



The Faces of HTA Reform

Real stories. Real people. Real reasons for change.

Why Health Technology Assessment
(HTA) reform matters

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The Faces of HTA Reform

Real stories. Real people. Real reasons for change.

Why Health Technology Assessment (HTA) reform matters

Introduction

Every day, people across Australia face difficult decisions, loss and financial hardship while waiting for access to treatments that could make a meaningful difference to their lives.

Reforming health technology assessment (HTA) is about more than improving a process. It is about how Australia chooses to invest in the health of its people and our shared future.

This is not just another publication.

The Faces of HTA Reform brings together real stories from patient communities across Australia. Each is deeply personal. Together, they show why reform matters and why it is not just a 'health issue' but an issue that deserves support across government and our community.

As a patient myself, I know how precious these stories are. I thank every person who has shared their experience, and every organisation that has helped their community's voice be heard. This collection of stories highlights not only the urgent need to act, it highlights the collaboration and readiness of Australian patient organisations to partner others for reform.

Sarah McGoram
President, Patient Voice Initiative

Please note: This initiative was independently developed by Patient Voice Initiative and has received no industry funding. It was created to support patient organisations and is driven by the experiences, priorities and voices of patients and patient communities.



Meet
Larissa

 **Patient Organisation: MBC Action Australia**

 **Condition: HER2-positive Metastatic Breast Cancer**

Larissa is a Brisbane mother of two, health and safety professional and patient advocate living with HER2-positive metastatic breast cancer. First diagnosed with breast cancer at 38 while breastfeeding her nine-month-old son, she underwent chemotherapy, surgery and radiation and was later told she was cancer-free. Just over a year later, the cancer returned in her brain.

Living with metastatic breast cancer means Larissa's ongoing treatment has cumulative side effects that affect her quality of life and create significant out-of-pocket costs for her family. Future treatment access remains uncertain and unaffordable for Larissa without PBS subsidy which presents yet another barrier and difficult decision for her to make about her future.

1



THEIR STORY

Who is the patient?

Before cancer, Larissa was focused on raising her young family, building her health and safety career, travelling, listening to live music and playing guitar. She is the proud mother of two boys and is passionate about helping others through her professional work and volunteer advocacy.

What matters most to Larissa is time with her family: being present for milestones, everyday moments and the life experiences still ahead. By sharing her story, she hopes to create lasting change for future generations of Australians affected by breast cancer, especially young women and women diagnosed during pregnancy or soon after birth.

2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

Living with metastatic breast cancer means ongoing treatment, cumulative side effects and additional health conditions that affect Larissa's quality of life and create significant out-of-pocket costs for her family. In the future, Larissa may need tucatinib (Tukysa), a treatment for HER2-positive metastatic breast cancer, but access remains uncertain and unaffordable without PBS subsidy. For Larissa, delayed or unaffordable access will present and impact her future treatment decisions, survival and quality of life and time with her children.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

HTA reform matters because Australians should be able to access effective treatments based on clinical need, not their postcode, timing or capacity to pay. For people living with cancer and metastatic cancer, timely access can mean better quality of life, more treatment options and precious time with loved ones. Reform should recognise patient experience, real-world consequences and the value of medicines that help people live longer and live well.

“Living with metastatic breast cancer means living with uncertainty, but it should not mean living without hope. Every treatment that keeps my cancer stable gives me more time with my children, more opportunities to contribute to my community and more moments that matter. HTA reform is about ensuring people like me can access treatments when we need them, so we can live longer and live well.”



ABOUT OUR ORGANISATION

MBC Action Australia is a consumer-led organisation dedicated to improving the lives of people living with metastatic breast cancer through advocacy, collaboration, information and support.

OUR COMMUNITY

-  In 2025, it was estimated that 20,950 Australians are living with metastatic breast cancer in Australia.
-  Led by people with lived experience, MBC Action Australia works to ensure the metastatic breast cancer community is seen, heard and supported.

CONNECT WITH US

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Meet
**Jill
Berensen**



Patient Organisation: MyFlareUp



Condition: Rheumatoid Arthritis

I have lived with Rheumatoid Arthritis for 25 years. And as Auto-Immune Diseases never work alone, I have endured Monoclonal B-Cell Lymphocytosis for 10 years, which has escalated in the last couple of years with constant Anaemia and very low Platelets, causing relentless fatigue and severe bruising.

Now at 72 years of age, I am a recent widow living in Sydney while my son, a Baroque Musician is living in Germany and my daughter, living with Type 1 Diabetes (since 11 years of age) in Western Australia with her husband.

1



THEIR STORY

Who is the patient?

One of the greatest pleasures in my life has been to work as a Registered Nurse for 43 years in the Public Health System and I specialized in Neurosurgery and Acute Spinal Injuries at the Royal North Shore Hospital. This great privilege was to listen to and care for my patients every day, ensuring they received all that was required to improve their health and save their lives. What saddens me now is to discover there are thousands of patients who know their voices go unheard and their lives are ignored due to failed Healthcare Technology and inaccessibility.

2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

Despite being able to continue working until I was 60 years old, I was unable to receive a pension until I was 67. The enormous cost of medications, regular specialist and GP consultations and constant blood testing, created extreme financial hardship. This became so much worse with my husband developing severe medical conditions as well. Enduring severe physical pain and unable to earn a wage also had harsh psychological consequences.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

Reforming Australia's process for deciding what is funded and subsidised in healthcare (Health Technology Assessment) is in every Australian's interests.

HTA reform is about creating a healthy, productive and vibrant Australia. Across our country, out of sight and out of mind, Australians are facing unbearable decisions, loss and financial hardship when innovative treatments subsidised by programs like our Pharmaceutical Benefits Scheme could make a difference. Help us reform HTA and the policies that guide investing in healthcare for all Australians by telling decision-makers that you back HTA reform and investing in health.



“The greatest reform to HTA would be to hear the patient voices. How could HTA possibly improve without the voice of lived-experience.”

ABOUT OUR ORGANISATION

My Flare Up (Dragon Claw Charity) welcomes Australians living with autoimmune inflammatory diseases who rely on ongoing specialist medical care. Unfortunately, many patients delay or forgo specialist appointments because they cannot afford the out-of-pocket gap fees. Our community is also experiencing a severe shortage of rheumatologists and other specialists with expertise in autoimmune diseases.

OUR COMMUNITY

More than five million Australians live with autoimmune conditions, many of which require lifelong management by medical specialists. Access to timely and affordable specialist care is essential to preventing disease progression, disability and avoidable hospital admissions.

Waiting times for appointments are often many months, delaying diagnosis and treatment during critical periods when early intervention can prevent irreversible damage.

CONNECT WITH US

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MyFlareUp



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Why Health Technology Assessment (HTA) reform matters



Meet
Kelly

 **Patient Organisation: Crohn's & Colitis Australia**

 **Condition: Crohn's disease**

Kelly is a 45 year old health services manager, living in NSW.

She was diagnosed with Crohn's disease when she was 32, at a time when adult life should be flourishing. Since then she has progressed through many treatments without significant remission, resulting in 6 Crohn's related surgeries. Since 2023 the disease has progressed to the more serious fistulising form.

