evohealth

October 2025

TRANSFORMING LIVES

Making haemophilia B gene therapy a reality in Australia

Evohealth acknowledges that we work on the traditional lands of many Aboriginal clans, tribes, and nations.

We commit to working in collaboration with Aboriginal and Torres Strait Islander communities and peoples to improve health, emotional and social well-being outcomes in the spirit of partnership.

About **Evohealth**

The delivery of healthcare is complex.
Our focus is not.

Better health for all.

TRANSFORMING LIVES

Making haemophilia B gene therapy a reality in Australia

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ABOUT **THIS REPORT**

Background

Transforming lives: Making haemophilia B gene therapy a reality in Australia is an evidence-based report examining the social and economic burden of haemophilia B in Australia. It reflects on the evolution of treatment for haemophilia B since the 1950s to the present, and the impact felt by Australians with the disease and their families and carers. The report recognises that those with haemophilia B, through no fault of their own, carry a higher burden of disease and therefore have greater needs.

In striving for a fair and equitable healthcare system, the report identifies gene therapy as a promising step towards transformative care, offering not just hope for better outcomes, but the potential to reduce social and economic burden. It outlines three key recommendations to help prepare Australia for the implementation of gene therapy and improve the lives of people living with the disease and their families.

Approach

The report was independently prepared by Evohealth, a specialist health advisory firm, in partnership with an expert Advisory Committee. It was informed by a comprehensive review of published academic and grey literature, interviews with Australian clinicians, researchers and patient advocacy groups, and a cohort-based economic model.

ACKNOWLEDGEMENTS

Evohealth wishes to acknowledge the ongoing support from the individuals and organisations who contributed to this project, particularly those who shared their stories and experiences with haemophilia B.

We thank the Advisory Committee, whose perceptive input was critical to the development of this report. The committee comprised the following members:

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The statements in this report do not necessarily represent the individual views of each committee member and were not a result of a formal consensus process.

Funding for report was received from CSL Behring. To ensure independence of the final report, CSL Behring attended Advisory Committee meetings as observers only and did not participate in the development of this report.

EXECUTIVE **SUMMARY**

Haemophilia B is a rare, genetic disorder that turns even minor injuries into serious health risks. Due to the absence of clotting factor IX, haemophilia B makes it difficult for the body to stop bleeding once it starts, resulting in prolonged or sustained bleeding episodes. [1, 2] Managing these bleeds becomes a lifelong challenge, demanding constant care and vigilance. This can require treatment every week, where the missing clotting factor IX is replaced through regular intravenous (IV) infusions. [3]

Despite major medical progress and improvements in life expectancy, people with haemophilia B live with more complexity, limitations and uncertainty than most Australians. Their journey toward the quality of life their peers enjoy is not yet complete. We need to continue to prioritise treatments and care that match the scale and persistence of their burden.

Hope is now on the horizon. Gene therapy represents a turning point, a one-time treatment with the power to substantially reduce or eliminate the need for ongoing prophylaxis, lessen disease burden, and improve long-term health and wellbeing. [4] More than just symptomatic relief, gene therapy can offer freedom from the constant anticipation of bleeding, treatment routines, and medical limitations. [5]

With a recent funding recommendation made for gene therapy and more undergoing various phases of clinical trial, we argue that this is the moment to redefine haemophilia B care in Australia. This report sets out the clear need for action by tracing the evolution of treatment from past to present, and by sharing the lived experiences of people who have faced this condition for decades. Finally, we call for decisive action to deliver timely, fair, and equitable access to gene therapy – because people with haemophilia B deserve more than just managing their disease. They deserve the chance to move beyond it.

646 Australians living with haemophilia B in 2025, affecting **499 males** and **147 females**. [6]

$220,000 per person in direct healthcare costs **for severe haemophilia B** each year, 20x higher than those with mild disease. [6]

The lifetime cost of severe haemophilia B is estimated to be **$32 million per person**, double that of moderate cases, and 8x higher than mild cases. [6]

The productivity loss for people with haemophilia B is **$6.4 million in 2025**, and **$6.7 million** for carers of people with severe disease. [6]

What is haemophilia B?

Haemophilia B is a genetic disease that results in a deficiency or absence of clotting factor IX. Without it, the blood clotting process is disrupted, leading to prolonged bleeding after injury or surgery, and spontaneous internal bleeds. [1, 7] Long-term joint damage, chronic pain, loss of mobility, disability and life-threatening complications can occur without effective and timely treatment. [1, 7]

While most cases of haemophilia B are diagnosed at birth or within the first 12 months of life, others go undetected until adolescence or adulthood. [8, 9] Disease severity leads to vastly different experiences of living with the disease, managing treatments, and physical, psychosocial and practical challenges. [10] While treatments are effective in controlling bleeds and limiting additional symptoms, they are not curative. As a result, people with severe haemophilia B require weekly preventative treatment, or prophylaxis, over their lifetime to manage the risk of spontaneous and life-threatening bleeds. In contrast, those with mild disease experience little change to their daily life and might only require infusions as needed. [2, 3]. In Australia, there are 362 individuals living with mild disease, 153 individuals living with moderate disease, and 131 individuals living with severe disease. Each of these 646 individuals will navigate lifelong disease and treatment burden. [6]

> *The dream for those with bleeding conditions is a future free from bleeds and pain, made possible by curative treatments.*
>
> **– David Stephenson, advocate for individuals affected by bleeding conditions**

To understand the need for timely implementation of gene therapy in Australia, it's necessary to understand the evolution of treatments and challenges faced by the haemophilia B community. From the contaminated blood crisis in the 1970s to the development of factor replacement therapies, innovation has improved substantially. With gene therapy now on the horizon, the time has come to take a bold step into the future.

Early patient experiences: surviving, not thriving

Throughout the 20th century, treatment of haemophilia B was focused on survival. The average life expectancy in 1960 for a person with severe haemophilia B was less than 20 years, with treatments administered reactively after bleeds had commenced. [11] While self-infusion of plasma-derived factor IX concentrates in the 1970s offered some relief, this was soon overshadowed by a devastating contaminated blood crisis. As a result of contaminated blood, many with haemophilia B acquired human immunodeficiency virus (HIV), hepatitis B, or hepatitis C, with the associated morbidity and mortality. [11] Even after the introduction of safer products, treatment remained reactive and burdensome for many.

The constant of today's prophylaxis treatment

Today, haemophilia B is more manageable, with bleeds able to be prevented or treated at home via factor IX replacement therapy. [12] Life expectancy is now aligned with the general Australian population, and those with the disease can lead full, more independent lives than previous generations. [2] However, the burden of managing this complex and lifelong disorder remains.

Despite prophylaxis treatment, breakthrough bleeds into joints and muscles continue to occur, compounding pain, joint damage, mobility restrictions and disability. The constant requirement for treatment imposes a mental and emotional toll requiring constant planning, adjustment, consideration, and care. These repeated treatments can lead to vein damage, scarring and access challenges, particularly for young children and older adults. [13]

Throughout the lifespan of a person with haemophilia B, these practical challenges touch nearly every aspect of daily living. From a young age, medical appointments, bleeding episodes or treatment disrupts participation in school and sports. In adulthood, physical activity, career choices and travel opportunities can be limited. [14] At all ages of life, careful planning is required to ensure treatment supply is sufficient and safely stored. This shapes life decisions in ways others rarely consider.

The impact of this burden extends beyond the individual. Carers and family members also require time away from work to manage both planned and unplanned treatment needs, leading to lost productivity. Evohealth modelling shows that these productivity losses rise significantly with disease severity. In 2025, carer productivity loss for severe haemophilia B is estimated at $20,000 per person, compared with $5,500 for mild disease. [6]

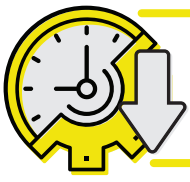
> *"Over the last year, we've been to the emergency department six to eight times, each time with an overnight stay. Sometimes it's twice a month. We've had to take over a month's worth of leave without pay. I have to take half a day off every Friday to drive our son down to the hospital for his infusion – he also misses half a day of school every Friday this year."*
>
> **– Kara and Mark, parents of son with severe haemophilia B**

Beyond productivity loss, the aggregate cost of severe haemophilia B over the lifespan can reach $32 million per person by age 83. [6] This underscores the cumulative impact of this disease and highlights the potential to significantly reduce the overall burden.

There is a need for a more equitable approach to care, one that recognises the lifelong challenges faced by people living with haemophilia B and ensures they can access innovations that provide meaningful relief and a better future.

