



Leukaemia
Foundation[®]
VISION TO CURE
MISSION TO CARE



My Life Counts

The Leukaemia Foundation's path to zero lives lost to blood cancer

September 2019

THE PATH TO ZERO LIVES LOST

Supporting and caring for people affected by leukaemia, lymphoma, myeloma and related blood disorders has been our mission since the Leukaemia Foundation was established in 1975.

Since that time, our guiding principle has been that every person living with blood cancer should have equal access to treatment, support and opportunities to help them live their best life.

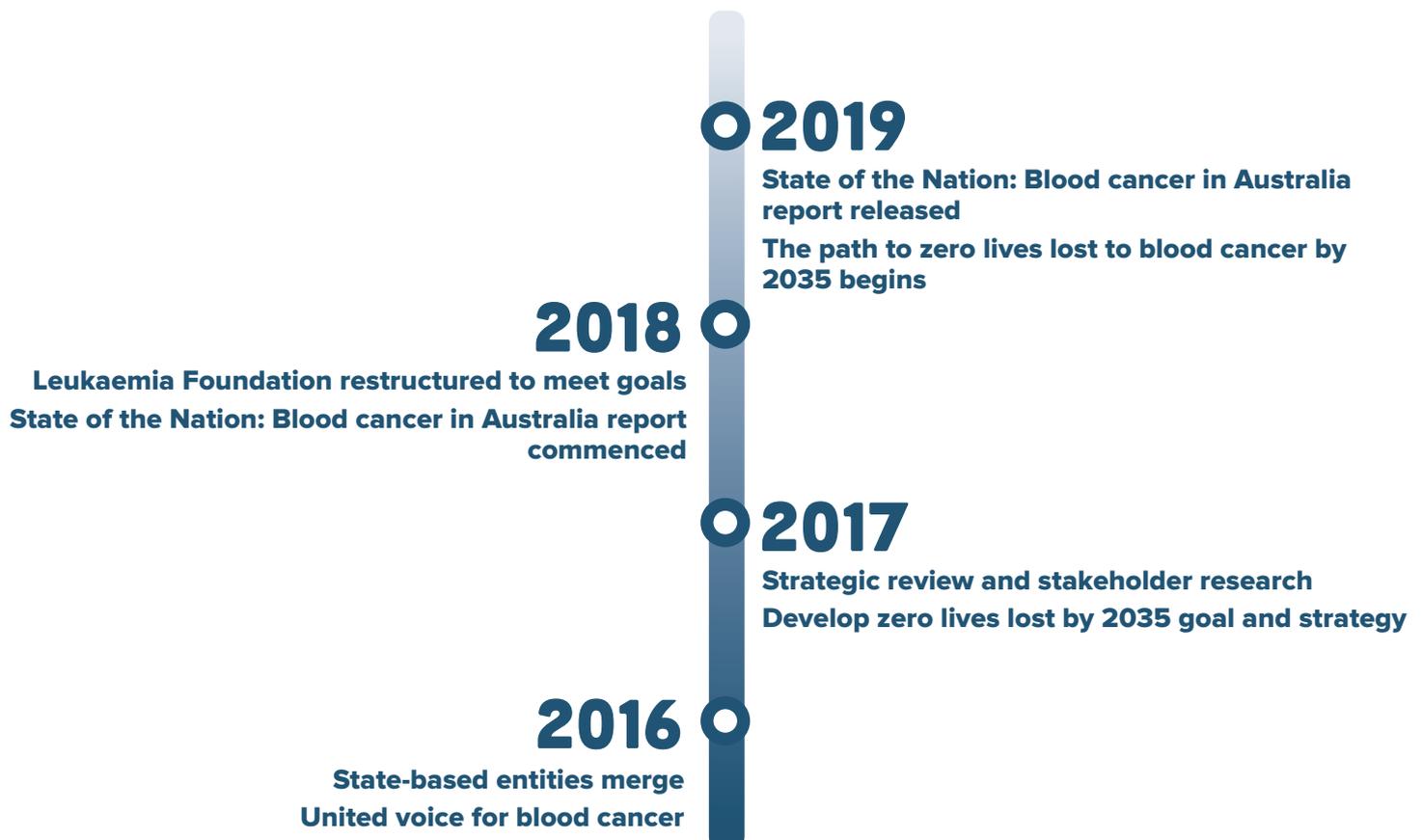
We provide access to extensive practical and emotional support including accommodation, transport, education and grief services.

That support, along with advances in treatments, research and the understanding of blood cancers, has seen significant improvements in survival.

But we still have a long way to go – some blood cancers exhibit five-year survival rates of less than 25%. Blood cancers remain among the most frequent causes of cancer death and in the top four most diagnosed cancers in Australia.