Treatments have been time consuming and resulted in severe side effects with both physical and psychological impacts. Illness has interrupted capacity to work and study, consumed all personal and holiday leave and limited her ability to support family and friends.

Now, currently with active disease, she has been escalated through available PBS treatments, and is managed on compassionate access to combination therapy. Still not in remission.

1



THEIR STORY

Who is the patient?

Kelly is a much-loved wife and favourite Aunt to her niece. She enjoys the arts, creating through mixed media: photography, fibre arts, and textiles. She likes to make people smile whenever she can.

She is studying post graduate research hoping to develop her professional skills to pursue her goal of improving equity and access to services and care.

She longs for stability in her health, not having to avoid others with communicable illnesses due to immunosuppression. Without equitable access to medicines she feels she'll lose the ability to make a meaningful contribution to her loved ones and the broader community. To be someone that can be counted on to help.

2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

With active disease, recurrent surgery and the possibility of a stoma in the future, the last option PBS therapies are failing Kelly.

There is a promising class of medicines available in other countries. Even though several drugs in this class are TGA approved and recommended by PBAC, the funding criteria and pricing decisions mean they are not listed and available in Australia. This is the most likely treatment to bring her into remission and avoid another surgery and disrupted work and study. Compounding this is the frustration that a potentially effective, safe treatment is available in other OECD countries.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

Reforming Australia's process for deciding what is funded and subsidised in healthcare (Health Technology Assessment) is in every Australian's interests. HTA reform can be the difference for Kelly and others with inflammatory bowel disease to be in remission, able to wholly contribute to a healthy, productive and vibrant Australia. Across our country, out of sight and out of mind, Australians are facing unbearable decisions, loss and financial hardship when innovative treatments subsidised by programs like our Pharmaceutical Benefits Scheme could make a difference. Help us reform HTA and the policies that guide investing in healthcare for all Australians by telling decision-makers that you back HTA reform and investing in health.



“ I just want to live my life. Most nights I worry about when the other shoe is going to drop and the medications fail. Sitting in a hospital bed with severe pain but this time without options to stop it getting worse. I know how destructive this disease can be and I am afraid. ”



ABOUT OUR ORGANISATION

Empower those with IBD to live fearlessly as we drive towards a cure and ultimately a future without Crohn's and Colitis.

OUR COMMUNITY

 For more than four decades, Crohn's & Colitis Australia has been empowering the almost 180,000 Australian men, women and children living with Crohn's disease or ulcerative colitis – collectively known as inflammatory bowel disease (IBD) – to live fearlessly.

CONNECT WITH US

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Meet
Nic

 **Patient Organisation:** The Immune Deficiencies Foundation Australia

 **Condition:** Common Variable Immunodeficiency (CVID)

Nic has experienced frequent illness throughout her life, but it wasn't until 2012, at the age of 34, that she received a diagnosis of Common Variable Immunodeficiency (CVID).

Before her diagnosis, years of unexplained illness made it difficult to understand what was happening with her health or access the right care. Even after diagnosis, Nic has faced challenges navigating the healthcare system, including being turned away by doctors who considered her 'too complex a case'. Her experience highlights the challenges people with immunodeficiencies can face in receiving timely diagnosis, appropriate care and ongoing support.

“Healthcare reform matters because people shouldn't have to fight for the treatment they need or be limited by where they live. I want the system to recognise the real impact of immunodeficiency and ensure people like me can access appropriate treatment when we need it.”



1



THEIR STORY

Who is the patient?

Located 600km south of mainland Australia, the picturesque island of Tasmania is home to Nic and her family. In Launceston, Nic works two days a week supporting students with their education, while much of her spare time is spent with her beloved dog, Bronson Branan Shearing Madden the 1st.



For Nic, spending time in nature plays an important role in keeping her grounded and supporting her physical and mental well being. Living with an immunodeficiency has also taught her to listen closely to her body – recognising when she needs to rest and understanding the difference between fatigue, an infection and simply needing to slow down.

2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

Nic's path to diagnosis and treatment has been challenging. After initially being diagnosed with hypogammaglobulinaemia, she travelled to Hobart and tirelessly advocated for herself before receiving a formal CVID diagnosis. Living in Tasmania also creates additional barriers, with fewer specialist services and treatment options available locally.

Accessing treatment has not been straightforward. Nic has been unable to access IVIg infusions because she does not meet the current eligibility criteria, despite the significant impact her immunodeficiency has had on her health. Her experience highlights the challenges people in regional and remote areas can face when accessing specialist care and appropriate treatment.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

Reforming Australia's process for deciding what is funded and subsidised in healthcare (Health Technology Assessment) is in every Australian's interests. HTA reform is about creating a healthy, productive and vibrant Australia.

Across our country, out of sight and out of mind, Australians are facing unbearable decisions, loss and financial hardship when innovative treatments subsidised by programs like our Pharmaceutical Benefits Scheme could make a difference.

Help us reform HTA and the policies that guide investing in healthcare for all Australians by telling decision-makers that you back HTA reform and investing in health.



ABOUT OUR ORGANISATION

IDFA Mission - Creating awareness of all immunodeficiencies, supporting and advocating for improved outcomes for patients, carers and families.

Our Vision - A future where all immunodeficiencies are diagnosed and treatment commenced early, enabling those impacted to lead productive and fulfilling lives.

OUR COMMUNITY

 IDFA is a national not-for-profit and leading peak body offering education, advocacy and awareness for Australians living with immunodeficiencies.

 With more than 2,400 members, IDFA provides free membership, webinars, resources, community events and opportunities for connection.

CONNECT WITH US

 idfa.org.au

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 [/ImmuneDeficiencyFoundationAustralia](https://www.facebook.com/ImmuneDeficiencyFoundationAustralia)

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Meet Yvonne*

*Pseudonym has been used.



Patient Organisation: Ovarian Cancer Australia



Condition: Mucinous Ovarian Cancer

Yvonne* is a 56yo mum and wife living with Mucinous Ovarian Cancer. After a complex and overwhelming investigative period, Yvonne* was diagnosed with advanced Mucinous Ovarian Cancer in 2024.

Yvonne* had extensive surgery, followed by chemotherapy, which has left her with significant ongoing side effects. Unfortunately, Yvonne* experienced disease progression whilst on chemotherapy and was encouraged to explore clinical trials, as her only available option.

Yvonne* has since participated in 3 clinical trials to treat the disease, each coming with their own challenges and impacts to her physically, socially and emotionally.

1



THEIR STORY

Who is the patient?

Yvonne* is a 56yo devoted mum and wife. Prior to her cancer diagnosis, she had a thriving candle business and a strong passion for art. She had welcomed a dog into their family, to train to become a therapy dog. All this alongside caring for her elderly father.



Her main loves in life are her family and when asked about her hopes for the future, Yvonne* just wants to spend as much quality time with her daughter as possible. They love spending time together, soaking up each others company.

2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

Yvonne's* only option following the progression of her disease was to explore clinical trials, with no other recommended effective treatment currently available on the PBS. A frequent experience in the ovarian cancer community.