Direct healthcare costs of $48.1 million in 2025, 87 per cent of which stem from treatment costs. [6]

Lifetime cost of severe haemophilia B can reach **$32 million per person** by age 83. [6]



Productivity loss for severe haemophilia B of **$19,000 per person** annually. [6]

Productivity loss for carers of severe haemophilia B of **$20,000 per person** annually. [6]

Embracing innovation

Despite the availability of effective treatments, significant challenges remain. Even with the best available care, the physical, psychosocial and practical needs of people with haemophilia B persist. [10] Achieving equity in care for people with haemophilia B means recognising the higher burden they face and providing access to innovation that can meaningfully reduce it. Gene therapy is this innovation: offering not just a clinical breakthrough, but a chance to reshape what life with this condition looks like. It offers the hope of freedom from regular infusions, constant planning, and the ever-present risk and fear of bleeding.

Gene therapy is delivered via a one-time infusion of a functional F9 gene, which enables the body to produce its own factor IX. This is a fundamental shift in treatment, moving toward a possibility of long-term bleed control and unlocking improvements to physical and psychosocial health, and quality of life. While the cohort is small, the body of evidence grows: a recent 13-year follow-up study demonstrated a reduction in bleeding episodes from 14 to just 1.5 per year, with some participants reporting no bleeds at all. [15]

Evohealth modelling estimates that if all adult Australians with severe haemophilia B were treated with gene therapy, the direct, indirect and societal costs of disease would fall from $31.1 million to just $1.2 million each year. This would reduce the national cost of haemophilia B by $27.1 million annually, equivalent to a 33 per cent reduction in the overall economic burden. [6]

Globally, gene therapy development for haemophilia B is advancing, with multiple therapies in different stages of research and use. In Australia, a major step was taken recently with a positive funding recommendation from the Medical Services Advisory Committee (MSAC) for Hemgenix®, a gene therapy for adults with haemophilia B. [16] Translating this recommendation into equitable patient access is critical to reducing the lifelong burden of the disease. Swift and effective implementation is now needed to meet the needs of people with haemophilia B and offer them a different future – one not defined by infusions, pain, or limitations.

> *Gene therapy offers the very real possibility of relieving a haemophilia B patient's burden of both disease and treatment, with a likelihood of a sustained benefit for years to come. It is truly life-changing, transformative therapy.*
>
> **– Dr Chee Wee Tan, Haematologist**

Transforming lives and reshaping care

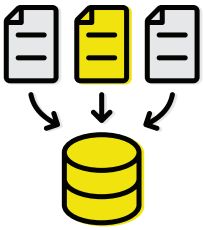
To progress quickly and prepare for the implementation of gene therapy for haemophilia B in Australia, barriers within the healthcare system must be urgently addressed. While the community is already actively engaged, a coordinated and well-resourced national effort is essential to ensure this transformative technology reaches those who need it most.

To pave the path forward for Australia's haemophilia B community, we propose the following three recommendations.

RECOMMENDATION 1

Fast-track implementation of Recommendation 16 from the Health Technology Assessment (HTA) Review to ensure innovative therapies are accessible as soon as possible.

Australians with rare and genetic diseases need access to innovative therapies to achieve equitable treatment and quality of life outcomes. [17] Recent progress has been made with a positive funding recommendation of Hemgenix®. The challenge is now to ensure bottlenecks in negotiation and funding do not slow translation of this recommendation into patient access. [16] Work is needed to ensure short-term transformative therapies, such as Hemgenix®, can be brought into the hands of patients as soon as possible. Recommendation 16 of the HTA Review calls for a new framework to facilitate timely access to high-cost, high-impact treatments. [18] Urgent implementation is needed to ensure Australia can provide patient access to innovative therapies fairly and deliver on the promise of innovation for those with haemophilia B and other rare diseases.



RECOMMENDATION 2

Implement sustainable data systems to enable gene therapy monitoring and support evidence-based care.

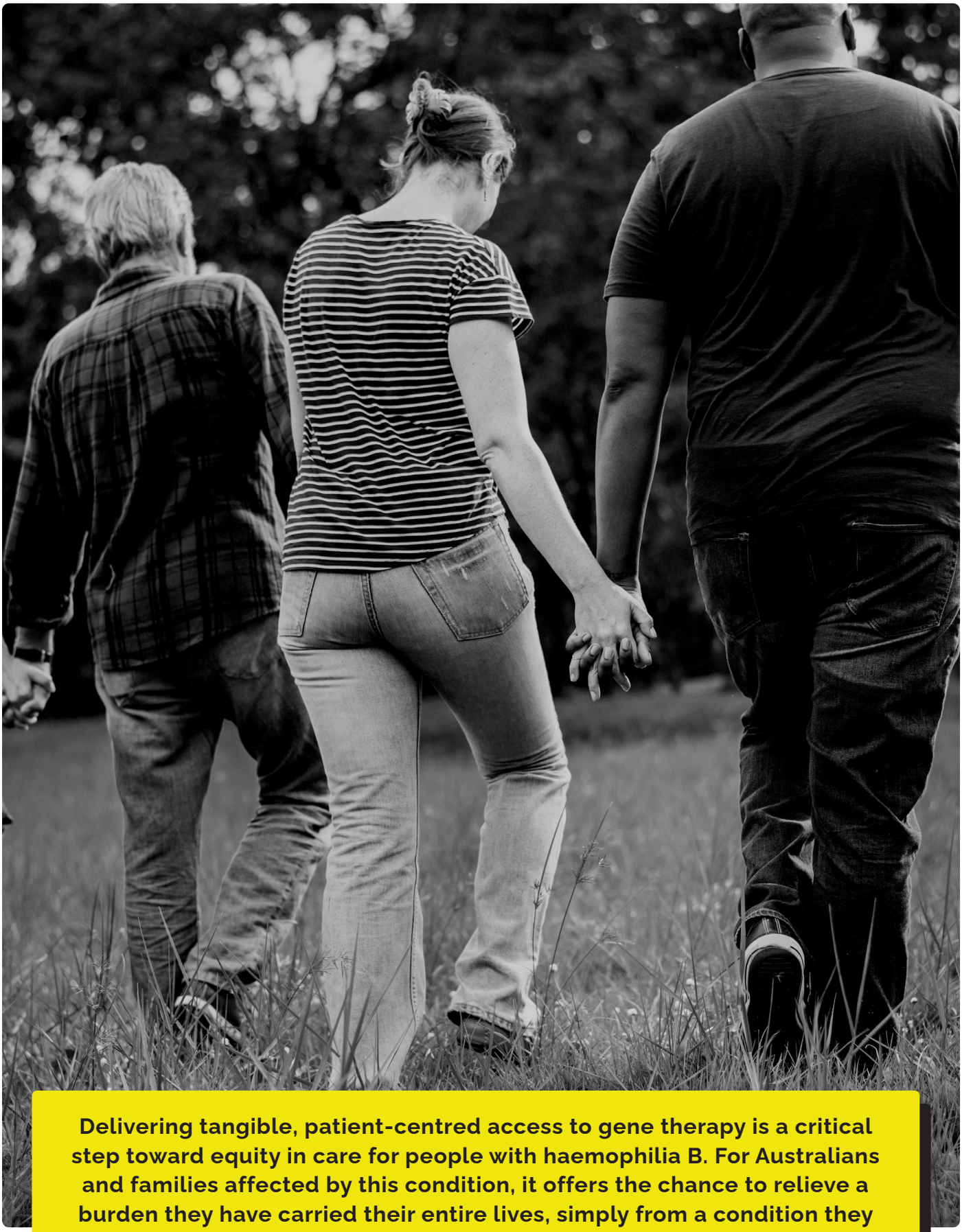
Gene therapy requires long-term monitoring to assess outcomes, manage risks, and guide future care. At a minimum, updating the national Australian Bleeding Disorders Registry (ABDR) with gene therapy-specific data fields and capabilities will be necessary to enable collection of real-world data. Enhancing the registry now will prevent delays in patient access, support generation of real-world evidence for efficacy and safety, and enable global data sharing. As the custodians of this registry, the National Blood Authority (NBA) are well placed to lead this work and ensure Australia's monitoring systems remain world-class, supporting safe, effective, and evidence-based gene therapy delivery.

RECOMMENDATION 3

Increase funding to deliver wraparound care for people living with haemophilia B.

The development of equitable, person-centred wraparound care is necessary to ensure appropriate support is available once gene therapy is implemented. Progress has already been made. In 2022, the Australian Haemophilia Centre Directors' Organisation (AHCDO) published a comprehensive clinical implementation plan for gene therapy. [19] Leveraging Australia's Haemophilia Treatment Centres (HTCs), where support for people living with haemophilia B naturally occurs, funding is required for this plan to be fully realised.

Alongside this work, development of accessible, evidence-based resources is needed to support informed decision-making. Haemophilia Foundation Australia (HFA) are developing these materials, in collaboration with AHCDO. Yet further investment is needed to scale access. [20] Strengthening funding for AHCDO, HTCs and HFA is essential to support wraparound care, that is comprehensive, co-ordinated and continuous, remains available throughout the treatment journey.