In 2016, the Leukaemia Foundation came together as a single national organisation to speak with a united voice for all people with blood cancer, and embarked on a strategic review to ask some big questions:

- » Why does the Leukaemia Foundation exist and is it meeting its mission?
- » Are we relevant to all blood cancer stakeholders and are we creating the impact they deserve?





Devoted 43 year old dad Brendan, with his family - he beat blood cancer after receiving a transplant #mylifecounts

To answer those questions, we spoke to the people who know best – people with a blood cancer diagnosis, their support networks, their clinicians, researchers and stakeholders who give so generously of their time and money.

What they told us helped identify the future needs of the blood cancer community and the Leukaemia Foundation's path to becoming the leader and innovator in the blood cancer ecosystem.

We learnt that people need more than what we were offering; they want simple and fast access to key advances in blood cancer such as:

- » Rapid change in global cancer research based on precision medicine.
- » Continued access to new medicines available but not yet listed on the Pharmaceutical Benefits Scheme (PBS).
- » Greater access to information enabling people to take control of their disease.
- » Timely and equal access to innovative clinical trials, the newest treatments and services.

Importantly, it made us more passionate than ever about attacking every blood cancer, from every direction, in every way we can, a mission underpinned by an ambitious goal ►

**ZERO LIVES
LOST TO
BLOOD
CANCER
BY 2035**

To achieve that bold goal and work towards conquering blood cancer, we commissioned a comprehensive and 'first of its kind' analysis in 2018. Its aim was to identify the challenges and opportunities that influence survival and quality of life for people with blood cancer.

The Leukaemia Foundation's ***State of the Nation: Blood Cancer in Australia***¹ report tells us that blood cancer is a major priority for the community and impacts Australians – young and old – in every region of Australia.

