



**ASTHMA
AUSTRALIA**

ASTHMA AUSTRALIA:
Join the journey
towards living
freely with asthma





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Australia.

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Asthma is a serious illness that is often underestimated.

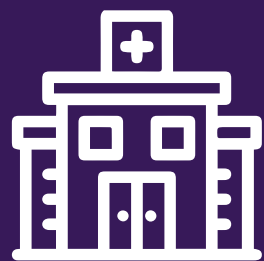


1 in 9

people in Australia have asthma, with children the most impacted.



We have one of the **highest rates of asthma** in the world.



Nearly **40,000** people are hospitalised each year with asthma, at a huge cost to the system, yet **80% of these hospitalisations** are considered potentially **avoidable**.

Death from asthma is preventable, yet in Australia, there is at least one asthma death every day.

JOIN THE JOURNEY

We can avoid asthma hospitalisations and deaths through increased, coordinated investment and collaborations.

'The problem we've got with asthma today is many people think, "It's just asthma." So how do you change that?'

William Crook, Astra Zeneca

Despite decades of advocacy and effort asthma has become a pervasive health condition that is **largely accepted as a routine health problem that people 'just live with'**. The numbers of deaths and hospitalisations have not been reduced, despite the evidence these can be significantly improved.

Asthma Australia was established in 2017 following the bold and challenging merger of six entities. As a national organisation, Asthma Australia has built strong networks with researchers, clinicians, consumers and policymakers and strengthened opportunities for coordinated major gains in asthma healthcare.

With ambitious targets and a clear strategy, Asthma Australia is seeking increased, coordinated investments and partnerships with funders and like-minded organisations to:

- transform healthcare for people with asthma
- seek a cure for asthma
- enable all Australians to breathe better.



This is the story of building Asthma Australia – the merger, lessons learned, what changed and an invitation to be part of the way forward. This story follows the journey of the network of national and state/territory-based asthma organisations who saw an opportunity for increased impact, who were challenged by the changing funding landscape and inspired to improve outcomes for people living with asthma and those who care for them.

This story was developed drawing on in-depth interviews with 32 diverse stakeholders from across Australia, representing the voice of community, medical research, government and the respiratory health sector. The authors thank them for their generosity in sharing their experiences and powerful insights.

This story is an invitation to join in the vision that no one experiences a life restricted by asthma.

Asthma Australia's impact goal is to halve avoidable hospitalisations due to asthma by 2030.

MERGER INTRODUCTION

Mergers in the community and for-purpose sector are notoriously difficult and take a lot of time and effort. Many are considered and abandoned. Asthma Australia’s merger story is one of challenge as well as triumph. It is viewed by stakeholders as a success story that offers a blueprint for improving organisational efficiency and impact by putting people with lived experience at the centre of how you respond.

This merger story unfolds over a series of phases. It begins with the **origins (1960–2000)** of the asthma organisations. Then the lengthy **exploration (2001–2014)** of merging and the role of Queensland and New South Wales in **paving the way (2015–2016)** for the ultimate **merger and alignment (2017–2018)** phase. The story continues with **building the foundations for impact (2019–2023)** and how Asthma Australia is collaborating with all stakeholders, **creating a better tomorrow** for those who live with, or are at risk of developing asthma.

‘Asthma Australia were one of the first to go through this merger model. It is a critical merger in the sector, showing the way. A big success story. I still talk about Asthma Australia as an organisation that successfully changed.’

Jane Magor, National Manager, Philanthropy and Non Profit Services, Perpetual Limited

ORIGINS (1960–2000)

Passionate parents and health professionals worked together to establish asthma organisations in Australia in the early 1960s. The first was in South Australia, followed by **Asthma Foundations** being established in all states and territories. In 1965, the **Federal Council of Asthma Foundations**, a small coordinating entity, formed to provide a mechanism for liaising with the Federal Government to influence the research priorities to be made nationally.

The state and territory Asthma Foundations delivered services, funded research and led community awareness and education campaigns around asthma prevention, treatment and care. The asthma community quickly grew into a federation of organisations supporting people with asthma, their carers and health professionals.

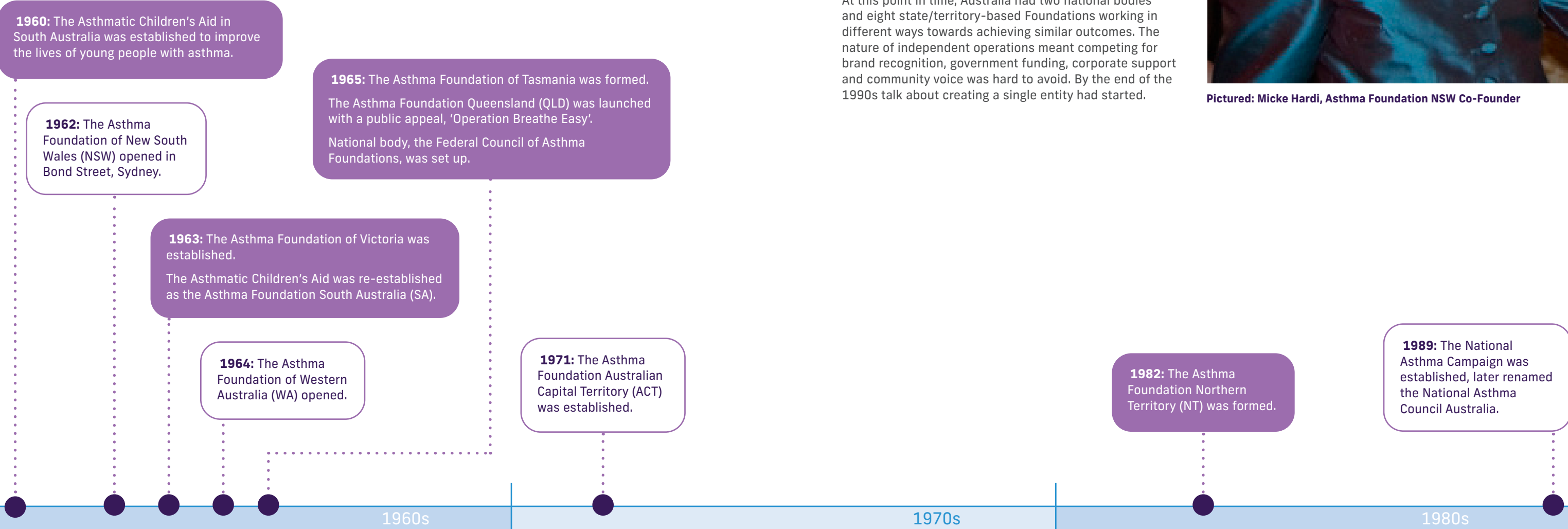
Though they worked together in a federated model and had shared interests, each asthma foundation operated independently, leading to duplicated efforts and inefficiencies.