Although Yvonne* is incredibly grateful to be able to access a clinical trial, trial participation is not without cost. Patients and their families often bear substantial financial and logistical burdens, including travel expenses, lost income, accommodation costs, time away from work, and increased caregiving responsibilities. Yvonne* and her family have experienced this all first-hand.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

While clinical trials are essential for bringing new treatments to patients, positive clinical trial outcomes do not necessarily translate into timely access to medicines. Treatments must still navigate a complex HTA (health technology assessment) process. For ovarian cancer patients, particularly those with few remaining treatment options, these processes can create a gap between scientific innovation and real-world access.

Reforming Australia's process for deciding what is funded and subsidised in healthcare is in every Australian's interests. HTA reform is about creating a healthy, productive and vibrant Australia. Across our country, out of sight and out of mind, Australians are facing unbearable decisions, loss and financial hardship when innovative treatments subsidised by programs like our Pharmaceutical Benefits Scheme could make a difference.

“When you have a rare cancer, every moment counts. It is heartbreaking to know that treatments exist but remain out of reach because the system has not kept pace. HTA reform is so important because it gives me hope that people like me will have faster access to new treatment options when we need them most.”



**OVARIAN
CANCER
AUSTRALIA**

ABOUT OUR ORGANISATION

We stand for, and walk with, women and all impacted by ovarian and gynaecological cancers. No one walks alone.

OUR COMMUNITY



Ovarian Cancer Australia is the national leader in ovarian cancer support and advocacy, standing alongside the 1900 women diagnosed each year and their families, soon expanding to support all women with gynaecological cancers, ensuring no one walks alone.

CONNECT WITH US



ovariancancer.net.au



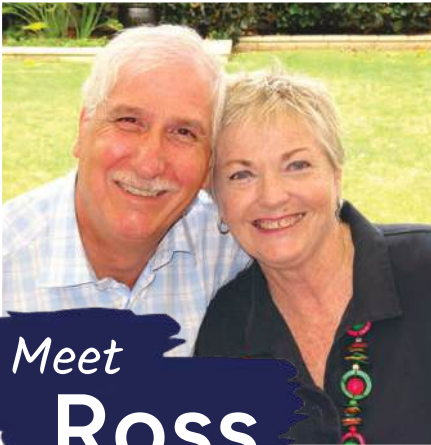
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Meet
Ross



Patient Organisation: Myeloma Australia
Musolino Family Myeloma Foundation



Condition: Multiple Myeloma

Ross was diagnosed with multiple myeloma in June 2017. He underwent a stem cell transplant in December 2017, followed by maintenance therapy with lenalidomide. The cancer progressed after 15 months, and pomalidomide, commenced in September 2019, proved ineffective. Daratumumab was not available on the PBS at this stage. Ross then began carfilzomib and dexamethasone in April 2020, continuing on this regimen until relapsing in February 2025.

By this point, PBS-funded options were limited, with daratumumab now only available as a second-line treatment. No clinical trials were available in South Australia, as prior daratumumab treatment was a prerequisite for all appropriate trials. Ross eventually found a suitable trial at St Vincent's Hospital in Melbourne, commencing in April 2025, which is ongoing

1



THEIR STORY

Who is the patient?

Ross is a husband and father of two girls, retired chartered accountant who enjoyed travelling and active sports, including golf, water and snow skiing.

Diagnosis coincided with retirement at age 64 which has had a severe impact on being able to continue with these activities.

Throughout the cancer journey, his families support and being able to spend time together has made it so much easier to deal with the highs and lows of treatment.

Rather than sit back, Ross has become actively involved within the myeloma community.

In 2025 driven by a desire to make a meaningful difference for others affected by the disease, Ross and Anne laid the foundation for and established the Musolino Family Myeloma Foundation—setting a vision for a charity committed to supporting patients, driving research, and raising awareness about multiple myeloma.

2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

Ross has experienced two occasions when recommended therapies were unavailable. After his stem cell transplant, lenalidomide maintenance was standard overseas but not PBS-subsidised in Australia, requiring compassionate access and self-funding for three months.

Following relapse in 2025, he was ineligible for PBS-funded daratumumab due to treatment-line restrictions, also limiting access to clinical trials and newer therapies.

With no suitable local options, Ross now travels monthly from Adelaide to Melbourne for a clinical trial, creating financial and emotional burdens. His experience highlights how PBS restrictions can delay access to effective treatments and disadvantage Australian patients compared with those overseas.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

Reforming Australia's process for deciding what is funded and subsidised in healthcare (Health Technology Assessment) is in every Australian's interests. HTA reform is about creating a healthy, productive and vibrant Australia. Across our country, out of sight and out of mind, Australians are facing unbearable decisions, loss and financial hardship when innovative treatments subsidised by programs like our Pharmaceutical Benefits Scheme could make a difference. Help us reform HTA and the policies that guide investing in healthcare for all Australians by telling decision-makers that you back HTA reform and investing in health.



ABOUT OUR ORGANISATION

Myeloma Australia actively and expertly supports Australians living with myeloma while driving progress towards cure.

OUR COMMUNITY



We support, inform, empower and bring hope to the 22,000



Australians living with myeloma and their support networks through our nurse-led services. We also raise community awareness; educate health professionals; and advocate for improved access to treatment.

CONNECT WITH US



myeloma.org.au



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Meet
**Melinda
Barrett**

 **Patient Organisation:** Lupus Voice Australia

 **Condition:** Systemic Lupus Erythematosus

Melinda is a 51-year-old mother, partner and patient advocate living in coastal Victoria. Diagnosed with systemic lupus erythematosus in her early twenties, she has lived with the disease for almost three decades. Lupus has affected her reproductive system, skin, brain, heart, lungs and pancreas. She has survived strokes, pulmonary embolism, cardiac arrest, cardiogenic shock, pancreatitis, sepsis, respiratory failure and weeks in a coma. Her health eventually forced her to leave a career she valued. Today, as Vice Chair of Lupus Voice Australia, Melinda uses her experience to advocate for earlier diagnosis, better treatment choices and a health system that understands the human cost when treatment progress and access come too late.

1



THEIR STORY

Who is the patient?

Melinda is a mother, partner, daughter and advocate who has lived in two countries, travelled widely and built a career supporting senior leaders and organisations. What matters most to her is her daughter Emilie, the people she loves and making life better for others with lupus. After illness ended the career she had worked hard to build, Melinda unexpectedly rediscovered purpose through advocacy. She now helps lead Lupus Voice Australia, creating education, support and opportunities for people with lupus to be heard. Her hope is that future patients will have more choices - and lose less of their lives waiting for progress.



2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

When Melinda was diagnosed, there were no medicines developed specifically for lupus. For decades, treatment relied on medicines created for other conditions after their effects were found to suppress the disease. These medicines helped keep her alive, but treatment involved trial and error, significant side effects, out-of-pocket costs and limited choices. By the time disease-specific options emerged, Melinda had already experienced irreversible organ damage and lost much of her health, independence and the career she loved. Her experience shows why HTA must recognise unmet need, lived experience and the lifelong cost when better treatment and access come too late.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

HTA reform matters because treatment value cannot be measured only in medicine costs or short-term clinical results. It must also account for what happens when people wait: irreversible organ damage, hospital admissions, lost employment, reduced independence and the burden carried by families. For people with complex diseases such as lupus, timely access to effective treatment may preserve health, careers, relationships and participation in community life. Australia needs a faster, fairer and more patient-centred system that recognises unmet need and properly values lived experience. Better access cannot return what Melinda and others have already lost, but it can change what future patients are able to keep.