1. Insight Economics with Leukaemia Foundation (2019), State of the Nation: Blood Cancer in Australia

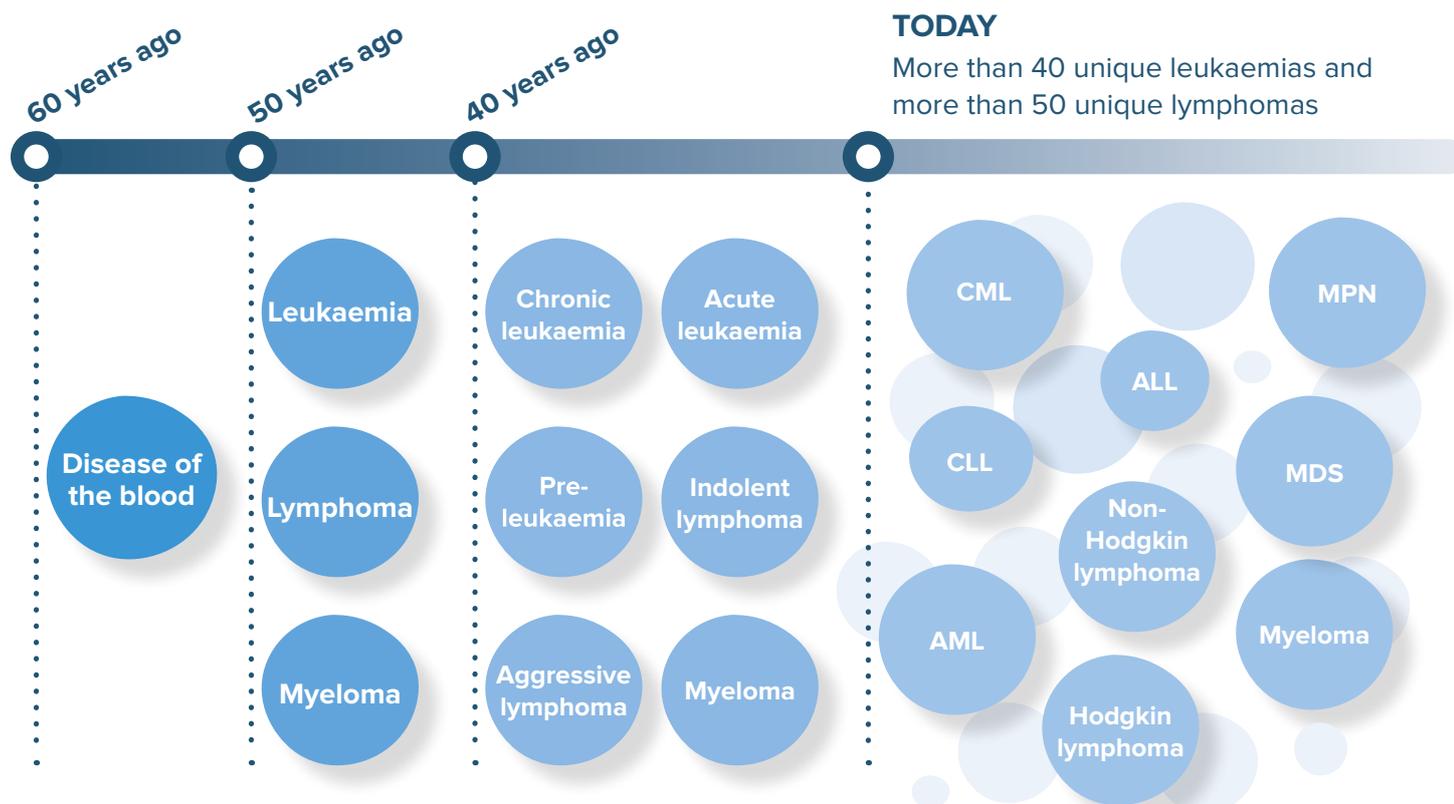
EVIDENCE BEHIND THE REPORT

The ***State of the Nation: Blood Cancer in Australia*** report was developed by an independent research firm, Insight Economics in consultation with the Leukaemia Foundation. Together, we consulted with more than 65 leading experts from across the blood cancer ecosystem including clinicians and haematologists, research institutes, government decision-makers, blood cancer NGOs and industry.

The Report draws on data from the Australian Institute of Health and Welfare (AIHW), Australian Bureau of Statistics (ABS) and state cancer registries along with survey data from more than 3,200 people living with a blood cancer, providing a statistically significant snapshot of the experiences of people living with a blood cancer in Australia today.

It is comprehensive, evidence-based, patient-centred and peer-reviewed.