Delivering tangible, patient-centred access to gene therapy is a critical step toward equity in care for people with haemophilia B. For Australians and families affected by this condition, it offers the chance to relieve a burden they have carried their entire lives, simply from a condition they were born with. Our three recommendations provide a clear path forward to make this possibility a reality, enabling a quality of life equal to other Australians. The time for action is now.

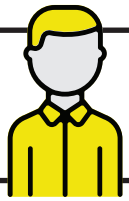
In 2025, **646 Australians** are estimated to be living with haemophilia B, equal to a rate of **2.4 per 100,000 people.** Of those diagnosed:

56% have mild disease (362 individuals)

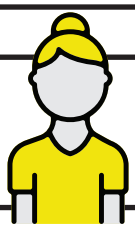
24% have moderate disease (153 individuals)

20% have severe disease (131 individuals)

Haemophilia B primarily affects males.

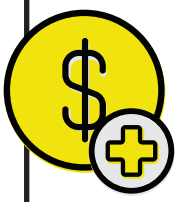


499 males diagnosed, or around 1 in every 25,000.



Among **females, 147 are diagnosed**, or around 1 in every 86,000 women.

In 2025, the total annual cost of haemophilia B in Australia is estimated at $81.6 million. This includes:

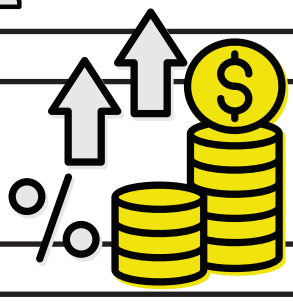


$48.1 million is spent on direct healthcare costs, with 87 per cent of this going towards treatment alone.

$13.3 million in indirect costs, such as productivity loss for people with haemophilia B and their carers or family members.

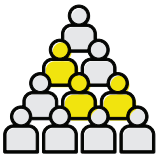
$20.2 million in societal costs, including disability burden.

Costs rise significantly with severity, including per-person direct costs that are **20x higher for severe disease** than mild, and a lifetime cost 8x greater for severe cases than mild.



By 2050, the number of people living with haemophilia B in Australia is **projected to rise to 892**, increasing at an average of 1.27 per cent each year.
This includes:

500 with mild disease



212 with moderate disease

180 with severe disease

With no change to the standard of care, the annual cost is projected to **increase to $108.5 million by 2050**, driven by rising prevalence and an ageing cohort.

If all Australian adults (aged 20+) with severe haemophilia B received gene therapy, the shift into mild, moderate, and non-haemophilic disease states would leave **only 37 people with severe disease**, 33 of whom are aged under 20.

This could result in in net **annual savings of $27.1 million dollars**, representing a 33 per cent reduction in the economic burden of haemophilia B in Australia.[1]

Source: [6]

[1] These estimates reflect potential cost offsets only and do not include the cost of delivering gene therapy.

THE HAEMOPHILIA B JOURNEY: **DIAGNOSIS, TREATMENT, AND HOPE**

What is haemophilia B?

Haemophilia B is a rare, lifelong genetic bleeding disorder caused by a deficiency or absence of clotting factor IX, a protein essential for normal blood clotting. Without this protein, the clotting process is disrupted, leading to prolonged bleeding after injury or surgery. In more severe cases, spontaneous internal bleeding can also occur. [1, 7]

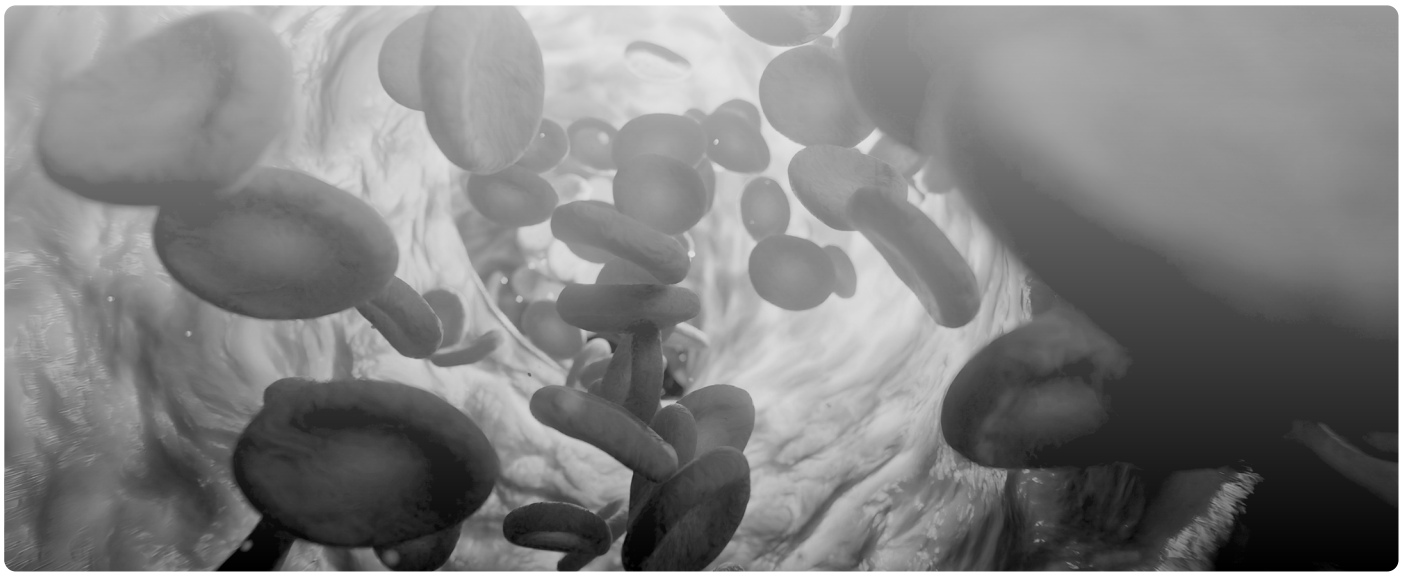
People with haemophilia B do not bleed more heavily than others, but they bleed for longer. Without timely and effective treatment, this can result in bleeding into joints and muscles, chronic pain, long-term joint damage, and potentially life-threatening complications, such as bleeding in the brain and gastrointestinal tract. [1, 7]

Two types of haemophilia

There are two main types of haemophilia, each caused by a deficiency in a different clotting factor:

- **Haemophilia A, or classic haemophilia:** Caused by a deficiency of **factor VIII**. This is the more common form, affecting about 80% of people with haemophilia. [21]
- **Haemophilia B, or Christmas disease:** Caused by a deficiency of **factor IX**. It is less common but managed similarly in the treatment approach. [21]

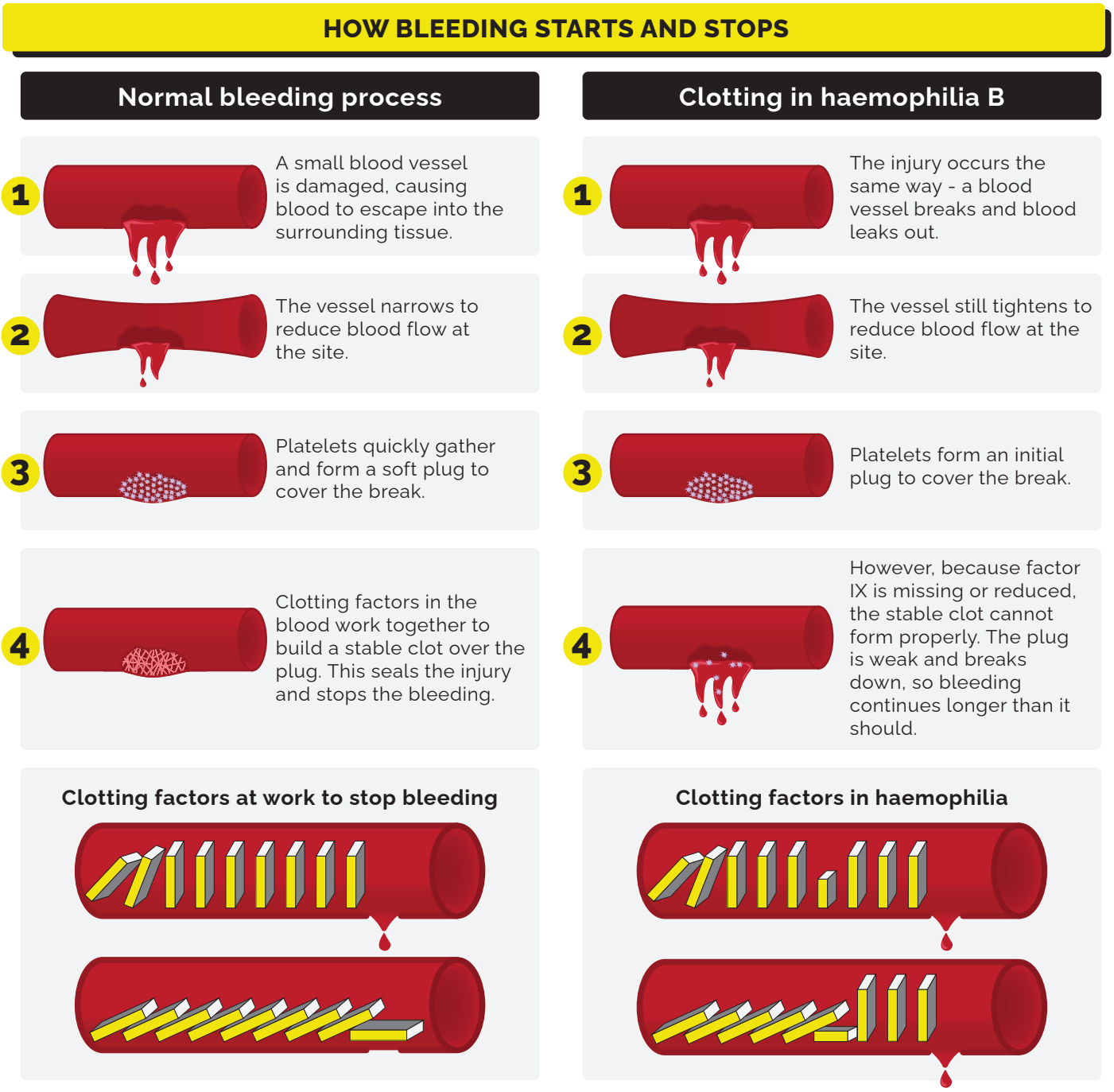
This report focuses on haemophilia B.