In 1989, the National Asthma Campaign was created, later renamed the **National Asthma Council Australia**. It was set up as a collaboration of major healthcare bodies to improve asthma outcomes with a focus on informing healthcare professionals on best practice in treating and supporting people living with asthma.

At this point in time, Australia had two national bodies and eight state/territory-based Foundations working in different ways towards achieving similar outcomes. The nature of independent operations meant competing for brand recognition, government funding, corporate support and community voice was hard to avoid. By the end of the 1990s talk about creating a single entity had started.



Pictured: Micke Hardi, Asthma Foundation NSW Co-Founder



EXPLORATION (2001-2014)

In 2001, the National Asthma Council Australia wrote the first memorandum of understanding for the merger and was an early champion of the idea under the consistent leadership of their CEO, **Kristine Whorlow**. Over more than a decade, the asthma entities debated, discussed, and worked towards creating a single entity that could lead on this national health issue.

For some, it made sense for the Foundations to merge and establish one voice with consistent messages and central administration. However, there was resistance from across the Foundations. Smaller jurisdictions were concerned about being forgotten and losing a local voice. Others were concerned about losing funding and support, as well as their uniqueness and identity – some Foundations had a long history.

Substantial resources were spent on investigating a merger over the decade leading up to the merger,

AN INTERNATIONAL PERSPECTIVE:

Stakeholders familiar with systems of other countries commented that Australia's federated system with individual state systems and organisations has contributed to competition, lack of trust, unnecessary duplication and a failure 'to see the bigger picture'. They viewed state-level siloes as powerful and suggested they can create unnecessary duplication, waste resources and compete against each other, so limited resources can get diluted even further.

including an independent report that found the federated model in place was not best positioned to grow the asthma movement or address day-to-day operational challenges. However, the report wasn't implemented, and progress stalled. A key barrier at this stage was an inability to resolve what a national merged entity's form, function, and governance model would be.

There were efforts to enhance collaboration, which included a single brand – the iconic blue balloon graphic – and nationally consistent resources and website. A National Research Program was established for those Foundations that chose to pool resources.

Though it was clear there would be significant benefits for people with asthma if everyone were to unite, achieving the merger was not easy.

'Basically, turf and funding are always the main issues. Everyone's jealous of everyone else's turf and money.'

Kristine Whorlow, Former CEO, National Asthma Council Australia

There were strong personalities across the boards and executive teams and a reluctance to give up state-based organisations. So, it must be acknowledged that ego played a role in jeopardizing the merger momentum – the fear of implications for individuals, rather than prioritizing the benefits for people with asthma.

The Queensland, New South Wales, and South Australia Foundations, which had strong balance sheets, assets, and relatively sophisticated systems, were the keenest to merge.

'I look back now and ask myself the question, "Why would the three strongest ones want to merge?" It's because they had really sensible boards that thought, "We can go from strength to strength and capitalise on those strengths"'

Mark Brooke, Former CEO, Asthma Australia Inc

In May 2014, the eight Foundations and **Asthma Australia Inc.** (the small, national coordinating body formed in 2009 of which each Asthma Foundation was a member) met to discuss respective roles and responsibilities within the context of their federated structure. While there was no agreed resolution about what the role of the merged 'Asthma Australia' should be, it was agreed to set up a Merger Sub-Committee to further explore options and invite the National Asthma Council Australia to be involved. Positive progress was being made.

Lessons

- **Mergers are complex, challenging and take time.**
- **It's critical to engage people in the vision and 'value' of the merger.**
- **Sell the benefits** as people cling to what they are giving up rather than what they are gaining.
- **Engage all stakeholders** (boards, staff and members) and listen to understand their concerns/fears. Allow them to contribute their ideas and work through barriers.



May 2014: The Merger Sub-Committee was established and the National Asthma Council Australia was invited to be involved in discussions.

2001: National Asthma Council Australia wrote the first MOU for the merger.

2009: All state and territory based Foundations agree to work together through the small national coordinating body Asthma Australia Inc.

2012: The Foundations agree to establish a National Research Fund and the development of a single brand - the blue balloon logo



2001–2005

2006–2010

2011–2014

PAVING THE WAY (2015–2016)

By 2015, a Memorandum of Understanding was signed by all the asthma organisations, which stated:

‘The Asthma Foundations, Asthma Australia Inc and the National Asthma Council Australia have each agreed that there should be a merger of all Participants to form one national entity with branches in each state and territory as appropriate.’

The merger now had real momentum and a critical mass of champions across the federation to drive the conversations, research, engagement and planning around the case for merger. The Merger Sub-Committee established five working groups¹ from across the asthma federation to conduct due diligence and develop the business case. Parallel to this, an ‘AIM High’ best practice project was undertaken to benchmark Asthma Foundation excellence, which involved each organisation providing access to core organisational data (program and financial). This proved critical in providing a transparent view of organisational strengths and weaknesses across the federation to reduce ‘unknowns’, build trust and enable practical negotiations.

The case for merging is clear

The business case and due diligence report made the case for merger very clear. The operating environment had changed substantially since the Asthma Foundations were established, including increased competition for funding and brand recognition. Community and funder expectations of services had increased (i.e. quality, scope and reach) and stakeholders were calling for greater efficiency and collaboration. The federated structure was over-governed with one director for every staff member, and ten CEOs for a team of 106 people across all asthma organisations. Whilst some Foundations were performing well, others were struggling financially and lacked the means to fully support people with asthma.