How the understanding of blood cancer has evolved²

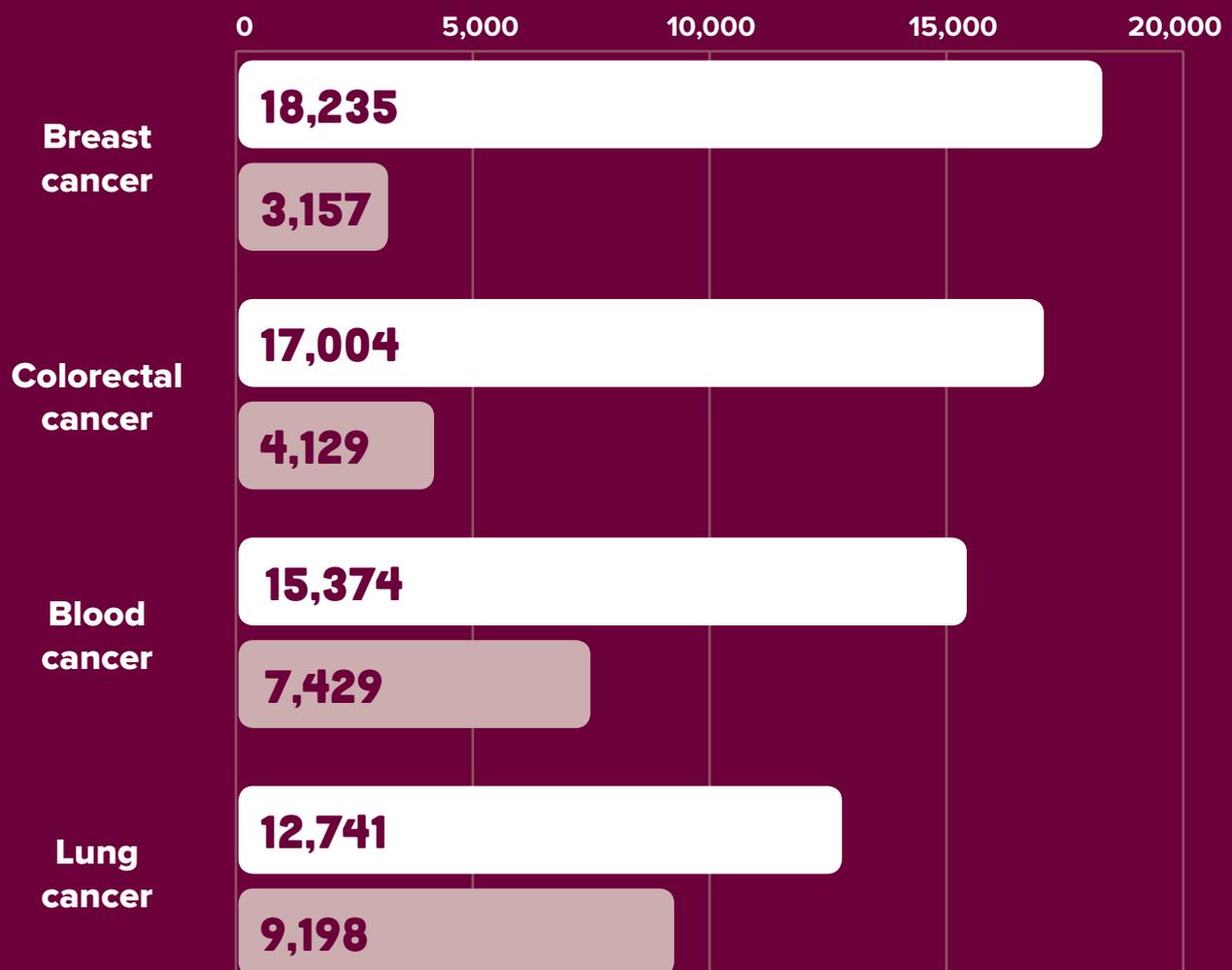


2. Insight Economics with Leukaemia Foundation. (2019, p. 10). State of the Nation: Blood Cancer in Australia.

PUTTING BLOOD CANCER IN PERSPECTIVE³

Blood cancers collectively are one of the most commonly diagnosed cancers in Australia and one of the biggest causes of cancer death.

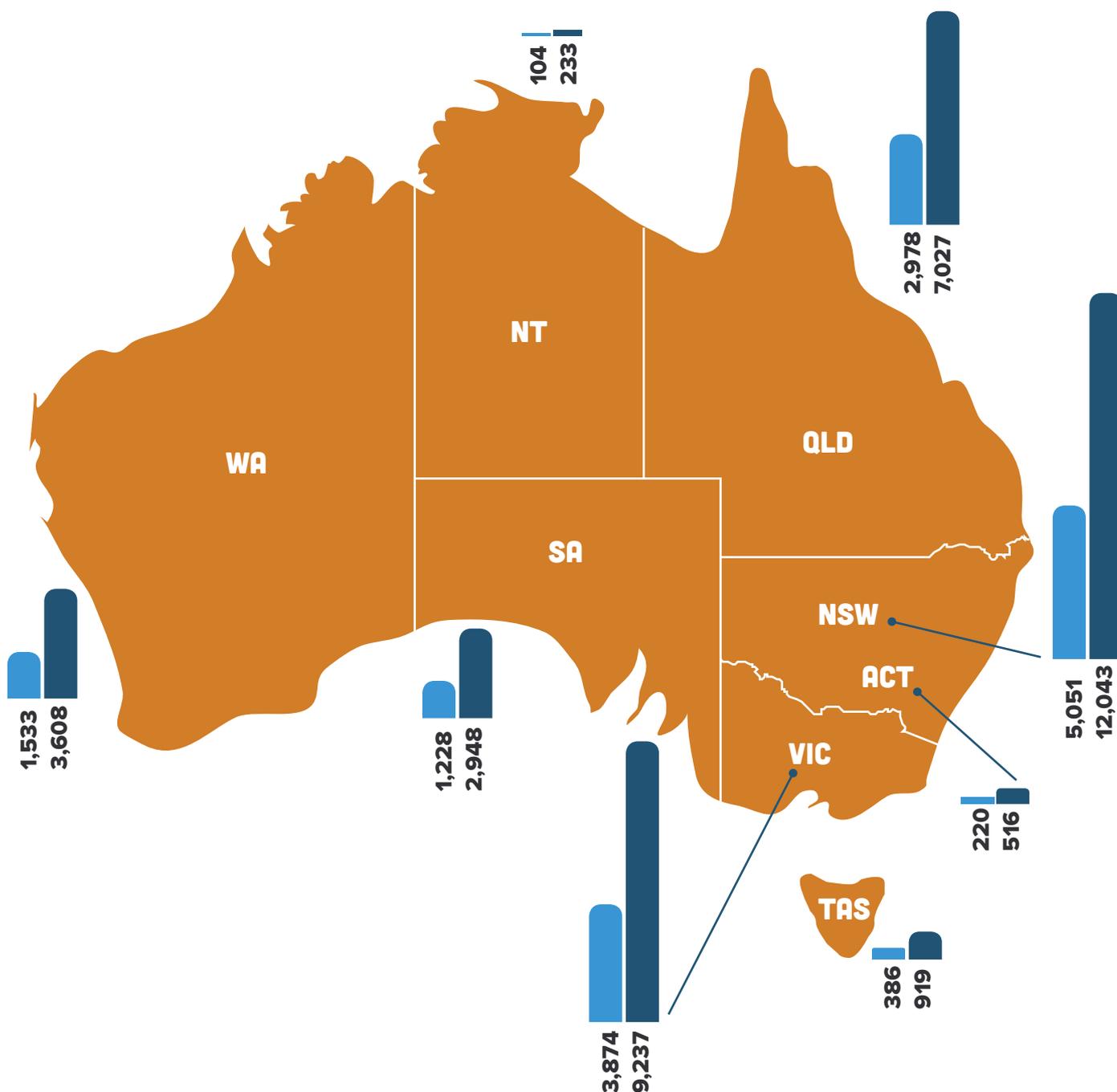
- Newly diagnosed in 2018
- Deaths in 2018