How blood normally clots

When a blood vessel is injured, the body activates a complex process called haemostasis to prevent excessive bleeding. [22] This involves activation of clotting factors, which are proteins in the blood that work like dominos in a chain reaction. If one is missing or not working properly, as with factor IX in haemophilia B, the cascade is disrupted, and the clot can not form effectively. [2] This difference in the clotting process is illustrated in Figure 1.

Figure 1: Comparison of the clotting process in individuals with normal factor IX levels and those with haemophilia B



Source: Evohealth, adapted from [2]

What causes haemophilia B?

Haemophilia B is caused by a mutation in the F9 gene, which provides instructions for making clotting factor IX. [2] It is usually inherited in an X-linked recessive pattern, as shown in Figure 2, meaning it primarily affects males. Females who carry the gene may also have low factor IX levels and experience bleeding symptoms; they are known as symptomatic carriers. In around one-third of cases, the mutation occurs spontaneously, with no known family history. [1, 2] In 2025, haemophilia B affects 646 people in Australia, a prevalence of 2.4 per 100,000. [6]

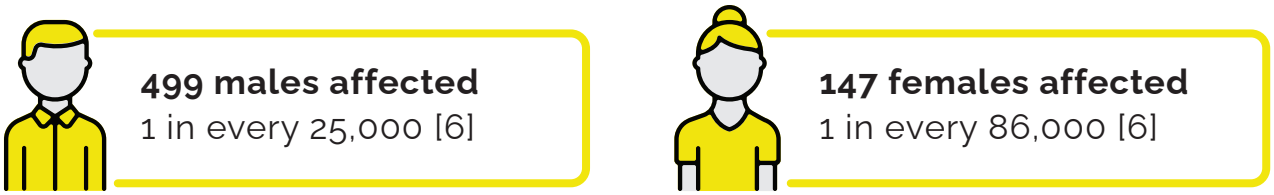
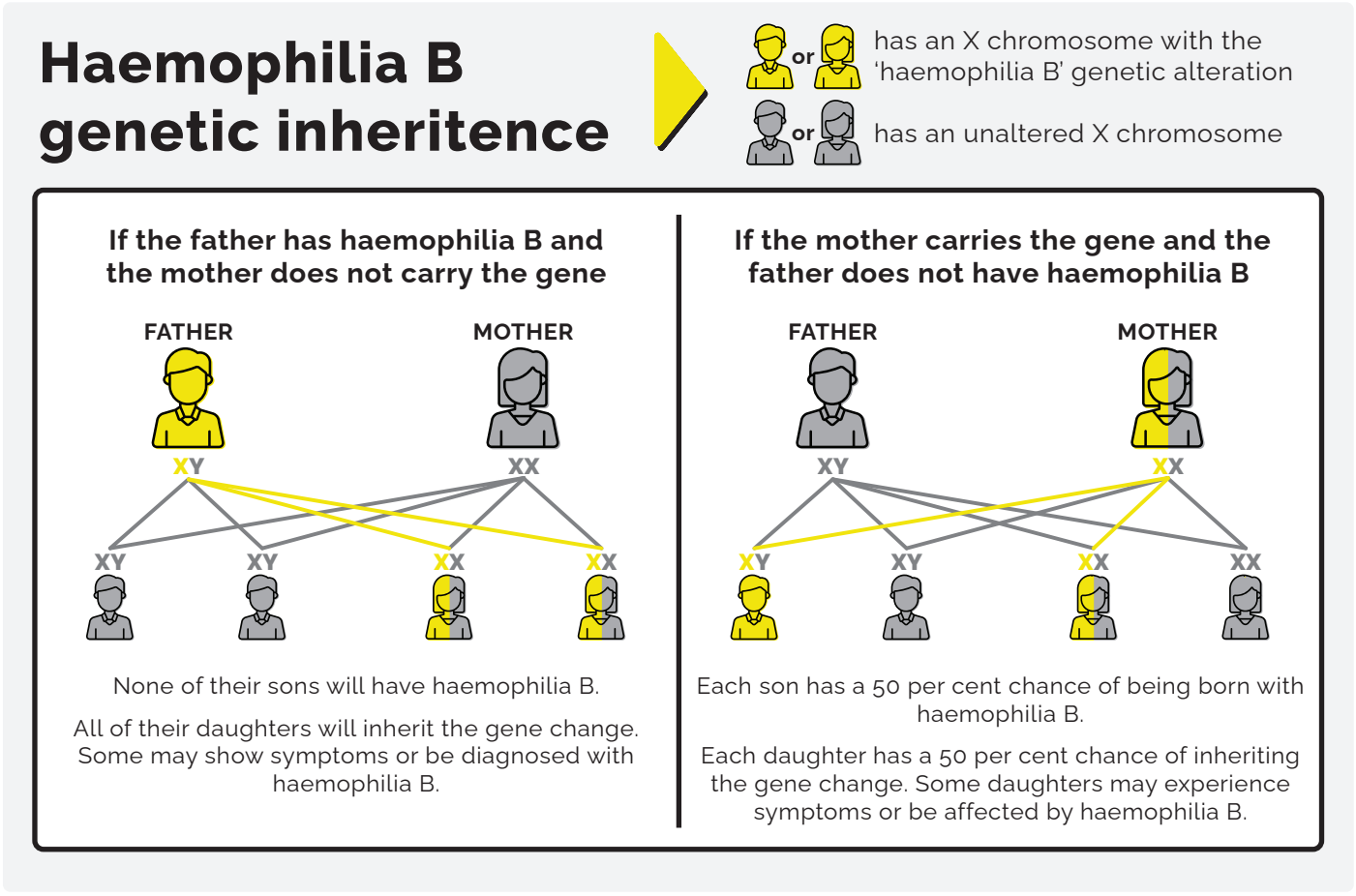


Figure 2: Inheritance of haemophilia B



Source: Evohealth, adapted from [2, 6]

Spectrum of severity

The severity of haemophilia B is determined by the amount of clotting factor IX in the blood, which has important implications for daily life and ongoing management. Table 1 illustrates how experiences differ across severity levels. Individuals with severe haemophilia B will always experience symptoms and require continuous treatment under the current standard of care. [2]

Regardless of severity, repeated bleeding, particularly into joints, can cause progressive joint deterioration, leading to chronic pain, loss of mobility, and disability if not adequately managed. [2, 23]