¹ Merger working groups included: Governance and Constitution; Human Resource and Industrial Relations; Programs and Service; Fundraising; and Marketing and Communications.

The challenge going forward was to honour the legacy and substantial local infrastructure which existed across the Asthma Foundations to create a national entity better positioned to drive organisational and service excellence.

Adaptive, relational leadership plays a key role

Champions and quality leadership were critical to moving through this phase and ultimately the merger success. Stakeholders described strong leaders competent at developing open and collaborative relationships and working in complexity as being key. The Asthma Australia merger was a team effort with key contributions from many leaders, including critical leadership from **Mark Brooke** (former CEO of both Asthma Foundation QLD and Asthma Australia Inc), **Terry Evans** (former President of Asthma Australia Inc) and **Michele Goldman** (former CEO of both Asthma Foundation of NSW and Asthma Australia Inc, and inaugural CEO of Asthma Australia).

Key to the effective leadership was a focus on people with asthma and aligning stakeholders around the common goal of creating a more agile and sustainable national entity capable of effectively meeting the needs of people with asthma.

‘We did a survey and the people with asthma couldn’t have cared less, quite frankly, whether or not we were a federated structure, what they wanted was timely access to medicine, better quality GP interactions. No one cared what type of organisation we were.’

Mark Brooke, Former CEO, Asthma Australia Inc

Many stakeholders felt the merger process was well-run, organised and there was good communication.

‘I left the face-to-face kick off meeting feeling that the merger was in very capable hands.’

Maria Walters, Former Chair, Asthma Foundation NT

Merger leaders had to make it clear they weren’t pushing the merger for personal gain:

‘One thing in our favour was that Mark [Brooke] intended to get another job if we merged and I was going to retire. So, there was no competition between us for the new merged national CEO job.’

Kristine Whorlow, Former CEO, National Asthma Council Australia

Queensland and New South Wales forge ahead

With the proposed merger taking a long time, the Queensland and New South Wales Asthma Foundations made the strategic decision to forge ahead and merged in 2015. This was a significant milestone that demonstrated successful merging was possible. It also signified that the merger could, and would, go ahead with or without everyone.

‘Thinking about what happened with Tasmania [coming on board later], another lesson is not to be afraid to start even if everyone hasn’t come on board.’

Simone Carton, Board Member, Asthma Australia and Former Board Member, Asthma Foundation ACT

Lessons

- **Start where you’re at** and take small steps. Don’t wait for everyone to be ready or it may never happen. Move forward regardless.
- **Focus on the common goal.** Bring people back to the ‘why’ – the outcomes you are striving to achieve for the intended beneficiaries.
- **Have clear processes mapped out** as much as possible and communicate it.
- **Sharing a transparent view of strengths and weaknesses of all entities** reduces ‘unknowns’, builds trust and enables practical negotiations.
- **Leaders need to be in the right headspace** – giving up their roles for the greater good.
- **Ensure ongoing engagement of all stakeholders in the change process, particularly the staff and membership of merging organisations, not just boards.** Find out how they are really feeling, and any unspoken concerns. Consult them and involve them in decisions. Be open in your communication, especially when you don’t have all the answers.
- **Don’t skip due diligence** or cut corners. Looking deeply into the operations of others can uncover hidden issues.
- **Sometimes the timing is right.** There was an opportunity for Asthma Australia with a few board members retiring at the time the merger was being explored.
- **Quality leaders** who are great at developing open and collaborative relationships and working in complexity are critical for success. The right leaders enable quicker progress.

The Asthma Foundation of NSW and Asthma Foundation QLD merge to form Asthma Foundation Queensland and New South Wales.

2015

The remaining six Asthma Foundations and the National Asthma Council Australia remained committed to progressing with the merger.

2016

November: Michele Goldman returned to the sector as CEO of Asthma Australia Inc and following the merger was appointed as CEO of Asthma Australia.

MERGER AND ALIGNMENT (2017–2018)

A changing funding environment

By 2017, there was a clear vision and articulation of why and how the merger would make the entities stronger and better support people with asthma as a result. At the same time, the funding environment was shifting and getting tougher. The Federal Government was calling for greater efficiency and in May 2017, the Federal **Department of Health** advised it would reduce its program funding to the Asthma Foundations and the National Asthma Council Australia by more than 60% over three years, reflecting the Department's overall reduced budgets. With different levels of financial viability among the Foundations, some would struggle to survive on their own.

'[The Asthma Foundation of Tasmania] might have just trundled along trying to do things on next to no budget ... our opportunity to make any impact or reach out was extremely limited. I don't even know if we'd still be here and we certainly wouldn't have been kicking too many goals [if we hadn't merged].'

Helen Pollard, Former Chair, Asthma Foundation of Tasmania

'I was extremely supportive of working with Michele [Goldman] to encourage that creation of a single entity. As a general principle it's far more effective to work with government with a peak voice so the government knows where to go, and they carry the status of support across the country.'

Greg Hunt, Federal Minister for Health 2017–2022

Structured merger negotiations

Once most of the Asthma Foundations were in agreement and alignment, the merger became a clearly structured administrative process with a pathway and key decision points. These decision 'gates' were set up at certain junctures so each organisation could decide if they would step through to the next level. This allowed them to go on a journey of discovery. This clear structure was critical for transparency and trust and keeping all parties at the negotiating table.

An independent merger facilitator was engaged to walk everyone through the merger options and process and to keep it moving. It was helpful to have an outsider driving the merger who understood what was involved, who asked the tough questions and who kept bringing the focus back to the 'why' – to more effectively address the needs of people with asthma.

'Once the merger got some impetus we began the discussions in earnest. They were long and drawn out and tedious, and there was a bit of two steps forward, one step back, but we got there in the end.'