“When I was diagnosed, every medicine used to treat my lupus had been borrowed from somewhere else. Those medicines helped keep me alive, but there was nothing designed specifically for us. Reform means making sure better treatments reach patients before they lose their health, independence and the lives they were building.”



ABOUT OUR ORGANISATION

Lupus Voice Australia is a patient-informed advocacy organisation working to improve the lives of Australians affected by lupus through awareness, education, support and representation. We ensure lived experience helps shape the policies, research, treatment decisions and services that affect our community.

ABOUT OUR COMMUNITY

 Around 26,000 Australians live with lupus, a complex autoimmune disease that disproportionately affects women and can damage almost any organ.

 Lupus Voice Australia connects patients and families, strengthens the patient voice and advocates for earlier diagnosis, equitable treatment access and better care.

CONNECT WITH US

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Patient Organisation: FOP Australia



Condition: Fibrodysplasia Ossificans Progressiva

Jarvis lives with Fibrodysplasia Ossificans Progressiva - an ultra rare disease affecting only 1 in a million people. FOP causes progressive, painful and permanent restriction of all movement as extra bone grows throughout the body. FOP bone invades muscles and other soft tissues, and this has stopped Jarvis being able to move his head and arms, and also affects how he walks. Jarvis has suffered painful flares of new bone growth since the age of 4. There are drugs undergoing clinical trials that give Jarvis and his family hope for a treatment that can stop FOP bone growth. But getting access for a new drug for a very rare disease is very challenging, as so few people have heard of it.



“It is time to review the HTA process and make sure that Australians with rare diseases get a fair go.”

1



THEIR STORY

Who is the patient?

Jarvis is a 15 years old, and attends school full time in Queensland. He continues to aim to be independent as a teenager, though this is increasingly hard for Jarvis and his family. Jarvis' mum Lara explains:

“He would just love to be out playing footy with his mates. But if he hit his knee, it can trigger a FOP flare and stop his leg moving. There is a constant threat that any small amount of bone could take more away from him”.

Jarvis and his family hope for a future where he does not have to fear that FOP will take his independence away.

2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

Jarvis is not able to take the only potential FOP treatment that is available in Australia. There are two treatments undergoing clinical trials overseas that may help stop FOP bone growth. Unfortunately neither of these drugs are available in Australia, and we have to expect that it will take many years before those drugs are available here. During those years, FOP continues to progressively take more and more of Jarvis' function and independence. We need regulatory bodies to understand the urgency involved in enabling medication access.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

HTA reform is important for all Australians, but especially those living with rare and ultra rare diseases. There are extra barriers to medication access when no one involved in the regulatory processes (even treating doctors!) have heard of the condition before. We are very fortunate to have the Pharmaceutical Benefits Scheme but it is important that the processes that inform that consider the needs of the most vulnerable Australians. The extra years that it takes to access drugs in Australia could mean watching my son lose his remaining independence, whilst drugs that would stop that are accessed overseas.

ABOUT OUR ORGANISATION

FOP Australia is a small registered charity that supports people in Australia and New Zealand living with Fibrodysplasia Ossificans Progressiva, and their fight for a cure.



OUR COMMUNITY



FOP Australia supports the 24 Australians and New Zealanders diagnosed with FOP, and their families. People are living with metastatic breast cancer in Australia.



We aim to help families and clinicians navigate access to information for best possible care, and support research towards a cure. We facilitate grant programs, support activities, and educational conferences.

CONNECT WITH US



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Meet Remy

 **Patient Organisation:** Cystic Fibrosis Queensland

 **Condition:** Cystic fibrosis

Remy is a two-year-old living with cystic fibrosis (CF), an inherited condition that causes thick, sticky mucus to build up in the lungs and digestive system. Born with meconium ileus, Remy underwent emergency surgery at three days old and required a stoma. During his first year, he experienced slow growth, persistent gut infections and repeated viral and chest infections. He was admitted to intensive care twice and spent 12 weeks in hospital. These early complications continue to affect his health. Although Remy can now access a CFTR modulator, he could not benefit from this treatment during that critical first year. Timely access to innovative, age-appropriate treatments is essential to help children like Remy protect their health and live long, happy lives.

1



THEIR STORY

Who is the patient?

Remy is just like any other two-year-old. He is full of life and has a huge personality despite his small stature. He delights in saying hello to everyone he passes at the supermarket and helping his dad coach his older brother's soccer team. Remy loves riding bikes, singing, dancing and helping to cook. In fact, he calls himself "Remy MasterChef". Looking at him, you would never know the challenges he has already faced and continues to face each day. His family hopes he can keep enjoying childhood, growing, learning and bringing his warmth and enthusiasm to everyone around him.



2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

Because of his age, Remy could not access a CFTR modulator during his first year, when it may have supported his growth and overall health. Although he can now receive modulator treatment, the effects of his early complications continue.

The impact extended across the whole family. Instead of enjoying life with their new baby, Remy's mother stayed with him in hospital while his father divided his time between hospital visits, work and caring for Remy's older brother.

His family wants what every parent wants: for Remy to live a happy, healthy life that is not dictated by cystic fibrosis.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

Reforming Australia's process for deciding what is funded and subsidised in healthcare is in every Australian's interest. For children like Remy, timely access to innovative, age-appropriate treatments can protect health during critical growth and development. HTA reform should recognise rare, progressive conditions, consider patient and family experience, and support faster, more equitable access as evidence and treatment options evolve. Earlier access could mean fewer hospital stays, less disruption for families and a better chance for children with CF to grow, learn and enjoy childhood without their condition determining every part of life. By investing in effective healthcare, Australia can give people with serious conditions more time, more choices and greater hope for the future.

“We want Remy to have every chance to grow up healthy and strong. Earlier access to effective treatments could mean fewer hospital stays, more family moments and a childhood defined by who he is — not by cystic fibrosis.”

ABOUT OUR ORGANISATION

Cystic Fibrosis Queensland supports people living with cystic fibrosis and their families through practical assistance, information, advocacy and connection. We work to improve quality of life, promote equitable access to care and treatments, and help our community embrace tomorrow.

OUR COMMUNITY

 Cystic Fibrosis Queensland supports people with CF and their families across Queensland, the Northern Territory and the Australian Capital Territory, including people receiving care through Queensland and ACT clinics. We advocate for timely, equitable access to treatments and services throughout every stage of life.

CONNECT WITH US

 cfqld.org.au
 admin@cfqld.org.au
 [/CysticFibrosisQLD](https://www.facebook.com/CysticFibrosisQLD)
 [/cysticfibrosisqueensland](https://www.instagram.com/cysticfibrosisqueensland)
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Meet
Judi Adams



Patient Organisation: Pankind the Australian Pancreatic Cancer Foundation



Condition: Pancreatic Cancer

In November 2021, Judi woke from what was to be a minor keyhole surgery to conduct a biopsy to discover she had undergone major surgery for what proved to be a large cancerous tumour in the tail of her pancreas.