Table 1 Haemophilia B severity classifications and typical bleeding patterns

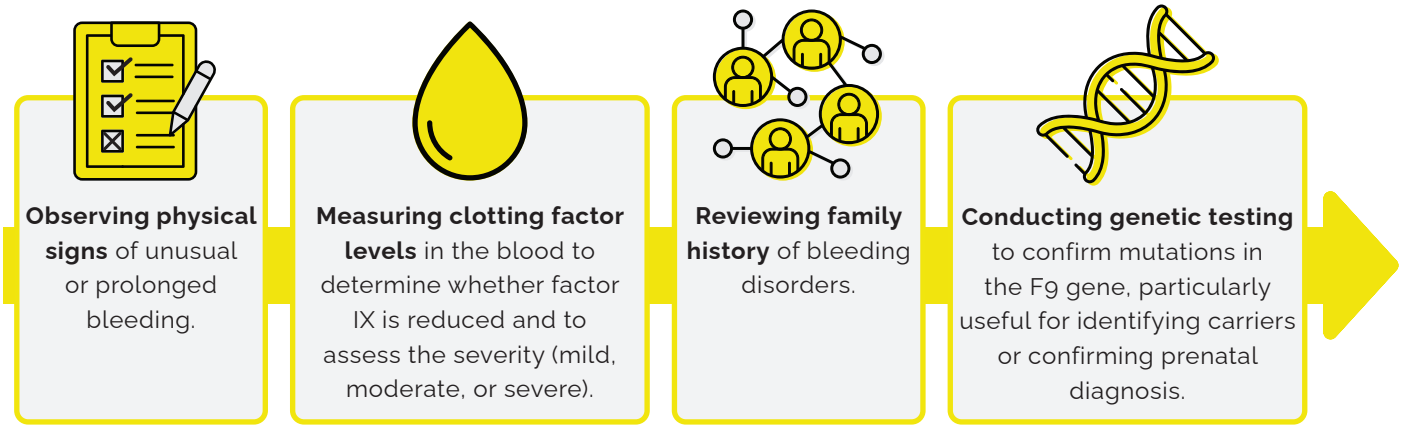
Severity	Factor IX activity	Prevalence (per cent of total cohort)	Bleeding patterns
Mild 	5 - 40 per cent	362 individuals (56 per cent)	• Bleeding usually only occurs after significant trauma, surgery, or dental procedures. • Day-to-day life is often unaffected, with little to no spontaneous bleeding. • Many individuals remain undiagnosed until an event, such as surgery or injury, triggers abnormal bleeding.
Moderate 	1 - 5 per cent	153 individuals (24 per cent)	• Occasional spontaneous bleeding, especially into joints and muscles. • Bleeding can also occur with minor injuries or medical procedures. • Without appropriate treatment, joint damage may accumulate over time, leading to pain, reduced mobility, and long-term complications.
Severe 	Less than 1 per cent	131 individuals (20 per cent)	• Frequent spontaneous bleeding, often without any clear cause, particularly into joints, muscles, and soft tissues. • Leads to painful swelling, joint damage (haemophilic arthropathy), and chronic pain. • Without effective management, there is a high risk of disability and potentially life-threatening bleeds, such as in the brain or internal organs.

Source: Adapted from [1, 2]

How and when haemophilia B is diagnosed

Haemophilia B is typically diagnosed via a combination of clinical assessment, blood tests, and, when relevant, genetic testing. [8] Diagnosis may be prompted by signs of unusual bleeding or bruising, or it may occur through proactive testing in families with a known history of the condition. [8, 9]

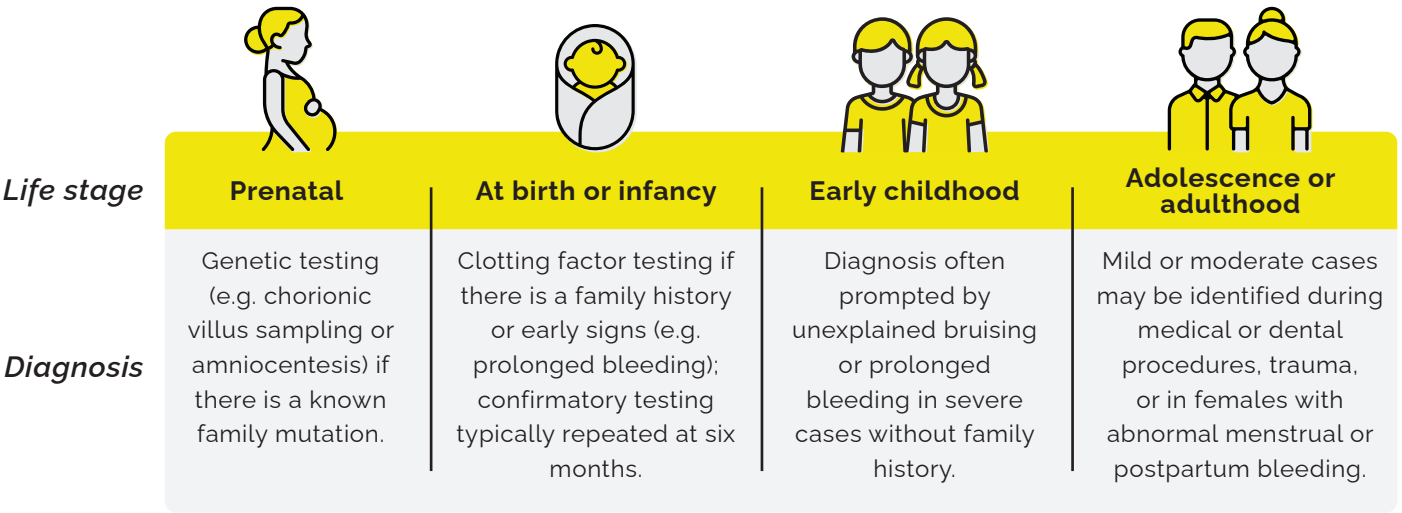
The key steps in diagnosis include: [8, 9]



The timing of diagnosing haemophilia B can vary significantly based on the severity of the condition and known family history.

Figure 3 illustrates how diagnosis can occur at various life stages, depending on symptom severity and individual circumstances.

Figure 3: Diagnosis at different life stages



Source: Adapted from [2, 8, 9]

Current treatment approaches

Treatment for haemophilia B is through factor IX replacement therapy to help prevent or control bleeding. [2, 3] Today, most people use recombinant factor IX products, which are synthetic forms of the clotting factor. [3] These approaches are explored further later in the report.

Current treatments are effective at preventing most bleeds, however, they are not curative. Care remains lifelong and is supported by haematologists, nurses and allied health professionals at HTCs across Australia. [3]

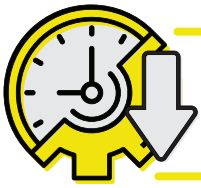
The ongoing burden of haemophilia B

Despite its rarity, haemophilia B imposes a significant toll on individuals, families, and the healthcare system. Evohealth modelling estimates that in 2025 alone, the total cost of the disease in Australia is $81.6 million, comprising $48.1 million in direct healthcare costs (87 per cent of which is from treatment), $13.3 million in indirect costs such as lost productivity, and $20.2 million in societal burden, including years lived with disability. [6]

Because current treatments allow people with haemophilia B to have a near-normal life expectancy, these costs accumulate over a lifetime. For an individual living to the Australian average of 83 years, the lifetime cost of severe haemophilia B is estimated at $32 million, compared to $16.9 million for moderate disease and $4.2 million for mild. If the current standard of care remains the only option, total costs are projected to rise as prevalence increases, reaching 892 people by 2050, with an estimated total burden of $108.5 million. [6]

Haemophilia B represents a **total economic burden** to Australia of **$81.6 million annually.** [6]

$48.1 million in direct healthcare costs, **87 per cent** of which is from treatment. [6]



$13.3 million in indirect costs, including **lost productivity.** [6]

$20.2 million in societal burden, including **years lived with disability.** [6]

Future outlook: The promise of gene therapy

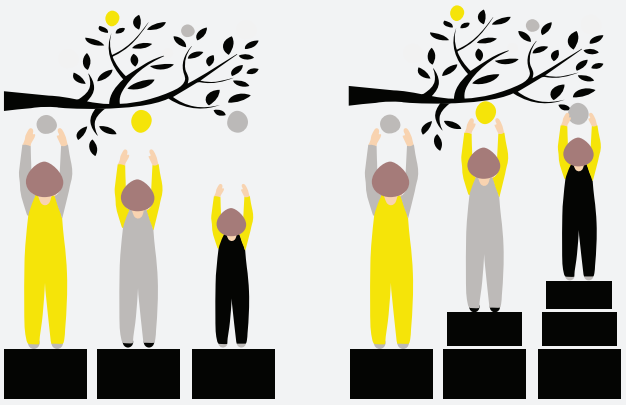
Gene therapy offers a transformative shift in haemophilia B treatment. [4] By delivering a functional copy of the F9 gene, it enables the body to produce its own clotting factor IX, potentially eliminating the need for ongoing prophylactic treatment. [5, 24] For many, this offers freedom from the constant anticipation of bleeding, the demands of regular infusions, and the constraints of lifelong management.Research and clinical development are advancing globally, with multiple therapies in different stages of investigation and clinical use.

In 2025, the MSAC issued a positive funding recommendation for Hemgenix® for adults with haemophilia B. [16] While this milestone is critical, the therapy will only become available once funding is formally approved and implementation pathways are established. If delivered, it will be the first and only gene therapy for haemophilia B accessible through the Australian health system, creating a tangible pathway to reduce the lifelong burden of the disease, improve quality of life, and deliver lasting health benefits. Rapid, coordinated action is now essential to ensure all people with haemophilia B can access the therapy without delay.