Terry Evans, Former President, Asthma Australia Inc

Getting the governance right

The Foundations were particularly interested in the governance structure – what it would look like was a stumbling block. There were assurances no organisation would be worse off.

'What we got right was to adopt a constitutional structure that left the jurisdictions with much of what they already had ... We made sure that they were confident that the best part of what they already had would be preserved and constitutionally embedded ... And we gave them a voice on committees.'

Terry Evans, Former President, Asthma Australia Inc

Ultimately it was decided to have a skills-based board with three independent members (including the Chair) and six other members – one representative from each merging organisation to provide the national representation. The new proposed governance arrangements also included forming a Professional Advisory Council and a Consumer Advisory Council. Whilst governance negotiations took a long time and a lot of patience from all parties, they proved to be a success.

'At no time did I feel as Chair that individual board members were thinking about territory. They were focused on what is in the best interest of the new organisation in which we were directors, not bringing anything over from the past onto the new board.'

Hon David Simmons OAM, Independent Chair of Inaugural Asthma Australia Board

'Vision is easy, but execution is difficult. Some people simply can't see what you are building towards or are reluctant to give up their influence in outdated business models. It takes brave people to put the framework forward and place their trust in a slimmed-down governance model to deliver on the promise.'

James Wright, Current Chair, Asthma Australia Board

Decision time – Foundations vote on merger

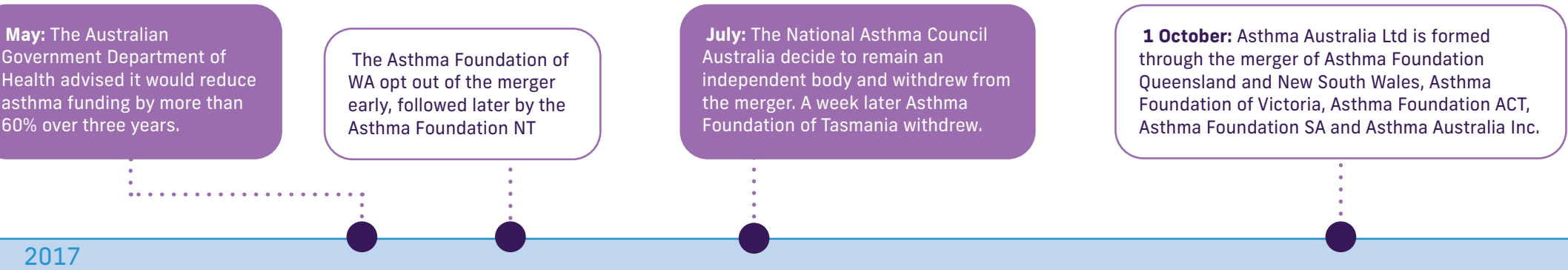
The Asthma WA opted out of the merger early, followed later by the Asthma Foundation NT.

The National Asthma Council Australia withdrew from the merger negotiations in July 2017, deciding to remain an independent body, and shortly after, the Asthma Foundation of Tasmania also withdrew.

Though the board of the Northern Territory supported the merger, their members ultimately voted not to merge. Whilst there was not complete clarity on why members voted against the merger, some perceived this as being a takeover and did not want to be a part of it. This highlights the importance of engaging all decision-makers around the case for change for membership-based organisations.

All but one director on the Northern Territory board resigned after the vote and whilst the Asthma Foundation NT continued to work with Asthma Australia, they have remained an independent entity. The Asthma Foundation of Tasmania took a different approach and under the leadership of a new Board, went back to the membership to engage them more deeply around the 'why' of the merger, resulting in a new vote in favour of joining the then merged national organisation.

Asthma Foundation SA was supportive of the merger, but decided to develop a contingency should things not proceed as planned. Part of their assets were transferred to the new merged entity, and part were retained in a trust fund, where as the Trustees they could distribute funds to Asthma Australia based on project proposals.



Merger

On 1 October 2017 **Asthma Australia** Ltd was formed (referred to as Asthma Australia in this document) through the merger of four Asthma Foundations (Queensland and New South Wales, Victoria, ACT and South Australia) and Asthma Australia Inc. In 2018, the Asthma Foundation of Tasmania became part of Asthma Australia.

‘We were perpetuating a range of different entities all seeking to achieve the same thing. It made good sense to consolidate and deploy our resources against our common purpose. In an environment where it was increasingly challenging to raise funds, this was one way we could work smarter, remove duplication, and be able to realise opportunities not afforded to smaller entities.’

Michele Goldman, Inaugural CEO, Asthma Australia

Once merged, the hard work of creating an agile, sustainable and purposeful national asthma organisation really began. Many of the detailed decisions around organisational structure, streamlining of programs/ services, integration of systems, harmonising of fundraising and marketing and importantly strategy, were intentionally left for the post-merger phase to avoid additional barriers to merging and allow time to work through the changes.

Streamlining of programs/services

The leadership team took a forensic look at what each organisation did and what worked. They systematically worked through over 130 activities (initiatives and services), making decisions about what to continue, streamline or cease doing.

‘They rationalised programs – streamlined them – and I thought there was a vast improvement. At the program level there was a significant change in the collaboration of the members of staff and the operational people – they had always wanted to collaborate and cooperate because they were the people who cared about the people with asthma and now they were not only allowed to do that, they had to.’

Terry Evans, Former President, Asthma Australia Inc

Building a new organisational structure and culture

The new organisational structure evolved slowly and allowed Asthma Australia to bring people on the journey. The focus was on building a strong, new organisation together rather than taking a quick approach to restructuring and staff cuts. A strong emphasis was put on communicating with staff as structural and job changes were implemented, however, the process was imperfect. Feedback from some staff reflect the process wasn’t always handled as well as it could have been, with some abrupt redundancies and last-minute contract renewals, while others appreciated securing two-year contracts which gave them short-term job security throughout the change.

Given the aspiration to build on the rich history of the Foundations and preserve a truly national footprint, deliberate decisions were made in appointing the leadership team, board directors and Consumer Advisory Councillors to ensure representation from each of the participating jurisdictions.