Following surgery and having completed six months of chemotherapy, Judi was then later diagnosed with a further cancer, which was detected in her lung during routine surveillance after her chemotherapy ended. This second cancer was removed in May 2025. Resection and chemotherapy were brutal and led to neuropathy and 'brain fog', ongoing digestion and bowel issues, and required pancreatic enzyme replacement as Judi's pancreas no longer produces enzymes and also led to a type 3 diabetes diagnosis. Following the diagnosis, as a result of the breakdown in her relationship, Judi returned to Tasmania to be closer to support from family and friends.

1



THEIR STORY

Who is the patient?

Judi says that she is now living her second life, the life you live when you realise you only have one.

Mortality saliency does not however mean that one abandons hope.

Unable to return to her former role, Judi focuses her time on helping others in the community by using her patient narrative of lived experience to help others.

Judi's mission is to raise awareness, coupled with a desire to not be defined by pancreatic cancer, but to instead channel this experience to help others. As a member of the national pancreatic cancer support group that meets nationally online via zoom, Judi is a passionate consumer advocate and voice for others impacted with pancreatic cancer.

She lives in the hope that there will be a drug or cure for pancreatic cancer that can extend her time with her loved ones.

2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

Judi sees firsthand how devastating a late pancreatic cancer diagnosis can be, with no cost-effective screening tool to catch it early. Ongoing costs for medications like Creon add real financial strain, and clinical trials remain out of reach for many, especially those in rural and regional areas. Hardest of all is hearing about a new drug with positive outcomes overseas, proven to extend the life of a pancreatic cancer patient, yet unavailable in Australia — with not even a timeline for when it might be. It's heartbreaking. Why should patients have to die waiting?



3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

A major issue for many diagnosed with pancreatic cancer is that their cancer is too advanced for surgery, and the only hope for many is to be accepted for a trial, which may involve not only specific criteria, but the added costs of travel, and medication which can be prohibitive.

Coupled with this is the issue that time is working against many pancreatic cancer patients, and therefore access to treatment and medications is time critical.

Equity issues around who gets access are matters that need to be addressed in the system, as too blockages.

Every pancreatic cancer patient's life depends on access to new drugs. I know that everyone living with pancreatic cancer would agree with me that investing in health is not only crucial but lifesaving. This is why HTA reform matters so much to me and all Australians.



ABOUT OUR ORGANISATION

Pancreatic cancer is one of the toughest common cancers. Our mission is to triple survival rates by 2030 and significantly improve the quality of life for those impacted. Making progress a reality through ground breaking research, compassionate support, and tireless advocacy

OUR COMMUNITY

Currently 78 Australians die from pancreatic cancer every week and 12 are diagnosed daily — now Australia's 3rd biggest cancer killer. 1 in 4 Australians know someone impacted. Symptoms rarely show early; over 80% are found once spread, making surgery impossible.

CONNECT WITH US

- pankind.org.au
- [/PanKindFoundation](https://www.facebook.com/PanKindFoundation)
- [/pankind_australia](https://www.instagram.com/pankind_australia)
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Meet Peter



Patient Organisation: Lived Experience Australia Ltd



Condition: Schizophrenia

Peter is in his late 50s and lives with his wife and adult children. Peter loves going to movies, listening to music, and spending time with his beloved dog 'Mollie'.

Peter has lived with schizophrenia most of his adult life. He receives support from a GP, his wife, and a small NDIS package to help him with daily activities and getting out in the local community.

Peter has had several changes in anti-psychotic medications over the years, many causing significant side effects or serious physical health conditions such as glaucoma, gynecomastia and diabetes. Peter has tried newer medications, without success. Choice, trust and being listened to are important to Peter. Unfortunately, the medications that suit Peter aren't on the PBS.

1



THEIR STORY

Who is the patient?

Peter is a devoted husband and father. His faith and family are what matters most to him, and Peter is always willing to be a listening ear to friends and family who may be having a rough time. Peter's greatest hope is to be healthier and to contribute where he can to his family.

“

Every bill matters for a person like Peter with severe mental health challenges, especially because they often experience multiple mental health and physical health conditions. Multiple disadvantages can make access to health care challenging and shorten their life expectancy by up to 20 years. HTA reform would help Peter's quality of life and that of his family.

”

2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

Peter's psychiatrist recommended Zuclopenthixol tablets, but they weren't on the PBS, costing \$200-\$300 each month. Peter already takes several medications for his many physical health conditions, seeing several specialists, so every cost is significant.

Peter became seriously unwell, went to hospital, and lost trust in treatment and understanding of his illness. Peter switched to having a fortnightly Zuclopenthixol Depot (\$25 per month). His Depot dose recently increased but the 50mg/1ML nebulas are not on the PBS, adding \$100 per month. This leaves Peter with little money to improve his quality of life in his community beyond NDIS support visits.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

Reforming Australia's process for deciding what is funded and subsidised in healthcare (Health Technology Assessment) is in every Australian's interests. HTA reform is about creating a healthy, productive and vibrant Australia.

Across our country, out of sight and out of mind, Australians are facing unbearable decisions, loss and financial hardship when innovative treatments subsidised by programs like our Pharmaceutical Benefits Scheme could make a difference. Help us reform HTA and the policies that guide investing in healthcare for all Australians by telling decision-makers that you back HTA reform and investing in health.



ABOUT OUR ORGANISATION

Lived Experience Australia is a national organisation for mental health consumers and carers, families and kin. We advocate for policies and systemic reform to improve mental health, suicide prevention, and psychosocial disability support services. Our research elevates Lived Experience voices.

OUR COMMUNITY



Our 'friends' include more than 14,000 people with lived experience of mental health challenges (consumers and family carers) across Australia.

CONNECT WITH US



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Meet Danielle



Patient Organisation: NeuroEndocrine Cancer Australia



Condition: Metastatic pheochromocytoma/paraganglioma

Danielle lives on the Mid North Coast of New South Wales. She is an assistant school principal, her family owns a transport business, and much of family life revolves around soccer, work and the ordinary hustle and bustle of raising two children.

In late 2022, after developing abdominal pain and feeling that something wasn't right, Danielle initially entered the health system with a suspected diagnosis of ovarian cancer. With no local neuroendocrine cancer centre of excellence near her home on the New South Wales Mid North Coast, she was referred to Sydney for specialist assessment and diagnosis. Since then, her care has largely been coordinated locally by an exceptionally supportive oncologist who has worked with neuroendocrine specialists and continues to advocate for treatment options as Danielle's disease has progressed.

1



THEIR STORY

Who is the patient?

Danielle does not define herself by cancer.

She is a wife, an educator and, above everything else, a mum. Her daughter is 14, her son is nine, and family life revolves around their soccer, school, work and being together.

Since her diagnosis, Danielle has repeatedly tried to return to the job she loves.

"I've worked. I've contributed. I want to continue to contribute."

She is not asking for an extraordinary future. She wants the future most parents assume they will have: watching her children grow up, sharing their milestones and simply being there.

As Danielle puts it:

"My bucket list is just be a mum."