3. Insight Economics with Leukaemia Foundation. (2019, p. 20). State of the Nation: Blood Cancer in Australia.

BLOOD CANCER IS A NATIONAL ISSUE THAT AFFECTS PEOPLE IN EVERY STATE AND TERRITORY⁴

- Newly diagnosed in 2018
- Newly diagnosed in 2035 (projected figures)



4. Insight Economics with Leukaemia Foundation. (2019, p. 15). State of the Nation: Blood Cancer in Australia.



At 3, Ethan is a lovable big brother and cowboy who survived his childhood blood cancer #mylifecounts

THE IMPACT OF BLOOD CANCER

For the first time, the Report helps us understand the true scale of blood cancer in Australia, by analysing the impact of blood cancers collectively. What really stood out was the size of the problem:

- » Around 15,000 people are currently diagnosed every year with a blood cancer – that’s one person every 36 minutes. This is projected to rise to more than 36,000 people by 2035 (refer to the chart below for yearly predictions).
- » More than 110,000 people are living with a blood cancer in Australia today and up to 7,500 of them lose their lives each year, making blood cancers, collectively, one of the biggest causes of cancer death.

People living with blood cancer face significant challenges every day in accessing reliable best practice treatment and care. Their experience varies depending on where they live, and lives are being lost because of those inconsistencies, for example:

- » A 13% improvement in survival outcomes could be achieved by removing variations between metro-regional areas (5% difference in survival outcomes) and ensuring consistent use of evidence-based practice and treatment nationally (8% difference in survival outcomes).

The evidence in the Report for change is compelling and demonstrates there is a path towards achieving the goal of zero lives lost to blood cancer by 2035.

Projected growth in the number of people diagnosed with blood cancer each year⁵



5. Insight Economics with Leukaemia Foundation. (2019, p. 12). State of the Nation: Blood Cancer in Australia.

RIGHT NOW IN AUSTRALIA...



15,000
people are newly
diagnosed with
blood cancer each
year (or >40 per day)

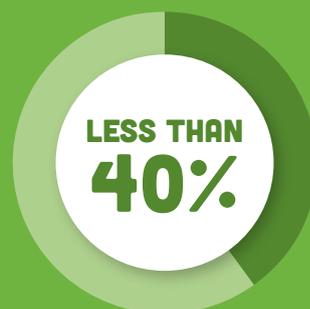
UP TO 7,500
people lose their life every
year, making blood cancer
one of the biggest causes
of cancer death

**MORE THAN
110,000**
people of all ages are
living with a blood
cancer today

FOR THOSE PEOPLE WITH BLOOD CANCER IN AUSTRALIA



access genetic and genomic
testing to inform their
diagnosis and treatment
planning



receive a written care plan
or are referred to patient
support services



participate in
a clinical trial



average difference in survival
outcomes between states and
metro/regional areas due to
treatment inconsistencies

AUSTRALIA IN 2035

If we don't act now, by 2035 many more Australians will die unnecessarily from blood cancer and the impact on the economy will be significant.

275,000

Australians will be living with a blood cancer in 2035

MORE THAN 186,000

people will die as a result of blood cancer between now and 2035

1.4 MILLION YEARS

of potential life will be lost by those 186,000 people

\$10.9 BILLION

is the expected annual cost to the health system in 2035 to treat and care for people with a blood cancer

2019
\$3.4
BILLION

2035
\$10.9
BILLION

\$71.9 BILLION

is the expected annual total cost of blood cancer to the Australian economy in 2035

