



Strategic Plan

2023 – 2025





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Mission:

The PURA Foundation Australia has been established to assist research, provide education, and raise awareness of PURA syndrome, supporting individuals diagnosed with PURA syndrome and their families, across Australia and New Zealand.

Context:

PURA syndrome was first described in 2014 as a rare neuro-developmental disorder. The condition is caused by mutations in the PURA gene. This gene encodes the transcription factor and RNA-transport protein PURA (formerly known as Pur-alpha). To date the consequences of its malfunctioning in PURA patients are not well understood. Research and increased education are urgently required.

The PURA Foundation Australia supports the PURA syndrome community both locally and globally. This community provides a place of belonging to those who may otherwise feel isolated by rare disease, enriches the medical research being completed and educates those outside the community about the condition.

Goals:

1. To facilitate education and awareness of PURA syndrome.
2. To assist in the advancement of research and treatments for PURA syndrome.
3. To provide support for families of, and individuals with, PURA syndrome.



Our Values:

Respect

We welcome and value every person's unique contribution with equitable treatment, access, and opportunity for all.

Community

We work together with families, clinicians, and researchers to define and achieve shared goals.

Optimism

We collaborate with one another to seek and find solutions, confident in our team's ability to achieve our shared goals.

Responsibility

We understand the importance of obligation and goal setting within the organization, planning for future growth and change.

Trust

We understand the importance of transparency and accountability in relationships, within the organization, and with those we serve and partner.

Foundation Affiliates

- Translational Centre for Speech Disorders, Melbourne Australia.
- Royal Children's Hospital, Melbourne Australia
- Murdoch Children's Research Institute, Melbourne Australia



Goal 1: Education and awareness

Objective - To facilitate education and awareness of PURA syndrome.

Strategic Intent: To increase awareness and provide current information about PURA syndrome across different facets of the community.

Summary	Key Objectives	Actions
	1.1 Build public awareness of PURA syndrome across Australia and New Zealand.	<ul style="list-style-type: none"> • Send targeted online PURA syndrome campaigns to paediatric and research hospitals, rare disease affiliates and organisations. • Create a social media and website presence through a co-ordinated plan to educate the public. • Make connections with media personnel of affiliate organisations who can assist to publicise the organisation.
	1.2 Encourage a better understanding by health professionals and health educators of PURA families, their support and information needs.	<ul style="list-style-type: none"> • Ensure PURA syndrome is known to national support services including NDIA (Australia), Whaikaha (NZ) and national allied health organisations. • Fund the research support position within the MCRI to assist the Foundation with research support, ethics and awareness for PURA syndrome in the medical and research community (see <i>Letter of Support MCRI</i>). • Provide information sessions and/or materials on PURA syndrome for organisations supporting rare disease.
	1.3 Actively engage with other patient organisations whose work aligns with the PURA Foundation Australia.	<ul style="list-style-type: none"> • Join appropriate organisations within Australia and New Zealand who advocate for rare disease. • Develop relationships with other newly formed PURA syndrome organisations globally. • Co-ordinate information and assistance for SWAN (Syndromes Without Name) and GSNV (Genetic Support Network Victoria) to support new diagnoses for PURA syndrome.
	1.4 Establish the “PURA Connect” program.	<ul style="list-style-type: none"> • Develop a program to provide regular digital communications to the public and PURA community, including social media, website, zoom meets and digital publications. • Initiate social media accounts across appropriate platforms. • Distribute digital newsletters to share the research updates and wider activities of the PURA Foundation Australia.

Goal 2: Research and treatment

Objective - To assist in the advancement of research and treatments for PURA syndrome.

Strategic Intent: To foster research, education and collaboration between scientists, clinicians, and the PURA Foundation Australia.