2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

Danielle underwent multiple treatments, including lutetium therapy, chemotherapy and sunitinib, but her cancer continued to progress. When sunitinib caused serious kidney toxicity, there were no further standard treatment options.

Her oncologist identified belzutifan and pursued compassionate access. Without it, treatment would cost around \$20,000 a month.

Danielle's family began considering selling their business, their home and even her parents' home to pay for treatment. She knew she could not ask them to do that.

Danielle was ultimately granted access, but without it, she says, "It's like having to accept that you're not going to see your children grow up."

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

For Danielle, the issue is bigger than one medicine. Innovative treatments may exist, and clinicians may believe they are appropriate, yet access can still depend on funding, indication, individual advocacy or compassionate access.

Rare cancer patients are particularly vulnerable because they have fewer treatment options and smaller patient populations.

For Danielle, this is also about the future. Her 14-year-old daughter carries the same genetic mutation associated with Danielle's disease.

HTA reform means ensuring patients can access clinically appropriate treatments while there is still time for them to make a difference, for people like Danielle today, and potentially for her daughter in the future.

“How can you put a price on somebody's life like that? I've worked, I've contributed and I want to continue to contribute. I'm eternally grateful that I was given access, but I know there are probably many people who miss out, and I just don't think that's fair.**”**

ABOUT OUR ORGANISATION OUR COMMUNITY



NeuroEndocrine Cancer Australia is the national charity dedicated to improving outcomes for Australians affected by neuroendocrine cancer through patient support, health professional education, advocacy, awareness and research.



NeuroEndocrine Cancer Australia provides specialist NET Nurse support, counselling, dietetic services, information and advocacy to people affected by neuroendocrine cancer across Australia, while working to improve diagnosis, treatment access and equitable specialist care regardless of postcode.

CONNECT WITH US



neuroendocrine.org.au



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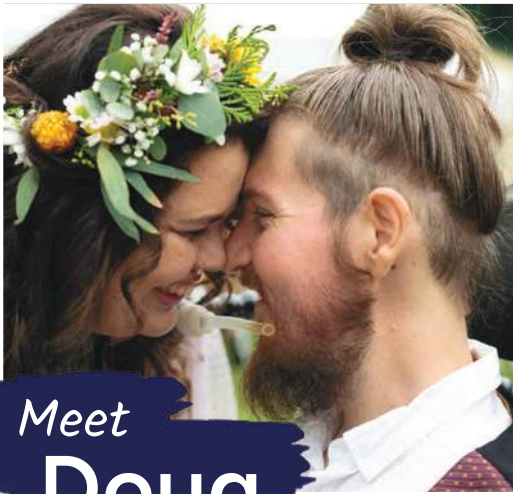
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Meet
Doug



Patient Organisation: Save Our Sons Duchenne Foundation



Condition: Duchenne Muscular Dystrophy

DMD is both the most severe and most common of the muscle wasting neurological, genetic conditions affecting 1 in 5000 males.

Manifesting in childhood and caused by one of thousands of possible variants of the dystrophin gene, DMD causes anticipated relentless degeneration of skeletal, cardiac, smooth muscles - including the heart and brain. Life-limiting severity and incidence across all races means there has been considerable global advocacy and investment during the genetic revolution. Standard preventative cardiac and respiratory care have extended the average lifespan beyond adolescence. Of the novel drugs approved overseas for Duchenne there are at least two oral medicines without variant restriction, which have demonstrated the best evidence profile to date. Neither are available, in part because sponsors are bypassing Australia in seeking regulatory approval.

1



THEIR STORY

Who is the patient?

At 38, Doug - a son, brother, husband, uncle, friend, colleague and community member; has doubled his predicted lifespan while living a full life and contributing to his community. His performing arts career spans acting, directing, writing, administration and advocacy, alongside disability services and work as a marriage celebrant. Living with DMD, Doug has used a wheelchair since age nine and continues pursuing opportunities despite significant physical and social barriers.

Over the past 15 years, increasing health challenges have required intensive daily support, including 24/7 ventilation, enteral nutrition and management of cardio-renal failure. He has survived several life-threatening medical crises while continuing to build his artistic and personal legacy.

2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

The DMD community faces restrictive labels and unharmonised vaccination programs that can exclude people who are chronologically young despite their "Elder Duchenne years." There is not always recognition of the vulnerability associated with complex care, immunosuppression, co-morbidities such as cardio-renal failure, and ventilator dependency. Outdated life-expectancy assumptions can also limit access to cardiac devices or invasive ventilation routinely offered to others, rather than supporting person-centred shared decision-making.

Australia's HTA framework can deter applications for innovative treatments, including those with strong safety and evidence profiles approved overseas. For advanced patients like Doug, these treatments may come too late to preserve remaining muscle.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

Reforming Australia's process for deciding what is funded and subsidised in healthcare (Health Technology Assessment) is in every Australian's interests. HTA reform is about creating a healthy, productive and vibrant Australia. Across our country, out of sight and out of mind, Australians are facing unbearable decisions, loss and financial hardship when innovative treatments subsidised by programs like our Pharmaceutical Benefits Scheme could make a difference. Help us reform HTA and the policies that guide investing in healthcare for all Australians by telling decision-makers that you back HTA reform and investing in health.



OUR COMMUNITY



Approx 1000 boys and young men life with B/DMD who are supported by their families and communities who will be affected both physically, emotionally and vocationally.

CONNECT WITH US



saveoursons.org.au



info@saveoursons.org.au



[/SOSDuchenneFoundation](https://www.facebook.com/SOSDuchenneFoundation)



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Meet
Sheridan



Patient Organisation: Fabry Australia



Condition: Fabry Disease

Fabry Disease is a Chronic, multisystemic genetic disorder. Common symptoms include fatigue, neuropathic and gastrointestinal pain. Long term, Fabry disease causes heart and kidney damage.

Sheridan is aged 50 years and lives in regional Victoria, with her family, including two teenage boys, also affected by Fabry disease. Many Fabry patients also find themselves in a carer role, with multiple members of the family affected.

Sheridan works as an osteopath, in her own practice.

Currently Sheridan is on a clinical trial for a new medication for Fabry disease. Although appreciative of the opportunity, it is a large commitment, having to travel frequently over 200kms to her nearest treatment center. Once medications are found to be effective, the process to listing may take many months to years.

1



THEIR STORY

Who is the patient?

Sheridan is an Osteopath, wife and mother of 3 boys, two of which are also affected by Fabry disease.

She enjoys art, playing tennis, reading, bush walking, travelling and spending time with family and friends.

As a Fabry patient, meeting treatment initiation guidelines can sometimes be challenging. Although this is improved in recent years, Australia falls behind what is considered best practice in other countries, with patients waiting longer to access treatment.

It is hoped that these unnecessary delays be removed. She hopes for improved access for all Fabry patients.

