NPON organisations offered various forms of education for healthcare professionals. The majority of organisations offered online information, gave presentations on request, offered webinars, provided written (hard copy) information and offered conferences.

### NPON organisations comments about information and education

*Whilst we do conferences and patient days, we find this to be the most challenging activity for our volunteer organisation. Funding from NDIS, or Dept of Health (that does not require lengthy grant application process) for volunteer NFP patient organisations to deliver conferences that provide unmatched support, information and resources to rare disease organisations would be a game changer for us and our community. This has to become a reality.*

*I would love a funded family conference, it would allow families to see each other and work on that connection, and also gives them the opportunity to hear from our current research advisory committee on the research projects we have underway and what is to come in a face-to-face setting.*

*The ATF is proactive in educating patients and HCP's about the importance of good thyroid health, identifying, testing, treatments and monitoring.*

*It would be good if NFP's did not have to self fund to attend and educate HCPs*

*Little to no information about Immune Thrombocytopenia for those working in the emergency departments of hospitals - resulting in unwell patients having to educate HCPs*

<p><b>NPON patient Information services</b></p> <ul style="list-style-type: none"> <li>• 96% offered online information</li> <li>• 80% offered research updates</li> <li>• 77% offered written information (hard copies)</li> <li>• 73% offered webinars</li> <li>• 67% offered patient information days or conferences</li> <li>• 60% offered clinical updates</li> <li>• 21% offered apps</li> </ul>	<p><b>NPON healthcare professional education</b></p> <ul style="list-style-type: none"> <li>• 78% offered information for professionals</li> <li>• 65% gave presentations on request</li> <li>• 59% offered webinars to professionals</li> <li>• 57% offered written information for professionals</li> <li>• 52% offered conferences to professionals</li> </ul>
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**Clinical trials and research**

Data was collected from NPON members in 2024 about participation in clinical trials and research.

Approximately 68% of organisations direct patients to clinical trial, and about half of the organisations participate in clinical trial co-design or connecting patients with researchers. There were 18 organisations (21.69%) that fund clinical trials and 12 organisations (14.63%) manage clinical registries.

The majority of NPON organisations were involved with research co-design and/or connecting patients with researchers (n=52, 62.65%). NPON organisations also funded research (n=33, 39.76%), conduct research (n=25, 30.12%), and develop national research strategy (n=22, 26.51%).

**NPON organisations comments about clinical trials and research**

*Same as previous comments. We have no income and few volunteers. We receive no funding and charge no membership fees. So our resources are extremely limited.*

*Our funds are reliant on donations by our community \$10K doesn't get far in terms of running an org funding research, and so on.*

*We do not have sufficient funds to lead research - but have advocated for research to be undertaken and assisted in design.*

<p><b>Clinical trials</b></p> <ul style="list-style-type: none"> <li>• 68% direct patients to clinical trials</li> <li>• 52% clinical trial co-design and/or connecting patients with researchers</li> <li>• 22% fund clinical trials</li> <li>• 15% manage a clinical registry</li> </ul>	<p><b>Research</b></p> <ul style="list-style-type: none"> <li>• 63% research co-design and/or connecting patients with researchers</li> <li>• 40% fund research</li> <li>• 30% conduct research</li> <li>• 27% develop national research strategy</li> </ul>
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## NPON palliative care and pain management

Data was collected from NPON members in 2024 about palliative care services and pain management services that the organisation is involved with or would like to initiate in the future.

The most common services offered for palliative care , were carer support, information, and advocacy and policy. Other services were support

or education for health professionals, and referral to palliative care.

The most common services or activities for pain management were to provide information, provide care support, and provide advocacy or policy. Other services were referrals to pain management specialists and to provide support or education for health professionals.

### NPON palliative care

- 28% provide carer support for palliative care
- 24% provide information about palliative care
- 23% provides advocacy or policy for palliative care
- 16% provide support or education for health professionals for palliative care
- 13% offer referral to palliative care services

### NPON pain management

- 37% provide information about pain management
- 28% provide carer support for pain management
- 25% provides advocacy or policy for pain management
- 19% offer referral to pain management specialists
- 13% provide support or education for health professionals for pain management

## NPON support services

Data was collected from NPON members in 2024 about programs and outreach to regional and rural populations, Aboriginal and Torres Strait Islander, people from a non-English speaking population, low income and/or homeless people, and LGBTQ+ populations,

Outreach programs were most commonly delivered to regional and rural populations (n=22, 26.51%). There were 7 organisations (8.43%) that offered outreach to non-English speaking background populations, 5 organisations (6.02%) that offered outreach to low income and/or homeless populations, and two organisations that each provided outreach to Aboriginal and Torres Strait Islander populations (2.41%), and LGBTQ+ populations (2.41%).