Summary	Key Objectives	Actions
	2.1 Provide access to research opportunities for individuals with PURA syndrome and their families.	<ul style="list-style-type: none"> • Fund a research support position to assist the Foundation with agreed research initiatives, ethics applications and creating awareness for PURA syndrome in the medical and research community. Position to be located at the MCRI Melbourne (see <i>Letter of Support MCRI</i>) • Fund storage for PURA patient bio-samples for research inclusion. To be located at the MCRI Melbourne (see <i>Letter of Support MCRI</i>) • Collaborate with professionals developing the global PURA Syndrome Natural History Study (UK) and global PURA Biobank (Germany), to assist with development of patient and clinician questionnaires. • Provide awareness of research opportunities both nationally and globally that families may wish to become involved in via the Foundation website.
	2.2 Develop an expert clinical team for PURA syndrome within Australia and New Zealand.	<ul style="list-style-type: none"> • Locate clinicians within Australia and NZ who can provide expert advice regarding health management of an individual with PURA syndrome. • Create a dedicated Australia and NZ Clinical Care Network for PURA syndrome, to be publicised on the Foundation website. • Connect geneticists, neurologists, and other health experts who have newly diagnosed PURA patients with PURA Clinical Care Network members.
	2.3 Develop new partnerships with researchers, clinicians, and testing facilities.	<ul style="list-style-type: none"> • Connect and develop alliances with known and potential PURA syndrome researchers, both nationally and globally. • Support PURA Foundation Australia attendance at rare disease and PURA syndrome specific conferences and gatherings, both online and in-person. • Ensure PURA syndrome is included on applicable diagnostic testing panels undertaken by testing labs and facilities across Australia and NZ.

Summary	Key Objectives	Actions
	2.4 Facilitate discussion regarding treatments that could be available for PURA syndrome.	<ul style="list-style-type: none"> • Liaise with expert team members regarding possible treatments that become available for patients via the PBS (Australia) and Pharmac (NZ). • Collaborate with PURA Syndrome Global Research Network regarding treatment options being researched and possible clinical trials for PURA syndrome patients. • Provide access to information on the emergence of new therapeutic interventions for PURA syndrome families and their clinicians.
	2.5 Advance the development of both clinical and scientific publications for PURA syndrome.	<ul style="list-style-type: none"> • Assist with development of new PURA syndrome Phenotype-Genotype studies within Australia and NZ (See <i>Letter of Support University of Melbourne</i>) • Support with co-ordination of family and/or patient inclusion within PURA clinical and scientific studies. • Provide open-access funding for publication of clinical manuscripts for PURA syndrome in approved reputable journals.



Goal 3: Support and community

Objective - To provide support for families of, and individuals with, PURA syndrome.

Strategic Intent: To develop a structured, engaged, and sustainable community and support organisation, for PURA syndrome within Australia and New Zealand.

Summary	Key Objectives	Actions
	3.1 Empower our community through the development of online tools and resources.	<ul style="list-style-type: none"> • Create a social media presence through a co-ordinated plan to activate the PURA community. • Ensure timely and accurate dissemination of information of interest to the PURA community. • Provide current information, and links to clinical and research material about the condition on the PURA Foundation Australia website.
	3.2 Support social inclusion for all PURA families by building an active PURA community in Australia and New Zealand.	<ul style="list-style-type: none"> • Establish a secure online social support group for the parents of Australia and NZ PURA patients to limit isolation amongst members. • Create in-person opportunities to allow families to connect with and support one another. • Provide accessible direct points of contact for families of PURA patients via specific parent liaison roles for Australia and New Zealand.
	3.3 Provide opportunity for education and dissemination of data from experts in the PURA research and clinical community.	<ul style="list-style-type: none"> • Hold online meetings to keep families connected and informed about the latest PURA Foundation Australia and research initiatives. • Provide access to information from PURA Clinical Care Network specialists regarding health management for PURA syndrome. • Enable access to global research overviews and conference video presentations via the PURA Foundation Australia social media and website.
	3.4 Identify common patient and family needs to provide direction for Foundation priorities.	<ul style="list-style-type: none"> • Provide online questionnaires for members regarding directions for the organisation. • Structure an accessible direct point of feedback for families via the parent liaison roles. • Make provision for community feedback through future event development and evaluation.
	3.5 Ensure longevity of the PURA Foundation Australia.	<ul style="list-style-type: none"> • Ensure the sustainability of the organisation by developing effective marketing and fundraising strategies to attract income and resources. • Utilise the contribution of volunteers and engage with the health sectors that assist PURA families to create a supportive and active community. • Develop diverse funding avenues to make operating feasible and sustainable long term.