Equity of access: Acting on the opportunity

Evohealth's reports, *Cell and Gene Therapies: Rising to the Challenge (2021)* and its follow up *Cell and Gene Therapies: Rising to the Challenge Scorecard (2023)*, highlighted the urgent need for nationally coordinated action to ensure equitable access to emerging cell and gene therapies (CGTs) in Australia. [17, 25] These findings reinforce a foundational principle: equity must be prioritised in healthcare, with interventions weighted toward those with the greatest need. Australians recognise that some groups require more support than others - a principle embedded in national policies such as safety nets, concession schemes, and progressive taxation.

For haemophilia B, the MSAC recommendation creates a pathway to transformative care, but benefits will only be realised if the system acts swiftly. Translating this decision into real-world access requires coordinated effort across health services, clinicians, and policymakers, keeping the needs of people with haemophilia B at the centre. Equitable implementation can finally reduce the lifelong burden of the condition and deliver a fundamentally different future for those affected.



We know that society is willing to pay more to make the distribution of health more even.

Haemophilia care has been shaped by decades of milestones and challenges, with each step contributing to meaningful progress. Yet none are as consequential for individuals, carers and our healthcare system as gene therapy. Tracing the evolution of haemophilia B treatment highlights just how transformative gene therapy can be. The following chapters explore the evolution of treatment over time, the realities of living with haemophilia B today, and how gene therapy could reshape life for Australians with the condition.

THE PAST: **MILESTONES AND LIMITATIONS IN HAEMOPHILIA B TREATMENT**

The historical treatment landscape

The treatment of haemophilia B has evolved remarkably over the past century. Early approaches offered only temporary relief, leaving individuals at high risk of complications, disability, and early mortality. [12] Each decade has brought improvements in safety and quality of life, as outlined in the timeline below. However, key challenges remain: achieving consistent bleed control, reducing treatment burden, and preventing long-term complications. [12, 26]

Pre-1960s
Whole blood and plasma transfusions

Before clotting factor concentrates, treatment relied on transfusions of whole blood or plasma delivered in hospital. These were insufficient to prevent or treat serious bleeds. Joint bleeds and urgent care visits were common, and frequently led to irreversible joint damage, chronic pain, and long-term disability. [12, 26, 27] Life expectancy for a person with severe haemophilia B was 20 years of age, or less. [11]

1970s
Plasma-derived factor IX concentrates

The introduction of plasma-derived factor IX concentrates was a turning point. Self-infusion at home was possible and offered greater independence and earlier intervention. However, early products were not treated to inactivate viruses, leading to the contaminated blood crisis. Thousands worldwide contracted life-threatening HIV and hepatitis C infections. [12, 26, 27] Up to 90 per cent of the Australian haemophilia community were infected with hepatitis C, and at least 250 people with haemophilia A or B were infected with HIV. [28]

1980s
Virus-inactivated plasma-derived factor IX

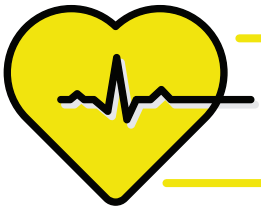
In response, virus-inactivated plasma-derived factor IX products became available. The risk of transmitting infections reduced significantly, improving treatment safety. However, dependence on plasma donations limited supply. [12, 26, 27]

1990s to today
Recombinant factor IX concentrates

Recombinant factor IX development was a breakthrough. As the first treatment not derived from human or animal plasma, the risk of blood-borne infections from treatment was eliminated. Reliance on hospital-based care was further reduced, as recombinant products offered a safer, more reliable treatment option. Yet, despite these advances, treatment today still requires regular infusions. [12, 26, 27]

Early patient experiences: surviving, not thriving

For much of the 20th century, living with haemophilia B was surviving, not thriving. The limited treatments available were reactive rather than preventative, typically administered after a bleeding episode had already caused damage. [11] People with severe haemophilia B frequently experienced repeated joint and muscle bleeds from a young age, leading to progressive joint damage, chronic pain, and permanent disability. [26]



In 1960, the life expectancy for a person with severe haemophilia was estimated to be **under 20 years of age.** [11]

Childhood and adolescence were often marked by long hospital stays, missed school, social isolation, and restrictions on physical activity. Families lived with constant anxiety about the risk of injury or spontaneous bleeds, and many parents had no choice but to become full-time carers. [12, 26]

The contaminated blood crisis of the 1970s and 1980s brought devastating consequences. Many Australians contracted HIV and/or hepatitis C, with life-altering impacts on health and wellbeing. [11, 26] Even after the introduction of safer recombinant products, treatment was still reactive, rather than preventative. [12] The heavy burden of regular infusions remained, particularly for children who required painful vein access multiple times a week. For some, treatment fatigue led to suboptimal adherence, increasing the risk of complications from bleeds. [12, 26]

Throughout this period, care focused on survival. Quality of life was secondary to managing immediate risks. [11] This is described vividly by Helen, who lived through these challenges while trying to raise and care for her son with haemophilia B.

Today's treatment landscape has been shaped by these lived experiences. Every breakthrough, from plasma-derived products to recombinant therapies, builds on the strength and hardship of the haemophilia B community.

Medical advances have turned haemophilia B from a life-threatening condition into one that can be managed. Safety and independence have improved, but treatment still carries a lifelong burden. Now, with gene therapy on the horizon, a future beyond this burden is in sight.

Helen's story: Living through the challenges of early haemophilia B treatment

Helen's son was diagnosed with severe haemophilia B in the late 1960s, when treatment was limited, unpredictable, and reactive. With no family history of the condition, the diagnosis came as a complete shock. Managing her son's condition quickly became a constant, enormous and exhausting priority of daily life.

In early years, treatment was only available in hospital settings and only administered after a bleed had already started. Frequent joint and muscle bleeds were common, leading to pain, long-term joint damage, and time-consuming hospital visits at any hour of the day or night.

"Frequently, it was the middle of the night," Helen recalled. "A small child plays during the day, does something that causes a bleed, and by 1 am it's a full-on bleed. You jump in the car and go to hospital. It had a very detrimental effect on our lifestyle."

The burden on the family was significant. School, work, and daily routines were constantly interrupted. Beyond the physical challenges, there was an emotional toll, particularly an overwhelming sense of guilt. "It was very difficult to watch your child suffer and be helpless to do anything about it," Helen explained.

Like many mothers of that time, she wrestled with the fear that the condition was somehow her fault: "I knew a lot of other mothers, because we had to go into the hospital so frequently, and we often spoke about the guilt we felt. Whether this problem came from a family history, or a mutation. When our brave little boy was suffering, I felt so guilty, and that feeling was universal for every mother I spoke to."

The introduction of home treatment improved family life considerably, but it came too late to prevent the long-term damage to joints. And just as the community was adjusting to this progress, the contaminated blood crisis struck.

"At a time when we thought treatment was manageable, around 25 per cent of the haemophilia A and B community died from AIDS. Because of the genetic link, so many families lost one or more members. The worst I heard of lost four boys," Helen recalled. "So many mothers felt dreadful, because they had administered the treatment to their child, and it killed them. I'll never forget the heartbreak I witnessed, and I'll never properly get over it. Certain songs come on the radio and I burst into tears… those were the songs from the many funerals I attended."

The crisis devastated the haemophilia community. Many families lost children, siblings, and friends. Nearly every person requiring frequent treatment was infected with hepatitis and hundreds contracted HIV. Many died from AIDs-related complications.

As a mother and advocate, Helen fought alongside others for safer treatments, better support, and recognition of the suffering that had been endured. It was a time defined by survival and the relentless determination of families to protect their children in the face of unimaginable challenges – not by choice, but by necessity.

THE PRESENT: **LIFE WITH HAEMOPHILIA B TODAY**

Modern medicine has transformed haemophilia B from a life-threatening disorder into a manageable condition. Bleeds that once resulted in hospitalisation and lifelong disability can now be prevented or treated at home. The life expectancy has increased significantly, from under 20 years in the 1960s to the average Australian life expectancy of 83 today. [2, 29] Children born with haemophilia B today can look forward to fuller, more independent lives than previous generations. Despite these advances, haemophilia B remains a complex, lifelong disorder.