Staff described the critical role Michele Goldman (CEO) and senior managers played in working with staff in the newly merged organisation to build an open, inclusive, collaborative workplace culture.

‘Building a new culture starts with leadership and shared values. We worked with the team to build our shared values and create a level of psychological safety in the organisation where it’s OK to not have all the answers. In organisations doing things for the first time, you need to have a learning mindset and be open, inclusive and collaborative. We all feel like we’ve got our fingerprints on the organisational values and culture now, we’ve all got skin in the game.’

Kathy Packenas, Director Customer and Marketing, Asthma Australia

Integrating systems, marketing and fundraising

Moving from a geographic jurisdiction approach to a national view and perspective had some challenges. While the marketing and fundraising areas quickly integrated, program areas and other functions were slower. There were so many differences between organisations and some resistance to change.

There was a lot of work to determine policies, procedures and systems which took a couple of years. Now systems are integrated and there is better data management that supports organisational learning.

‘From my point of view, the actual merger date was symbolic. It was not a physical merging of systems, so for me the actual merger work happened in the following year or two when we had to combine all of our systems and processes.’

Lauren Vaughan, Strategic Marketing and Communications, Asthma Australia

Following the merger, the Northern Territory and West Australian Asthma Foundations remained independent entities, along with the National Asthma Council Australia. Asthma Australia continues to collaborate and, together, they form part of the wider asthma network.

Consumer Advisory Council formed to increase the focus on person-centred care. All Council members are people with asthma or are caring for children with asthma. They meet bi-monthly, steward consumer engagement activities and influence key initiatives.

Professional Advisory Council formed, with members from across primary and tertiary care, respiratory research, health policy, health economics, behavioural psychology and social marketing.

Lessons

- **Don’t cut organisations out of merger talks too early**, it is good to have critical friends on the journey and they may change their minds. It also builds trust and respect.
- **Aim for pragmatic, not perfect.**
- **Be proactive in communicating with staff about the organisational structure** and the likelihood of additional changes as the organisation learns what’s working.
- **Try to plan big milestones over the first 12–18 months** to give structure and manage staff expectations about how long things will take.
- **Increase communication with staff**, even if there is not much to say. Manage expectations about the challenges and time it will take to merge and align. Help staff prepare for the messiness and likelihood of redundancies.
- **Use an independent consultant** to facilitate honest conversations and step through what is involved and fully understand the process.
- **Governance** can be a stumbling block so invest the time in getting it right and address concerns.
- **Be agile and have the right mindset** – test, trial and take opportunities.
- **Focus on culture** – build the right culture and shared values.
- **Money is helpful** – a solid balance sheet with pooled funds allows less focus on fundraising and more on building the team, strategy and foundations.
- **Have some systems ready to go**, e.g. file storage and structure, and databases.

BUILDING THE FOUNDATIONS FOR IMPACT (2019-2023)

This phase saw Asthma Australia build on and consolidate its strengths as a national organisation and start to grow its impact and influence. Stakeholders described a post-merger organisation that was increasingly capable, strategic, collaborative, consumer-centred², agile and innovative. As a result of the organisational changes, Asthma Australia was able to build its foundations for increased reach, influence and impact across the sector and in the lives of people with asthma.

‘The separate state bodies for asthma were effective, but they weren’t nearly as engaged and totally informed as they are now ... it was only when they came together as Asthma Australia that they started to have a bigger footprint in a meaningful way ... They have a much better presence, a much more sustained contribution, a much more meaningful exploration of where the gaps are and what they can be doing.’

Christine Jenkins, Respiratory Specialist and Researcher

² Consumer-centred refers to Asthma Australia working actively with its ‘consumers’ (people with asthma and their carers) as partners in designing and shaping the organisations strategy and activities.

Organisational impact of the merger

Following the early internal changes to structure and operations, Asthma Australia was able to focus on building a stronger organisation and developing an innovative strategic plan to shift the dial on asthma.

The financial efficiencies of operating a single organisation were realised. Savings were made from the reduction in multiple high-salaried CEOs and finance managers, and funds were redeployed to increase organisational capability with functional leaders appointed in Marketing, Communication and Engagement; People and Culture; Fundraising; Programs, and Research, Policy and Advocacy. More money was invested in services to support people with asthma, and in advocacy and research.

The board and organisation were stable and well-governed, with increased sophistication and savviness. Asthma Australia brought in more expertise, such as staff and advisory council members with research, policy and advocacy skills; lived experience of asthma; and measurement and evaluation skills.

‘We have brought in expertise which means we can do different and better work. We can do much more strategic, systemic work because we’re a maturing organisation and because as a national organisation we have a lot more resources.’

Rose Bell, Research and Evaluation Coordinator, Asthma Australia

‘[Asthma Australia are] a great team of experts. Easy to work with. Efficient, streamlined.’

Swapnil Chaudhari, Medical Manager at GlaxoSmithKline

Asthma Australia had developed a clear vision, purpose and strategy. A rebrand process, developed through extensive consultation with people living with asthma and their carers, led to the refined organisational purpose **‘to help people breathe better so they can live freely’**. A reinvigorated website and online presence also ensured their communications were responsive, which was critical during the Black Summer Bushfires and COVID-19 pandemic.

‘The rebrand was a really important decision in terms of positioning us as this new organisation that had a new story to tell. We were moving forward as a national body with a new image.’

Simone Carton, Board Member, Asthma Australia and Former Bord Member, Asthma Foundation ACT

A transformational Strategic Plan (2022–2024) was launched in 2021. It addressed the complexity of asthma and the systems that enable or hinder better asthma outcomes and ensured activities were more calculated and had people with asthma at the centre. Priority areas of the strategy included:

- delivering data and digitally enabled personalised support at scale
- addressing the needs of communities with high risk and asthma burden
- influencing accessibility of treatments and medications
- community safety
- improving care systems and protocols
- addressing environmental triggers and air quality
- investing in and influencing research.

‘They’ve nailed their vision, mission and goal for 2030. They wouldn’t have got there without the merger.’