2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

For Sheridan, accessing a promising new treatment comes at a cost. Participating in a clinical trial has given her earlier access to a new medication, but it means regularly travelling more than 250 kilometres to her nearest treatment centre. Each visit means hours on the road and time away from her business and family. Sheridan's experience highlights an often-overlooked reality of accessing new treatments: availability doesn't always mean accessibility. For people living far from specialist centres, accessing treatment can demand significant time, travel and personal sacrifice, adding another burden to an already challenging health journey.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

Fabry Australia continues to campaign to improve access to Fabry treatments, allowing Fabry patients to be healthier, productive participants in their communities. Reforming Australia's process for deciding what is funded and subsidised in healthcare (Health Technology Assessment) is in every Australian's interests. HTA reform is about creating a healthy, productive and vibrant Australia. Across our country, out of sight and out of mind, Australians are facing unbearable decisions, loss and financial hardship when innovative treatments subsidised by programs like our Pharmaceutical Benefits Scheme could make a difference. Help us reform HTA and the policies that guide investing in healthcare for all Australians by telling decision-makers that you back HTA reform and investing in health.

“HTA reform is essential, to allow patients access to the best treatment available, when it's needed.”



ABOUT OUR ORGANISATION

Fabry Australia – Uniting and supporting the Australian Fabry Community.

OUR COMMUNITY



Fabry current prevalence is estimated as 1 to 5/10,000 people and can be difficult to diagnose, due to the range of symptoms.



We support over 500 individuals with Fabry disease, their carers and family.

CONNECT WITH US



fabry.net.au



admin@fabry.com.au



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Meet
Larissa
King



Patient Organisation: Breast Cancer Network Australia



Condition: Stage 3 Breast Cancer

Larissa King is 52 and lives in Melbourne, where she works as a psychologist in a counselling service. She shares her life with her husband Angus and her three children. Larissa was diagnosed with Stage 3 breast cancer in 2017 and was cancer-free for five years before she was diagnosed with metastatic breast cancer three and a half years ago, with metastases in her spine and liver. Ten months ago breast cancer spread to her brain.

For the past eight months, her only treatment option has been the oral medicine tucatinib, at a considerable cost to her family.

This treatment, despite being assessed, proven, and recommended for use, is not listed on the Pharmaceutical Benefits Scheme.

1



THEIR STORY

Who is the patient?

Larissa is a psychologist who has spent her career supporting others through various counselling roles. She shares her life with her husband Angus and her three children, supported by her brother, sister and mum in Melbourne. She loves gardening, playing basketball, reading and travelling.

“

Watching your superannuation disappear to pay for treatment is its own kind of grief. The money that is meant for your future, not for fighting to stay alive. Every dollar I use to survive, is a dollar I can't spend making memories with the people I love most.

”

What matters most to Larissa is time with her family, kindness and looking out for one another. She cares deeply about an equitable health system and social justice. Her hope is to stay alive long enough to watch her children grow up, to keep contributing to work she loves, and make new memories with her husband.

2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

Larissa's breast cancer returned as metastatic disease in 2022, with metastases now in her spine, liver and brain. For the last eight months, her only treatment option has been tucatinib, unfunded on the PBS and costing up to \$4,500 per cycle. Larissa was forced to access her superannuation early, watching her savings disappear. Her sister created a fundraising page, with friends and family generously contributing to fund the treatment. Larissa's experience highlights the urgent need for policy change to ensure people with metastatic breast cancer have access to appropriate treatments. No one should have to deplete their savings or rely on the generosity of friends, family and the community to ensure equitable access to a treatment that may extend life and give families more time together.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

Reforming Australia's process for deciding what is funded and subsidised in healthcare (Health Technology Assessment) is in every Australian's interests.

HTA reform is about creating a healthy, productive and vibrant Australia. Across our country, out of sight and out of mind, Australians are facing unbearable decisions, loss and financial hardship when innovative treatments subsidised by programs like our Pharmaceutical Benefits Scheme could make a difference.

Help ensure equitable and timely access to medicines required for Australians by supporting and implementing HTA reform.



Breast
Cancer
Network
Australia



ABOUT OUR ORGANISATION

BCNA is Australia's leading breast cancer consumer organisation an integral part of Australia's breast cancer support system. We stand beside people and carers. We amplify lived experience and confront gaps in care. We challenge what's not working until systems change.

OUR COMMUNITY



BCNA has the largest consumer network in Australia (250,000+)



56 people will be diagnosed with breast cancer every day. 20,950 people are living with metastatic breast cancer in Australia.



In 2024-25, 1.1 million people accessed BCNA's trusted information and resources.

CONNECT WITH US



bcna.org.au



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Meet Tammy

Patient Organisation: Hearts4heart

Condition: Cardiomyopathy of unknown origin

Meet Tammy Merton, a 51-year-old wife and mother of two adult children. Currently unable to work due to her health, she enjoys walking her dog along the basin and beaches of NSW's Jervis Bay area, attending community gatherings, taking part in research and advocacy opportunities, and spending time with family and friends.

Tammy survived sudden cardiac arrest at 45, caused by non-ischemic cardiomyopathy of unknown origin, with scarring on her heart and ventricular fibrillation. She is now eligible for Medicare-covered genetic testing and awaits her results. The hypoxic brain injury she sustained during the arrest left her with a functional neurological disorder.

Tammy lives with a remotely monitored ICD but attends yearly cardiologist appointments for physical checks and device data review. Ongoing travel for appointments and rehabilitation has been costly and time-consuming, taking a physical and financial toll on both Tammy and her husband.

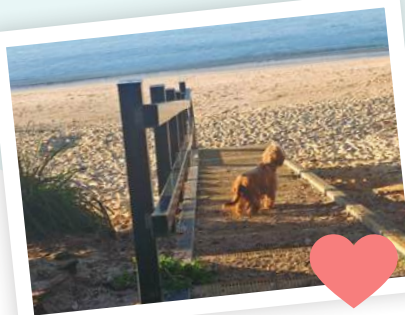
1



THEIR STORY

Who is the patient?

Tammy is a very outgoing person who loves her social life and being with her family and friends. She finds value in participating in research and advocacy opportunities and does what she can to help others like her. She spends a lot of time trying to rehabilitate herself through community and health professionals. Trying her best to lose weight and be fit and healthy for the day when she may require a heart transplant. She hopes to find employment in the near future to fulfil her mind and spirit.



2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

Living in regional areas has meant lots of travel, over night stays away from home and having to personally finance this.

Many of Tammy's scans, procedures, therapies and now medications have cost a lot of money. She has used up all her savings and Superannuation and now relies on the Disability pension.

Her Husband has now given up his career to become her full-time carer and has actually cared for her since the SCA happened. He has had little to no assistance with this, and it is taking a big mental toll on him.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

Reforming Australia's process for deciding what is funded and subsidised in healthcare (Health Technology Assessment) is in every Australian's interests. HTA reform is about creating a healthy, productive and vibrant Australia. Across our country, out of sight and out of mind, Australians are facing unbearable decisions, loss and financial hardship when innovative treatments subsidised by programs like our Pharmaceutical Benefits Scheme could make a difference. Help us reform HTA and the policies that guide investing in healthcare for all Australians by telling decision-makers that you back HTA reform and investing in health.

“ I gained weight after my SCA due to what I call the “cardiac blues” and debilitating depression. I’m desperately doing everything I can to lose the weight so that, when the time comes, I can be given the gift of a new heart. An affordable GLP-1 medication would help me with this, but at the moment I simply can’t find any more money to pay for it. ”

ABOUT OUR ORGANISATION

To empower people living with heart disease through peer support, education and advocacy, and to influence healthcare, research and policy so that every patient receives timely, equitable and person-centred care.