Modern treatment: Factor IX replacement therapy

The current standard of care is factor IX replacement therapy, which replaces the missing clotting factor to prevent or control bleeding. [3] Treatment involves infusing factor IX concentrate directly into the bloodstream, enabling functional blood clotting and preventing prolonged or spontaneous bleeds. [2, 3]

There are two main types of recombinant factor IX products in use:

- **Standard half-life (SHL)** factor IX, which typically lasts 18 - 40 hours and requires more frequent dosing. [30]
- **Extended half-life (EHL)** factor IX, modified to stay in the bloodstream three to five times longer, allowing infusions as infrequently as once a week or less. [30] Today, EHL products are the most commonly used option in Australia for prophylactic treatment. [2, 3]

Recombinant factor IX products are effective for many, but not for all. Around 3 per cent of people with haemophilia B develop inhibitors; antibodies that block the activity of infused factor IX. [31, 32] Inhibitors are rare but serious, leading to more severe bleeding and further limiting treatment options. Management typically requires:

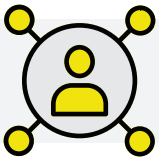
- **Bypassing agents**, which help the blood to clot without relying on factor IX. [33]
- **Immune tolerance induction (ITI)**, where repeated exposure to factor IX aims to retrain the immune system to accept it. [31, 33]

How treatment is delivered

Factor replacement therapy is usually administered via IV infusion. With training from a HTC, many people manage infusions at home, giving them greater independence and faster control of bleeds. [34] For young children, infusions may be given through an implantable port (central venous access device), which makes regular access easier and less distressing. [2, 3]

The role of HTCs

Care for people with haemophilia B is coordinated through specialist HTCs that provide comprehensive, multidisciplinary care. [35] There is at least one HTC for both adults and children in every state and territory in Australia, each located within a major public hospital. [36] They deliver:

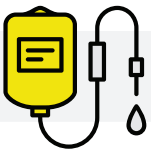


Individualised treatment plans based on severity, lifestyle, and clinical history

Regular monitoring of joint health, bleeding patterns, and factor levels

Access to physiotherapy, psychosocial support, and genetic counselling

Education and training for home infusions and bleed management



Support for family members, addressing challenges related to daily living, schooling, employment, and family planning [35]

HTCs also oversee the ABDR, a secure, national database administered by the NBA. The ABDR tracks treatment use, bleeding episodes, and health outcomes to support patient care, service evaluation, and public health planning. [35]

Transition from paediatric to adult care

Individuals diagnosed with haemophilia B in childhood will eventually transition from paediatric to adult care, often between ages 14 and 18. While handover processes are in place between teams, people living with the disease and clinicians alike note that this period can be challenging. Individuals must adjust to new clinicians, fewer touch points and more personal responsibility for treatments. Clinicians report that some people with mild disease are also at risk of being lost to follow-up, particularly if they have fewer symptoms.

Living with haemophilia B today

While modern treatments have transformed outcomes compared to previous generations, living with haemophilia B still means managing a complex and often exhausting set of physical, emotional, social, and logistical challenges.

The physical burden: Pain, bleeds, and long-term damage

Even with prophylaxis, breakthrough bleeds still occur, often affecting joints and muscles. These bleeds can cause acute pain and, over time, lead to permanent joint damage, reduced mobility, and chronic discomfort. [37-39] Some individuals develop "target joints", which are prone to repeated bleeding, can limit physical activity, and may worsen over time. [39]

A multinational study found **over half of adults** with severe haemophilia B reported problems with **mobility, ongoing pain and discomfort.** [13]

Physical challenges also arise from treatment itself, particularly the difficulty of maintaining healthy veins. [13] Repeated needle sticks can cause vein damage, scarring, and loss of access sites, especially in young children with small veins or older adults with fragile veins. This can be daunting for parents and carers responsible for infusions. [40] Some will require an implanted port placed under the skin to enable reliable access to a vein. While ports can ease the stress of finding a vein, they carry risks such as infections, blood clots, surgical placement, and eventual removal or replacement. [41]

> *He doesn't like going to the hospital and often tries to hide his pain so we don't have to go. We can't anticipate what the visit will be like - we never know if he will react or be upset. A five-year-old should not have to go through this, and it breaks you as a parent to witness him suffering.*
>
> **– Kara and Mark, parents of son with severe haemophilia B**

The long-term impacts of bleeding episodes can become more pronounced as people age. [42] Chronic joint disease, arthritis, and declining mobility increasingly affect quality of life, effects that are compounded by ageing. [42]

The mental and emotional toll

The mental load of managing haemophilia B is constant and, at times, overwhelming. [10, 14] Regular, lifelong treatment is a major contributor to this burden, requiring discipline, technical skill, and emotional commitment to stay adherent, manage the fear of bleeds, and maintain a sense of normalcy. [38]

Travel, work, school, and social events must be planned carefully around infusion schedules. Simple activities like going on holiday or travelling for work can become complex logistical challenges, with treatment supply, safe storage, and access to medical support all requiring careful coordination. [14, 43] Unsurprisingly, this ongoing management is mentally exhausting. [38]

> *You have to make sure the treatment stays at the right temperature, so I always use carry on, never check-in. If I'm going for a four-week holiday, I'll bring six to eight weeks of treatment, just in case.*
>
> **– Morgan, lives with severe haemophilia B**

For people living in rural or regional areas, the burden is greater. Specialist care is concentrated in major cities, requiring long travel distances for appointments, vein training, or emergency care. [36] These geographical barriers increase emotional strain and feelings of isolation.

The unpredictability of bleeds adds further anxiety. Many live in a state of hypervigilance, constantly asking: *Will a bleed disrupt an important event? Will I be able to find a vein today? Is this pain normal, or the start of a bleed?* This ongoing uncertainty can contribute to stress, fatigue, anxiety, and, for some, depression. [10, 14, 44] A survey of 299 adults with haemophilia B found that 41 per cent reported moderate or severe problems with anxiety or depression. [10]

> *Before surgery, I'm more anxious than I used to be, as I was told that prophylaxis doesn't work all the time. I'm worried the treatment won't work when it needs to.*
>
> **– Duncan, lives with mild haemophilia B**

Social impacts

The physical and emotional demands of haemophilia B inevitably spill over into education, work, and social participation. [14] Children and adolescents often miss school due to bleeds, treatment, or medical appointments, and some families choose schools based on proximity to healthcare or the school's ability to accommodate the child's needs. [14]. Participating in sports and other activities can be limited by fear of injury or prior joint damage, affecting peer relationships and self-esteem. [14]

> *When [our sons with haemophilia B] were looking for jobs, they'd have to be careful about whether they can do it, or if they will hurt themselves, and how much time they have off work. When they're looking at a position, they'd think "I might blow a week's sick leave through one event."*
>
> **– Denise and Stephen, parents of two sons with moderate haemophilia B**

Counting the personal cost

As adults, people with haemophilia B may shape career choices around their condition. [14] Some modify work hours, choose less physically demanding jobs, or leave employment entirely. Even with modern treatment, periods of reduced productivity and absenteeism remain. [14]

Evohealth modelling estimates that productivity losses for people with haemophilia B are $6.4 million in 2025, driven by time off for treatment, bleeds, or medical appointments. [6] Losses are most pronounced in severe disease, averaging nearly $19,000 per person per year, compared to around $6,000 for mild haemophilia B, reflecting greater joint damage, chronic pain, and intensive treatment regimens. [6]

> *A lot of the jobs in my area are field engineer work. Going to the field is really hard with haemophilia B, because it's a significant safety risk for the company. It makes it so much harder for me to work. I also can't work in another country. It's really frustrating, I wish I'd known before I went down this path, I would have gone into a different degree.*
>
> **– Morgan, lives with severe haemophilia B**

Carers, particularly parents of young children, face significant demands. Managing complex medical care alongside work and family responsibilities often requires time away from employment, resulting in substantial productivity loss. [14]

Evohealth modelling shows that carer productivity losses are estimated to be $6.75 million in 2025. [6]

Disease severity increases this burden, and carers of individuals with severe disease incur average losses of nearly $20,000 per year, compared to just over $5,500 for those caring for someone with mild disease. [6]

In 2025, **total carer productivity loss** from haemophilia B is **$6.7 million.** [6]

In 2025, carer productivity loss **for severe haemophilia B** is estimated at **$20,000 per person**, compared to $5,500 for mild disease. [6]