Melissa Alexander, Pitcher Partners

‘The team is outstanding. Consumer representation is outstanding ... Asthma Australia has a vision, a goal and a plan on how to get there.’

Adam Jaffe, Clinician, Researcher and Chair of Asthma Australia’s Research Advisory Committee

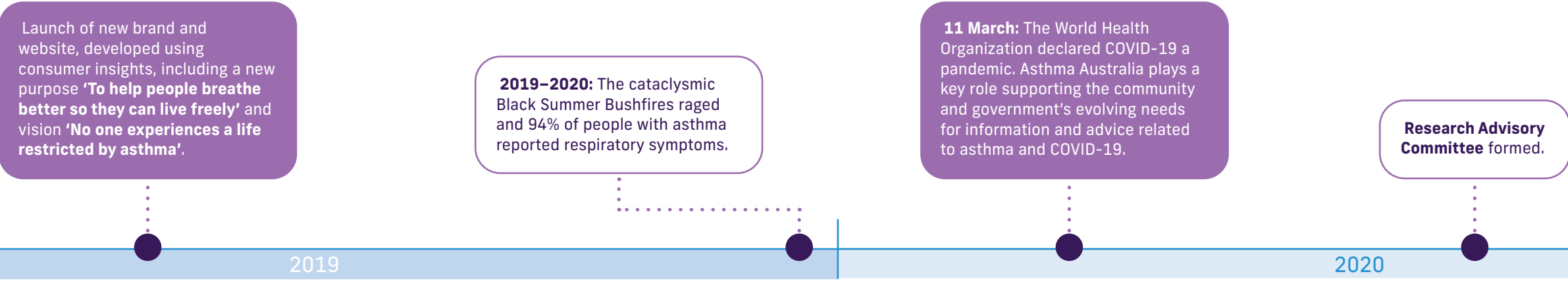
‘Years living with asthma, alongside other members of my family, has instilled a deep understanding of its challenges and the need for improved support ... Asthma Australia’s strong financial position has allowed us to attract a highly talented team, invest in innovation, and begin to deliver on our ambitious plans to improve the lives of all those living with asthma.’

James Wright, Current Chair, Asthma Australia Board

As the organisation has matured, their ability to innovate and work at scale has increased. Programs can be piloted and tested and then scaled where effective.

‘We have turned our minds to a key strategic challenge: how do we deliver the personalised supports that are changing people’s lives at the scale required to reduce the burden for the huge number of Australians living with asthma? We have invested in the capability and technology to support meaningful audience segmentation and to leverage digital channels to deliver the right information, to the right people, at the right time.’

Michele Goldman, Inaugural CEO, Asthma Australia



Impact for people with asthma

Taking a consumer-centred approach across the organisation and actively engaging people with asthma and their carers ensures people with asthma have a stronger voice and are better able to manage their asthma.

A stronger voice

Stakeholders consistently described Asthma Australia as having a strong voice and being consumer-centred. Innovation is driven through the voices of consumers which has shaped the work. Research and consumer feedback is constantly flowing through representation on the board, the Professional Advisory Council, the Consumer Advisory Council, the Research Advisory Committee and through advocacy work to inform the organisation's strategic thinking, decision-making and work to influence policy and practice change.

'Asthma Australia are being brave to do something different and break the mould and look at things from a different perspective. And particularly letting consumers have their voice, I think that's a big attribute too.'

Tracy Ellem, parent of a child with asthma and member of the Asthma Australia Consumer Advisory Council 2018–2023

'I think the opinions of myself and others on the Consumer Advisory Council are really valued – I've seen [research grant] applications get over the line that we've all agreed should. So, in that regard, they're going really well.'

Judy Wettenhall, person with asthma and Chair of the Consumer Advisory Council, Asthma Australia

Improved knowledge and asthma self-management

As a national organisation, Asthma Australia has increased its reach and is able to deliver consistent information and support through a variety of channels including 1800 ASTHMA phone support, website resources, educational programs and the AirSmart air quality app. An independent evaluation by the Centre of Health Economic Research and Evaluation (CHERE) of the COACH Program³, delivered by Asthma Australia, concluded it is playing an important role in enhanced asthma management and mitigating the risk of hospitalisations through multidisciplinary care. Consumer feedback also highlighted improved asthma outcomes, however, clearly showcased the need for a more flexible and personalised service, tailored to the need of the individual. COACH was retired and a new service was co-designed to better meet consumer needs.

'We have a greater reach now than we ever did because we've been able to build the profile ... the investment we've made into technology has supported that because we're reaching people in different spaces.'

Simone Carton, Board Member, Asthma Australia and former member of Asthma Foundation ACT Board

Best practice resources and tools help people with asthma, their families and health practitioners access and improve their knowledge and confidence to manage asthma.

'Following Asthma Australia helps me be proactive with my own asthma management ... I remember receiving an email recently about woodsmoke in winter, which was a reminder to think about my management and start increasing my preventer dose.'

Jane, person with asthma

³ The COACH Program is a self-management education program delivered by Asthma Australia which commenced in 2016. It provides education to people with asthma through regular scheduled calls with a trained Asthma Educator to improve an individual's asthma control and overall general health. COACH was retired in 2022 and a more flexible service designed and implemented.

Data from 2023 showed that:

- 84% of Asthma Australia adult consumers report adhering to their preventer medication versus 48% in the general population of adults with asthma
- 72% of Asthma Australia adult consumers report having seen a healthcare professional for a planned asthma review in the last 12 months versus 60% in the general population of adults with asthma.

'Because of Asthma Australia's information I finally came to understand and accept my asthma diagnosis ... after a decade of experiencing symptoms and starting to learn what it means for me. I've started to be more careful about how much reliever medication I use and have sought the advice of a respiratory specialist.'

Peter, person with asthma

Asthma Australia is also working to tackle asthma in populations who face a range of health inequities and complexities including children and young people, and First Nations Peoples and Communities. This work encompasses tailored programs and partnerships, as well as research that looks at how chronic disease is linked to environmental, economic and social factors, and strongly influenced by social disadvantage.