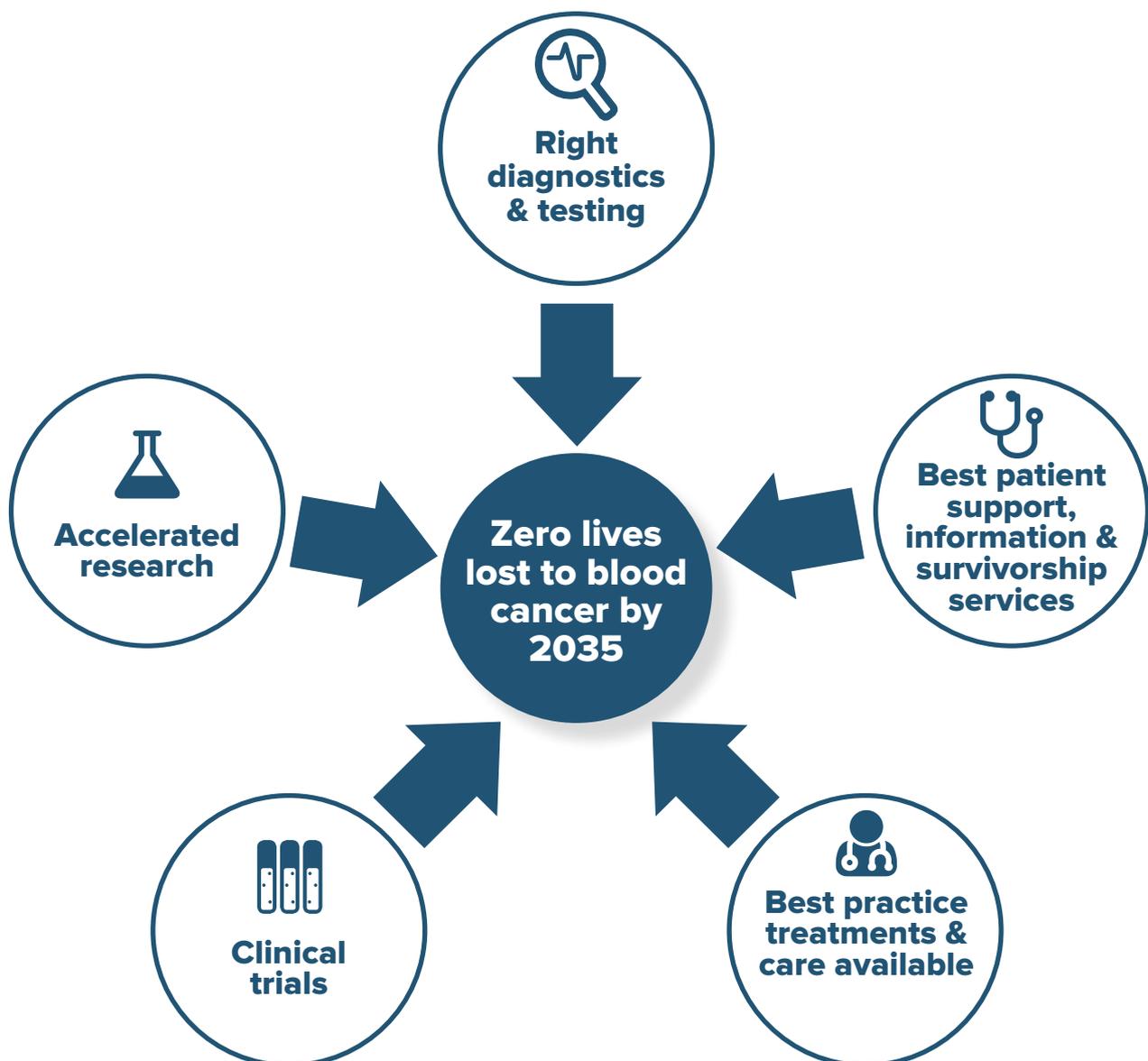
2019
\$22.9
BILLION

2035
\$71.9
BILLION

IT'S ALL ABOUT *Access*

Blood cancers, as a group, are amongst the most prevalent and deadly cancers affecting Australians today. They are also expensive to treat. We need to change this. Our goal is to save lives. To reach zero lives lost to blood cancer we need to ensure all Australians, regardless of where they live, have access to the best possible treatments, information and care.

The ***State of the Nation: Blood Cancer in Australia*** report provides us with a blueprint for action. It was clear from consultation with blood cancer experts and individuals living with a blood cancer that access is critical to conquering this disease. The Report provides meaningful ways to help people living with a blood cancer gain access to the best possible information, treatments and care, as well as prepare for future challenges.

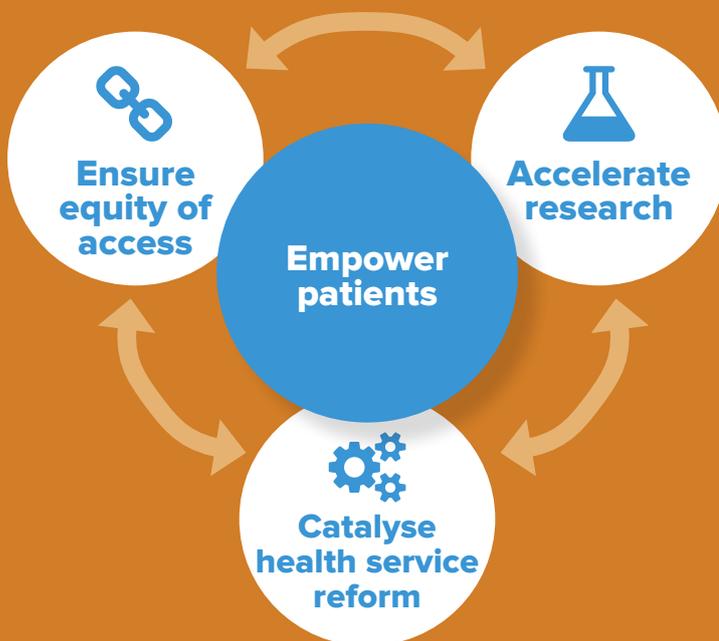


PRIORITIES FOR THE LEUKAEMIA FOUNDATION

A Way Forward

To reach zero lives lost and 100% access to best practice treatments, trials and services, we must prioritise how we move forward.