OUR COMMUNITY



Hearts4heart is a leading voice for people living with heart disease across Australia.



More than 4 million Australians live with cardiovascular disease, making it one of Australia's leading health challenges. We work to improve diagnosis, treatment and access to care.

CONNECT WITH US

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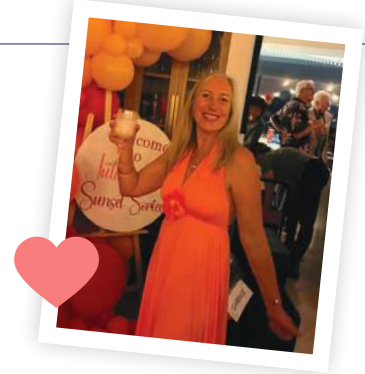


Meet
Julie

 **Patient Organisation:** Myasthenia Alliance Australia
Myasthenia Gravis Association of QLD

 **Condition:** Myasthenia Gravis

I have just recently celebrated my 60th birthday and am grateful to have come this far. My home is in a glorious location in Palm Beach, QLD. I am retired and the kids have grown so there is time to focus on health and wellbeing.



1



THEIR STORY

Who is the patient?

I have lived with myasthenia gravis since 2012. I am much more than my diagnosis. I am a professional, a member of my community and a committee member of the Myasthenia Gravis Association of Queensland, where I advocate for others living with this rare and unpredictable disease.

What matters most to me is maintaining my independence, participating in life and having the opportunity to live well despite MG. I want Australians living with rare diseases to have access to effective, innovative treatments without unnecessary delays simply because our patient population is small.

2



THEIR CHALLENGE

What barrier did they face because of the current HTA system?

Myasthenia gravis can fluctuate dramatically and affect almost every aspect of daily life, including mobility, vision, speech, swallowing, energy and independence. Yet the impact of MG cannot always be captured by clinical measurements alone. Patients can experience significant loss of quality of life while waiting for new treatments to become available or funded. For people with rare diseases, the evidence base can also be smaller than for common conditions. Australia needs an HTA system that recognises unmet clinical need, values real-world and patient evidence, and allows promising treatments to be assessed proportionately and in a timely way.

3



WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

HTA reform matters because Australians should not have to wait unnecessarily for treatments that could improve their health, independence and quality of life. The Government's current reforms provide an important opportunity to make the system more responsive to patients by involving consumers earlier, recognising lived experience, better addressing high unmet clinical need, using real-world evidence and reducing unnecessary delays in assessment.

For people with rare diseases such as myasthenia gravis, these changes could be transformative. A fair HTA system should recognise not only the number of people affected, but also the severity of the disease, the consequences of inadequate treatment and the value of giving patients the opportunity to remain independent and participate fully in society.

“ I have lived with myasthenia gravis for 14 years. I know what it means when treatment doesn't adequately control your disease. HTA reform must make sure that the voice of patients with rare diseases is heard early, that our lived experience counts, and that Australians are not left waiting unnecessarily for treatments that could change their lives. ”



Myasthenia
Alliance Australia



ABOUT OUR ORGANISATION

The Myasthenia Gravis Association of Queensland (MGAQ) supports people living with myasthenia gravis, their families and carers through information, education, peer support, and advocacy. MGAQ is a partner of Myasthenia Alliance Australia (MAA), which supports research, provides patient resources, and advocates for better care and equitable treatment access.

OUR COMMUNITY

 Myasthenia gravis is a rare autoimmune neuromuscular disease, causing fluctuating weakness and, in severe cases, life-threatening breathing and swallowing difficulties.

 MGAQ and MAA support the approximately 3,000 people affected by MG in Australia.

CONNECT WITH US

 mgaq.org.au | myastheniaalliance.org.au

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 /myasthenia-gravis-association-of-queensland



Meet
Alanna
Jinks

 **Patient Organisation:** Hearts4heart

 **Condition:** Mitochondrial Cardiomyopathy (with hypertrophic phenotype)

Alanna is a 40-year-old speech pathologist who loves travel, swimming, spending time with friends and family, and finding joy in everyday moments. Alanna lives with mitochondrial cardiomyopathy (with hypertrophic phenotype), the first manifestation of a rare neurodegenerative multisystem condition. She required open-heart surgery soon after diagnosis at age 34, going into acute heart failure. A six-year delay in diagnosis delayed her access to appropriate care. In this time, the condition has resulted in a stroke and significant neuromuscular symptoms.

Living in regional Australia has compounded these challenges through limited access to specialist care, requiring travel to Sydney for assessment and support. Prolonged diagnostic delays have profoundly affected her health, treatment, independence, and ability to make informed life-stage decisions. Prolonged diagnostic delays have profoundly affected her health, treatment, independence, quality of life and ability to plan for pregnancy and having a family.

1 THEIR STORY

Who is the patient?

Alanna is a dedicated speech pathologist, health advocate and someone who has spent nearly two decades working alongside people with disability. She cares deeply about inclusion, human rights and connection. I want to keep working, contributing and using my lived experience to co-produce change. I also want a life beyond my diagnoses, to have meaningful relationships, continue my career, travel and have the opportunity to create a family and become a mother.

“For young Australians with complex and rare conditions, timely access to treatment means the freedom to study, work, build relationships and plan a future with dignity. When care is delayed or unaffordable, life choices are limited. That is why HTA reform matters. It can turn hope into opportunity and ensure no young person is left behind.”

2 THEIR CHALLENGE

What barrier did they face because of the current HTA system?

While there is no treatment for my underlying condition, innovative therapies could substantially improve my symptoms and reduce future health risks. Despite experiencing significant related health complications, I do not currently meet PBS criteria for these treatments, and private access is unaffordable. This has left me in limbo, affecting not only my health but also my ability to make important life-stage decisions about my future, including starting a family.



3 WHY HTA REFORM MATTERS TO ALL AUSTRALIANS

How would reform improve lives?

Reforming Australia's process for deciding what is funded and subsidised in healthcare (Health Technology Assessment) is in every Australian's interests.

HTA reform is about reducing barriers to treatment and ensuring Australians can access the care they need when they need it.

Across the nation, out of sight and out of mind, Australians are facing unbearable decisions like loss and financial hardship when innovative treatments subsidised by programs like our Pharmaceutical Benefits Scheme could make a difference. Help us reform HTA and the policies that guide investing in healthcare for all Australians by telling decision-makers that you back HTA reform and investing in health.



ABOUT OUR ORGANISATION

To empower people living with heart disease through peer support, education and advocacy, and to influence healthcare, research and policy so that every patient receives timely, equitable and person-centred care.

OUR COMMUNITY

-  Hearts4heart is a leading voice for people living with heart disease across Australia.
-  More than 4 million Australians live with cardiovascular disease, making it one of Australia's leading health challenges. We work to improve diagnosis, treatment and access to care.

CONNECT WITH US

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The Faces of HTA Reform
Real stories. Real people. Real reasons for change.

Patient Voice Initiative

Your guide to having a voice in Australia's healthcare system.



www.patientvoiceinitiative.org



www.patientvoicehub.org