'In Australia, Aboriginal and Torres Strait Islander people are three times more likely to die from asthma and have poor clinical outcomes. Health education that is culturally appropriate is important to reduce language and context barriers to health equity.'

Asthma Australia website



Contribution to systemic change

Stakeholders consistently shared that, since the merger, Asthma Australia has a stronger public profile, is more collaborative and has significantly increased their capacity to make a more sustained contribution to shifting the dial on asthma. They are a respected independent voice in respiratory health, have a strong media presence and have expanded their partnerships, networks and influence.

Equitable access to asthma healthcare

Asthma Australia has been working to increase equitable access to asthma healthcare for people with asthma and remove barriers which are prevalent outside of metropolitan areas including delays in accessing appointments, travelling long distances for medical appointments, and the cost of healthcare.

This has included advocating for the Medicare Benefits Schedule item number for telehealth services, introduced during the COVID-19 pandemic, to be permanently maintained. Telehealth services levelled the playing field, enabling anyone with access to a phone or a computer with internet to access telehealth consultations.

‘The medications and the treatment available have obviously improved a lot, but the cost of the medication is huge to some people in particular. Access to respiratory specialists is very limited outside metropolitan areas in remote and rural areas – it is still pretty primitive in a lot of places. Asthma Australia is doing huge things to improve that access, and there’s still a heck of a lot of work to be done.’

Judy Wettenhall, person with asthma and Chair of the Consumer Advisory Council, Asthma Australia

Influencing policy and practice change

As a national entity with increased capability, Asthma Australia has been strategic regarding big policy issues and has taken a more holistic, systems change approach. They are responsive to emerging needs and unexpected crisis events. Having a consistent, single voice has provided unity across the country, and ensures people with asthma have a voice during bushfires, floods, and on local issues around the country. This was evident during the COVID-19 pandemic too.

‘In the whole political field, you really do have to have that united front and drive and be able

to bring change. There may be some unique aspects to each state in the sense of different geographical or environmental impacts, but at the same time, I think most states have been touched by floods and mould and bushfires – all those things are happening everywhere.’

Tracy Ellem, parent of a child with asthma and member of the Asthma Australia Consumer Advisory Council 2018–2023

‘Asthma Australia is now a strong and respected national authority on what needs to change in health policy and practice to improve asthma health care and reduce the consequences of asthma. This is built on the depth of expertise that is brought together in the professional and consumer advisory councils, the organisation’s leadership and support for strategic asthma research. It is a “blueprint” approach to preventing and improving chronic health conditions: building expertise in supporting consumer understanding, literacy and self-care capability about the health condition; tackling the social and economic determinants that affect the health of people living with or at risk of developing the condition; and informing and influencing quality health care and effective health policy addressing the condition and its impacts.’

Rosemary Calder, Current Board Member, Asthma Australia and Chair of the Asthma Australia Professional Advisory Council

‘In their advocacy work, Asthma Australia will always have local people who are impacted by asthma, who are participating and really leading the discussion. I think that is really important.’

Rebecca Vassarotti, ACT Minister for the Environment, Parks and Land Management

First Asthma Australia Impact Report published reflecting a greater focus on impact for people with asthma.

As a single entity they are also able to build and maintain strong connections with the Federal Government. This has been particularly important during the nation’s times of crisis such as the 2019/2020 Summer Bushfires and COVID-19. Pre-merger, there had been fear of losing relationships with state and territory governments, but with state-based teams and a strong focus these relationships continue to be well maintained.

‘Asthma Australia became a very effective organisation that was easy to deal with ... there was a single point of leadership, well represented. They were focused and driven during COVID. It became especially important to have a single voice ... Secondly, as we developed a national asthma strategy it was critical to have their input ... [Without the merger] the amount of voices seeking recognition and input would have been harder, and it may have been that some programs were not implemented as early or not implemented as effectively ... I think that they were very effective and gave confidence to the asthma community to say, “we hear you, we are responding and there is a respiratory plan which incorporates asthma at the heart of it”’

Greg Hunt, Federal Minister for Health 2017–2022

‘It’s important to be a national body able to speak to a national government.’

Hon David Simmons OAM, Independent Chair of Inaugural Asthma Australia Board

The effectiveness of Asthma Australia’s advocacy was also seen in their work coordinating a coalition of clinicians and key organisations to stop the removal of Fluticasone (a medication for young children) from the Pharmaceutical Benefits Scheme. The Minister for Health accepted the recommendations, reinstating equitable access of the medicine to children with asthma.

‘I feel that the clout of Asthma Australia as a unified body with a fair number of the states, together with the energy of leaders like Michele Goldman and Kathy Packenas and all the team ... they get things over the line when they’re talking to parliamentarians on things like PBS [Pharmaceutical Benefits Scheme] on medication.’

Judy Wettenhall, person with asthma and Chair of the Consumer Advisory Council, Asthma Australia

Research and partnerships for impact

Guided by a Research Advisory Committee, Asthma Australia have undertaken important research, aiming to have a larger impact for people with asthma. For example, their National Asthma Research Agenda project has identified the top ten priority research areas important to people with asthma, their carers and treating healthcare professionals. This has transformed the approach to research from one which was largely investigator-led, to one which seeks to answer the questions that matter most to those living with the disease. This project also sparked a conversation with leading researchers and led to the nationwide CURE Asthma⁴ collaboration.

Working collaboratively in research and lobbying for evidence-based change, Asthma Australia are better positioned to partner and drive conversations across the respiratory health sector as is evident through their roles in the Lung Health Alliance, the Climate and Health Alliance and through their contributions to the Centre of Research Excellence in Severe Asthma’s work. Researchers described how Asthma Australia bring consumer-driven insights to shape better outcomes.

‘What was competitive is now collaborative.’

Adam Jaffe, Clinician, Researcher and Chair of Asthma Australia’s Research Advisory Committee

‘Asthma Australia is part of the Centre for Research Excellence in Severe Asthma ... before, if you had five different Foundations then they couldn’t have had all five people on board ... now you have one person which works much, much better. One voice from one place, it’s really helpful. You’re getting good consumer info and insight. They’ve been really helpful in driving forward things like the National Research Agenda and oral steroids stewardship, which is fantastic.’