The *State of the Nation: Blood Cancer in Australia* shows us the opportunities to change survival outcomes for people living with blood cancer and improve their quality of life, identifying four priority areas. These are:



Each priority contributes to our goal of zero lives lost to blood cancer. Some we can **deliver** ourselves, some will need us to **partner** with the entire blood cancer community and others require us to **advocate** at a national level for change.

As the only national organisation that represents the needs of all people living with blood cancer in Australia, the Leukaemia Foundation will focus on leading actions to **empower patients** and address key changes, including:

- ✓ Advocating for access to new medicines on the PBS.
- ✓ Creating a 'one stop shop' for information on blood cancers.
- ✓ Developing new support services such as improved help with fatigue - one of the most debilitating side-effects of blood cancer.
- ✓ Advocating for policies to ensure access to new diagnostic tests and services.
- ✓ Supporting clinicians and scientists to undertake innovative research that drives rapid advancement in treatments, discovers new diagnostics and novel therapies, and enables Australian patients to access clinical trials.

These are just the first steps we will take to deliver, partner and advocate to save the lives of people with a blood cancer.

We've started delivering change

With our focus on actions to **empower patients**, the Leukaemia Foundation is already pushing ahead with policy reforms and projects to improve survival outcomes and wellness for people living with a blood cancer,

- ✓ We've appointed a **Blood Cancer Expert Panel** of leading experts on blood cancer in Australia, to help guide the policy discussion and put the voice of people with blood cancer at the forefront of policy change.
- ✓ Through our efforts, the Australian Government will establish a **Blood Cancer Taskforce**. This group of leading experts will deliver a **National Strategic Action Plan** for

blood cancer, with recommendations that will help shape government and health system policies and practices.

- ✓ New projects to provide better and more tailored support services for people living with blood cancer are underway, with the Leukaemia Foundation's **Inform Me** and **Cancer Concierge** programs launched in 2019.
- ✓ We are **investing and partnering in ground-breaking research**. This includes research for new therapies, preventing and treating the potentially deadly graft-versus-host disease (GVHD) and investing in technologies that support precision medicine, such as diagnostics and genomic screening.



Bill Petch, Leukaemia Foundation CEO with Professor Maher Gandhi, Mater Research CEO (Brisbane)

Improvements will make a big difference

Our research shows that more than **22,000 lives could be saved** between now and 2035 just by more consistently doing what has been proven to work and is already funded in Australia.

That means:

- » A 13% improvement in survival outcomes by removing variations between metro/regional areas (5% improvement in survival outcomes) and ensuring consistent use of evidence-based practice and treatment nationally (8% improvement in survival outcomes).

Our experts tell us that we could see a **potential reduction in deaths of up to a third** through new approaches to evidence development and the use of globally available best practice technologies.

Working in Partnership

WHAT WE ARE DOING IN 2019–20

The Leukaemia Foundation is committed to working in partnership with the blood cancer community and governments to make the necessary changes and ensure national leadership and coordination to improve blood cancer survival rates.

Key partnerships and advocacy discussions are already underway, including:

Government leadership

In 2019-20 we will work with the Federal government to establish a **Blood Cancer Taskforce**. For the first time, this Taskforce will bring together experts to deliver Australia's first **National Strategic Action Plan for Blood Cancer**, with recommendations for government and health system policies to help save lives and improve outcomes for people living with blood cancer.

Research partnerships

Since 2002, the Leukaemia Foundation has invested over \$50 million in blood cancer research. We support a range of pioneering research such as the Australian Genomic Cancer Medicine Program to expand the current program beyond solid tumours into blood cancer.

There is an increasing understanding that cancer is not one disease, but many, influenced by genetic mutations that affect disease development and treatment options.