Specific programs were most commonly delivered to regional and rural populations (n=15, 18.07%). There were 8 organisations (9.64%) that offered specific programs for non-English speaking background populations, 3 organisations (3.61%) that offered specific programs for Aboriginal and

Torres Strait Islander populations, two organisations that each provided specific programs for low income and/or homeless populations (2.41%), and LGBTQ+ populations (2.41%).

NPON organisations reported that all programs have a component that addresses the following: regional and rural populations (n=36, 43.37%), Aboriginal and Torres Strait Islander populations (n=17, 20.48%), non-English speaking background (n=16, 19.28%), LGBTQ+ populations (n=15, 18.07%), and low income and/or homeless populations (n=14, 16.87%).

### NPON organisations comments about support services

*In rural and remote areas of Australia, some services may not be available at all. As most cancer treatment centres and experts are based in metro areas, many people living outside of major cities need to travel, often at significant expense, spending extended time away from their jobs, support systems and families. Regional and Rural*

populations can access our online support groups and services. We promote the health of our regional and rural populations but assisting with transport and travel cost to ensure they can access services.

We are in the process of developing a program plan which includes hiring a Health Promotion Officer.

We provide each patient with access to their own Specialist Cancer Navigator for personalised clinical, emotional, financial and practical support throughout their diagnosis, treatment and beyond.

The ATSI population are greatly impacted by T2 diabetes and inturn amputation resulting from this disease. We have been looking into ways that we can assist with greater education and access to information to support those members of our community.

We utilise interpreter services when necessary to ensure that we are able to deliver adequate support and intervention to those who come from a non english speaking background. We are in the process of translating our reading materials and support guides so they are more accessible to those who don't speak English as their first language.

Our services are truly personalised. We have provided letters to government agencies for housing, healthcare cards, etc. If a person has an issue related to their NF then we are willing to support them in whatever is needed. It can be hard for people to explain the impacts of NF so we always aim to provide assistant to low income populations where required.

<p><b>Regional and rural populations</b></p> <ul style="list-style-type: none"> <li>• 27% offer outreach programs</li> <li>• 18% delivers specific programs</li> <li>• 43% all programs have a component that addresses this population</li> </ul>	<p><b>Low-income and/or homeless populations</b></p> <ul style="list-style-type: none"> <li>• 6% offer outreach programs</li> <li>• 2% delivers specific programs</li> <li>• 17% all programs have a component that addresses this population</li> </ul>
<p><b>Aboriginal and Torres Strait Islander populations</b></p> <ul style="list-style-type: none"> <li>• 2% offer outreach programs</li> <li>• 4% delivers specific programs</li> <li>• 20% all programs have a component that addresses this population</li> </ul>	<p><b>LGBTQ+ populations</b></p> <ul style="list-style-type: none"> <li>• 2% offer outreach programs</li> <li>• 2% delivers specific programs</li> <li>• 18% all programs have a component that addresses this population</li> </ul>
<p><b>Non-English speaking background populations</b></p> <ul style="list-style-type: none"> <li>• 8% offer outreach programs</li> <li>• 10% delivers specific programs</li> <li>• 19% all programs have a component that addresses this population</li> </ul>	

**Importance and accessibility of aspects of care and treatment**

Data was collected from NPON members in 2024 about The importance of aspects of care and treatment and how accessible they were.

The top five aspects of treatment and care that were described as extremely important or very important were: access to appropriate treatments/devices in a timely manner (n=72,

94.74%), affordable treatments (n=70, 92.11%), access to specialists (n=72, 94.74%), up to date information and research findings (n=67, 88.16%), and access to allied health professionals (n=66, 86.84%).

For these aspects of care of treatments, NPON organisations described these as extremely

accessible or very accessible: access to appropriate treatments/devices in a timely manner (n=7, 9.21%), access to affordable treatments (n=7, 9.21%), access to specialists (n=10, 13.16%), access

to allied health professionals (n=12, 15.79%), and access to up to date information and research findings (n=21, 27.63%).