John Blakey, Clinician and Asthma Specialist

Asthma Australia are currently involved in 16 research partnerships worth over \$35 million. Due to increasing partnership requests, they have established research partnership guidelines aligned with the strategic priorities in the National Asthma Research Agenda.

⁴ CURE asthma means treating a patient who has a validated asthma diagnosis in a way which reverses the mechanisms that cause disease symptoms; permanently, and efficiently producing a lasting disease-free state.

Better environments

Air quality is critical to Asthma Australia’s work to ensure the environments that people with asthma live in are safe and support good asthma outcomes. During the 2019/2020 Summer Bushfires, a rapid response survey of people with asthma provided powerful information about the almost ‘real-time’ impacts of bushfire smoke on people with asthma. Asthma Australia responded quickly using its national reach to provide targeted advice as many parts of Australia suffered with smoke-filled air. Asthma Australia has also achieved progress around air quality through their wood smoke advocacy work contributing to policy change with the ACT Government committing to phasing out wood heaters.

‘Asthma Australia’s advocacy and research has been a really important input into the phase out of wood fire heating here in the ACT ... We’ve appreciated them engaging with us around the policy development and strategy elements ... they’ve contributed research on the impact of wood fire heaters and highlighted particular issues of air quality here in the ACT. They also identified individuals here, who can really speak to some of the issues. That has been very impactful.’

Rebecca Vassarotti, ACT Minister for the Environment, Parks and Land Management

Asthma Australia have worked actively with the Climate and Health Alliance to highlight the link between environment and health, and informed the Federal Government’s work on the first National Climate Change and Health Strategy. Stakeholders highlighted Asthma Australia as one of the only health not-for-profits with a strong voice around the link between environment and health.

In 2022, Asthma Australia also released its Homes, Health and Asthma Report following a survey of 5,041 highlighting the health risks found in homes. Asthma Australia supports holistic approaches to improving the conditions of new and existing housing and continues to advocate for a number of key priorities.

‘Environmental factors are not going anywhere. They’re just going to get worse. So that’s going to mean that there’ll be a continued increase [of asthma] in some areas and there’ll be acute hot spots. It won’t be just chronic asthma.’

Tracy Ellem, parent of a child with asthma and member of the Asthma Australia Consumer Advisory Council 2018–2023

Asthma Australia is also working to create safe school environments. Each year, almost 30,000 school staff undertake Asthma Australia’s Asthma First Aid training, helping to keep children and young people safe in their learning environment.

Better asthma outcomes

In the last ten years, there has been little change in the deaths from asthma or in hospitalisations for adults, though a decreasing trend for children. Whilst there were fewer asthma hospitalisations during the pandemic years, this was likely due to COVID-19 protection measures leading to:

- fewer respiratory infections (cold and flu)
- less outdoor air pollution
- better hand-hygiene, mask wearing and social distancing
- access to telehealth, avoiding doctor and hospital visits.

It is expected that asthma hospitalisations will rise once these protective measures are no longer taken, and the incidence of respiratory infections increases.

Asthma Australia’s work has contributed to improved asthma outcomes including improved self-management and reduced hospitalisations for those accessing their services, so there is promise that tangible progress on avoidable hospitalisations at a national level (a key goal) and reduced deaths is possible if effective services can be scaled to the many who would benefit from them.

Significantly improving asthma outcomes across the country is a long game. Asthma Australia are making inroads as they build the foundations for impact, and are delivering a strategy that sets up long-term success to help people with asthma breathe better so they can live freely.

Lessons

- Build a brand centred on the people you want to serve and include their lived experience.
- Develop a robust strategy to deliver on your purpose and guide decision-making.
- Put together a quality team and build the organisation’s capability to deliver its strategy and purpose.
- Be agile and have the right mindset – test, trial and take opportunities.
- Leaders need to be able to develop strong relationships with key stakeholders across the sector, including government and potential collaborators.
- Build your impact foundations including theory of change, outcomes framework and organisational approaches to data collection, analysis, reporting and learning.



CREATING A BETTER TOMORROW

Asthma is a disease that, as yet, has no cure. A daily burden for many families, it endures over many years. There are too many avoidable hospitalisations and too many preventable deaths.

'They really don't know where asthma comes from, as in causes – there's so much room for ongoing research. It will never be something that's a disease of the past, because it tends to be a lifelong sentence.' Judy Wettenhall, person with asthma and Chair of the Consumer Advisory Council, Asthma Australia

'Asthma affects people day-to-day in their lives over many, many years. It can reduce their productivity, it increases absenteeism, it increases presenteeism. It causes parents to have difficulty and challenges managing their children and it's costly to working families – there are big costs associated with medications and doctors' visits.'

Christine Jenkins, Respiratory Specialist and Researcher

Asthma Australia has taken on the biggest challenges of asthma including the goal to halve avoidable hospitalisations by 2030. With a commitment to tackle asthma's high impact on **children**, the serious **health inequities for rural/remote and hard to reach communities**, and the increasing **environmental health risks** from climate change, Asthma Australia invites new funders and collaborators to join this journey to maximise impact.

Asthma is the number 1 burden of disease in Australian children aged 0–14 years.




Indigenous Australians were 1.6 times more likely to report having asthma in 2018–19 compared with non-Indigenous Australians.

Air pollution is the most important environmental health risk of our time⁵.



⁵ United Nations Environment Programme website: unep.org/explore-topics/air

'The national organisation now provides the platform to trial innovative solutions to the complex system problem of managing asthma. Programs are trialled and professionally evaluated for their impact. Our generous donors and partners can now have a real understanding of the outcomes their contributions are having. Together, we now have a chance to make a real difference.'

James Wright, Current Chair, Asthma Australia



You can help Asthma Australia achieve the vision **'that no one experiences a life restricted by asthma'**.

Contact the team at Asthma Australia to discuss opportunities:
email info@asthma.org.au



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