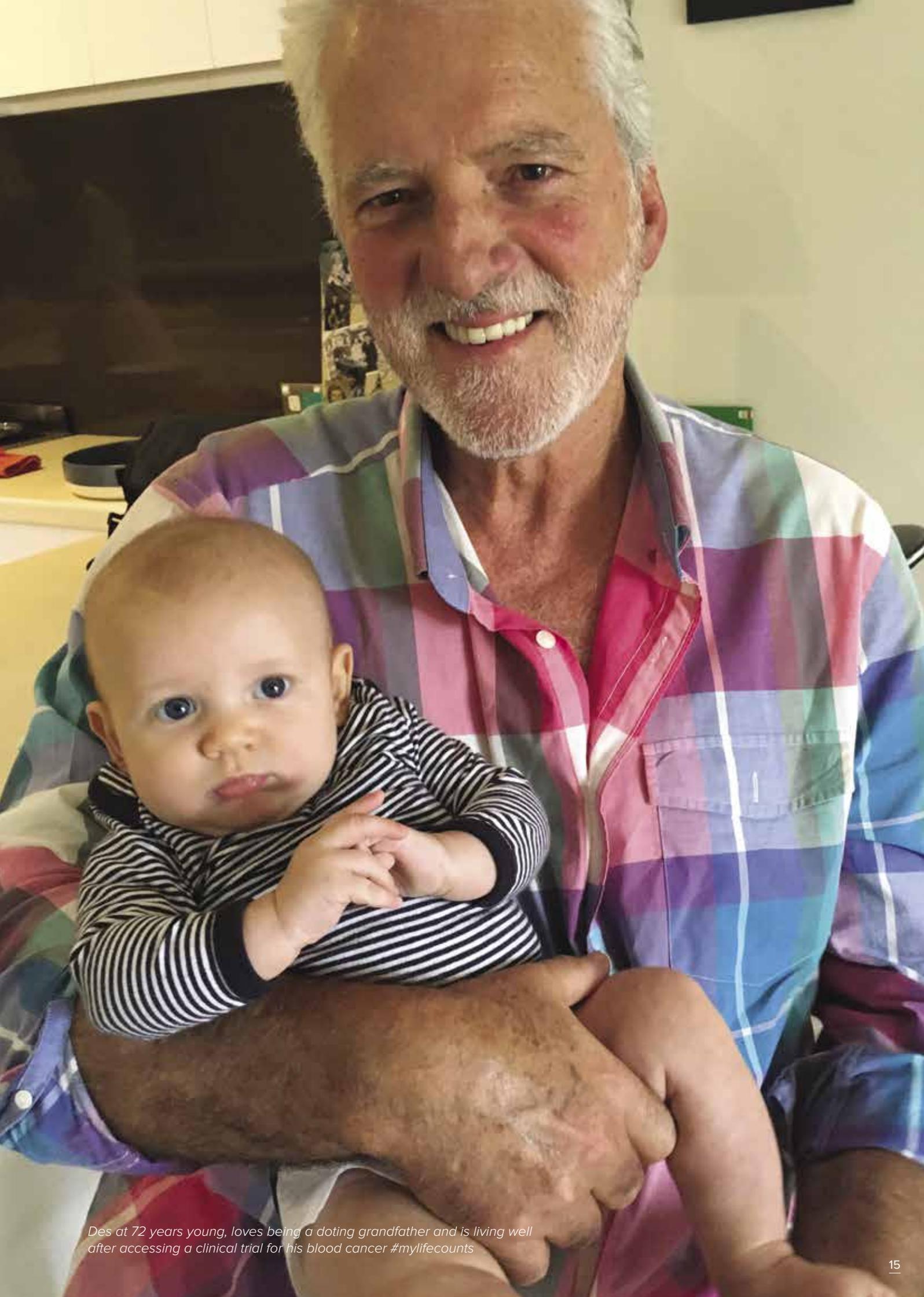
The transition to precision medicine, which targets specific changes in cancer DNA, while also taking into account genetic variations between individuals, brings challenges and opportunities.

A primary challenge, arising from an increasing understanding of the genetic basis for disease, is the fragmentation of patient populations into even smaller target markets. This may lead to delays in access to new therapies. Blood cancer patients have long understood this challenge, where medicines are not brought to market for their sub-type or are slow getting to market because their disease is 'rare' or 'less common.'

Blood Cancer Genomics Trial

Over 2019-21, in partnership with Tour de Cure, the Leukaemia Foundation will invest \$1.8 million to expand the Australian Genomic Cancer Medicine Program into blood cancers, working with the Garvan Institute in Sydney, SA Genomics (a multi-institutional alliance) in Adelaide and QIMR Berghofer in Brisbane.

Our research partnerships and investments will use genomics to improve the understanding, early detection, prevention and disease management for people living with blood cancer.



Des at 72 years young, loves being a doting grandfather and is living well after accessing a clinical trial for his blood cancer #mylifecounts



*Ultimately the path to conquering blood cancer requires us to work together and ensure **100% access** to the right information, the best treatments and services, and the latest trials, tests and diagnostic tools, to help people not just to survive - but also to live well.*

Bill Petch, Leukaemia Foundation CEO
September 2019