<b>Aspects of care and treatment</b>	<b>Extremely or very Important</b>	<b>Extremely or very accessible</b>
Access to appropriate treatments/devices in a timely manner	95%	9%
Access to specialists	95%	13%
Access to affordable treatments	92%	9%
Access to up to date information and research findings	88%	28%
Access to allied health professionals	87%	16%
Access to earlier diagnostic tests	86%	12%
Access to clinical trials	76%	14%
Support for carers	74%	17%
Reducing stigma related to their condition/illness	72%	14%
Support in navigating the health system/ coordination of care	64%	12%
Access to genetic testing	62%	13%
Access to home care	62%	12%
Support in navigating the NDIS	59%	8%
Access to equipment	58%	11%
Access to pain management	50%	16%
Access to palliative care	33%	11%

## **NPON Australia Members**

22q Foundation Australia & NZ  
Addisons Australia  
Allergy & Anaphylaxis Australia  
Angelman Syndrome Association Australia  
Ankylosing Spondylitis Victoria Inc  
Arthritis Australia  
Arthritis NSW  
Arthritis Queensland  
ausEE Inc.  
Australia Alopecia Areata Foundation  
Australian Dysphonia Network  
Australian Sickle Cell Advocacy Inc  
Australian Thyroid Foundation  
Australiasian Mastocytosis Society  
Batten Disease Australia  
BEAT Bladder Cancer  
Better Access Australia  
Brain Foundation  
Brain Tumour Alliance Australia  
Brainwave  
Cancer Council Australia  
Cancer Voices NSW  
Cataract Kids Australia  
Centre for Community-Driven Research  
Charcot-Marie-Tooth Association Australia  
CHARGE Syndrome Australasia  
Childhood Dementia Initiative  
Cystic Fibrosis Australia  
Cystic Fibrosis Community Care  
Cystic Fibrosis Queensland  
Dystonia Network of Australia Inc.  
Eczema Association Australasia  
Eczema Support Australia  
Ehlers-Danlos Syndrome Australia  
FARA  
FOP Australia  
Foundation for Angelman Syndrome Therapeutics  
Australia  
Fragile X Association of Australia  
Genetic Alliance Australia  
Genetic Support Network of Victoria  
Global Healthy Living Foundation Australia  
HAE Australasia  
Haemochromatosis Australia  
HCU Network Australia  
Head and Neck Cancer Australia  
HeartKids  
Her Heart  
Hidradentitis Suppurativa  
HSP Research Foundation Inc  
Hyperemesis Gravidarum Australia  
Hypersomnolence Australia  
Immune Deficiencies Foundation Australia (IDFA)  
ITP Australia Ltd  
Kidney Health Australia  
Leukaemia Foundation  
Limbs4Life  
Lipoedema Australia  
Liver Kids Australia  
LiverWELL  
Lyme Disease Association of Australia  
Lymphoma Australia  
Migraine Australia  
Miracle Babies  
Mito Foundation  
MND Australia  
Multiple Sclerosis Australia  
Muscular Dystrophy Australia  
Muscular Dystrophy New South Wales  
Musculoskeletal Australia  
Myeloproliferative Neoplasms Alliance Australia  
Neuroendocrine Australia  
Neuromuscular WA  
Pain Australia  
Pancare  
Parenteral Nutrition Down Under Inc. (PNDU)  
Pink Hope  
PKD Australia  
Prader-Willi Research Foundation Australia  
Primary Ciliary Dyskinesia Australia  
Racing for MNDi Foundation  
Rare Cancers Australia  
Rett Syndrome Association of Australia  
Sanfilippo Children's Foundation  
SATB2 Australia  
Save Our Sons Duchenne Foundation  
Scleroderma Victoria  
SCNA2  
Sleep Disorders Australia  
So Brave Ltd.  
Sotos Syndrome Association of Australasia  
Spark of Gold  
Stroke Foundation  
Syndromes Without A Name (SWAN) Australia  
Thalassaemia and Sickle Cell Australia  
The Children's Tumour Foundation  
The Obesity Collective  
Tourette Syndrome Association of Australia inc  
Tuberous Sclerosis Australia  
UsherKids Australia Ltd  
Without A Ribbon