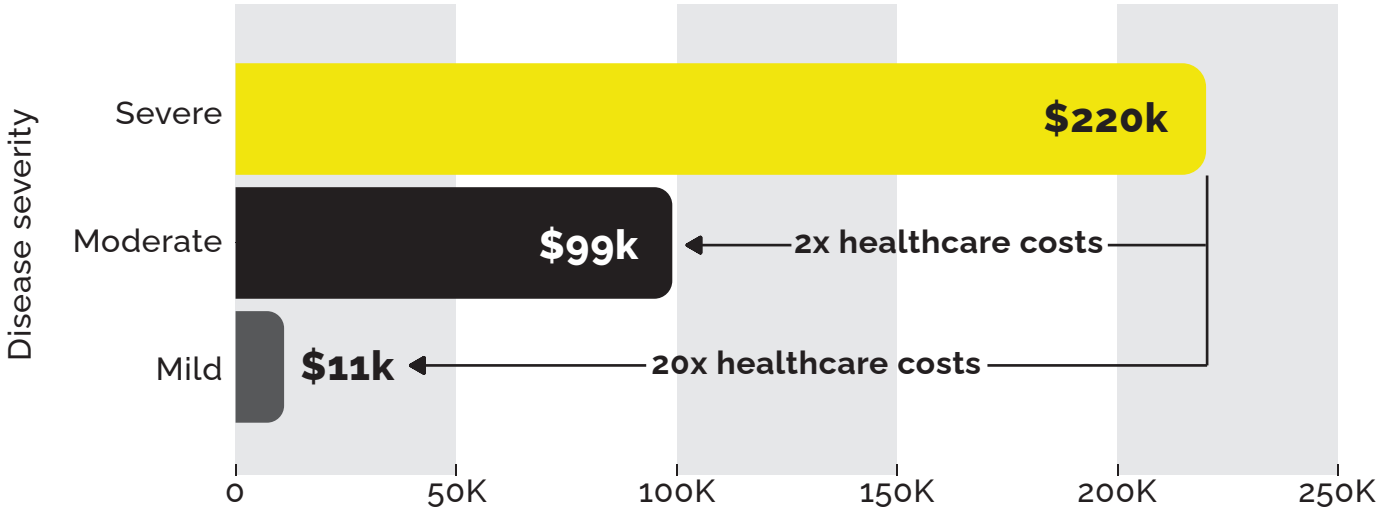
> *I'd been offered an expat assignment abroad. We were prepared – we'd been working to get the [factor replacement] shipped, we were ready to take out the insurance for any medical services, including medivac requirements. In the end, the company wouldn't take the risk. Even though we felt it was covered, they said it was an unacceptable risk, because they were accountable for our medical support and trying to ship this product around the world wasn't easy. So, I couldn't take the position.*
>
> **– Donna and Brenton, parents of son with severe haemophilia B**

System impacts: cost, resource use, and workforce strain

Current haemophilia B treatments are high-cost and resource-intensive, requiring specialist care and coordination across hospitals and HTCs. In 2025, direct healthcare costs are estimated at $48.1 million, 87 per cent of which is attributable to the cost of treatment. Public and private hospital care, general practitioner visits, pathology, and emergency department presentations account for a smaller but still meaningful share of expenditure. [6]

Figure 4 shows that healthcare utilisation is strongly linked to disease severity. People living with severe haemophilia B require nearly $220,000 in direct health system costs each year, more than double the cost of moderate disease ($99,000), and 20 times that of mild disease ($11,000). [6]

Figure 4: Annual per-person direct healthcare costs of haemophilia B by severity in 2025



Source: Evohealth [6]

Overall, the total annual cost of haemophilia B in Australia is estimated to be $81.6 million in 2025 – from a cohort of just 646 Australians. This is drawn from:

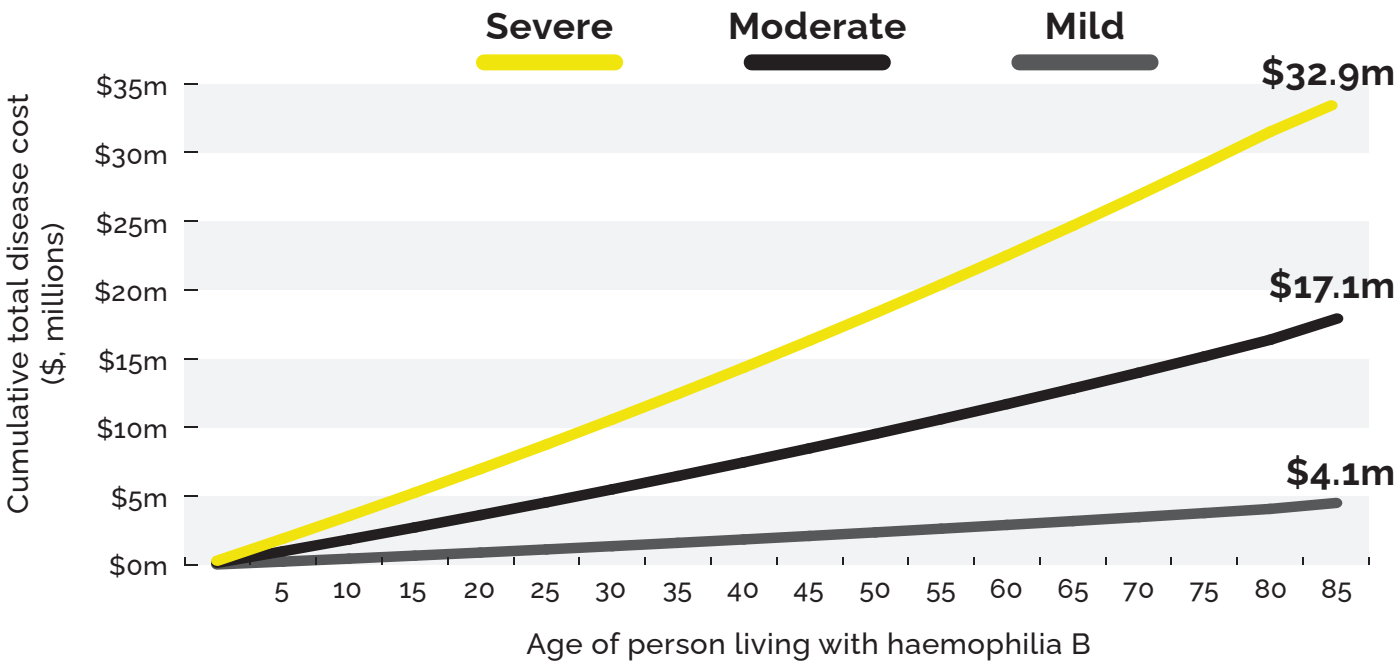
$48.1 million in direct healthcare costs, 87 per cent of which is treatment costs. [6]

$13.3 million from indirect costs, including productivity loss incurred by people with the disease and their carers or family members. [6]

$20.2 million in societal costs, including the disability burden imposed by haemophilia B. [6]

With prophylaxis, people with haemophilia B have near-normal life expectancy, meaning high treatment costs persist over decades. As shown in Figure 5, the cumulative cost of severe haemophilia B reaches almost $33 million per person by age 83, illustrating the long-term value of preventative approaches. [6]

Figure 5: Cumulative cost per person with haemophilia B by severity from birth to age 83



Source: Evohealth [6]

By 2050, this group is projected to grow to 892 people, with treatment costs, indirect and societal costs rising in tandem. Beyond the physical, psychosocial and practical burdens for people with haemophilia B, alongside their carers and families, there is a strong economic need to invest in improved care and treatment.

With no change to the standard of care, the **annual cost of haemophilia B** in Australia is projected to **increase to $108.5 million by 2050**, driven by rising prevalence and ageing of the cohort. [6]

Turning progress into possibility

A significant step forward has been made to address the lifelong burden of haemophilia B. Gene therapy offers the chance to live without the constant demands of regular infusions, planning around bleeds, and the uncertainty that shapes daily life. Now, with a positive funding recommendation, this possibility is no longer a future vision – gene therapy is a tangible treatment option for adults with haemophilia B.

> *For those of us who went through the contaminated blood era, the thought of having gene therapy is absolutely wonderful. Having a one-time treatment means you won't watch your husband or child suffer all the time…. it would be freedom from treatment all the time. The peace of mind would be wonderful.*
>
> **– Helen, parent of son with severe haemophilia B**

THE FUTURE: **REALISING THE PROMISE OF GENE THERAPY**

For people living with haemophilia B, the future holds significant promise. After decades of managing symptoms and navigating the daily demands of treatment, we are entering an era where the condition itself may be fundamentally altered.

Emerging therapies, particularly gene therapy, aim to reduce or even eliminate the need for regular infusions. For individuals and families, this not only means fewer bleeds, but freedom from the routines and the constant vigilance that have defined life with haemophilia B.

> *It would just make everything easier. You would forget you had haemophilia for the most part. I'd apply for every international job that I wanted to. Another thing I love is go-karting – I haven't been able to because of the crash risk. If I had gene therapy, I would buy a go-kart the same day.*
>
> **– Morgan, lives with severe haemophilia B**

What is gene therapy and how does it work?

Gene therapy targets the underlying cause of haemophilia B. [4] Instead of relying on lifelong infusions to supply factor IX externally, it delivers a working copy of the F9 gene directly to the liver. This is done by a single IV infusion of an inactivated viral vector, most commonly an adeno-associated virus (AAV) that is engineered to carry the correct genetic instructions. The vector delivers the F9 gene to liver cells, enabling the ability of these cells to produce functional factor IX. [4]. The liver then takes over the role of making factor IX naturally, eliminating the need for regular infusions. [4] This process is depicted in Figure 6.

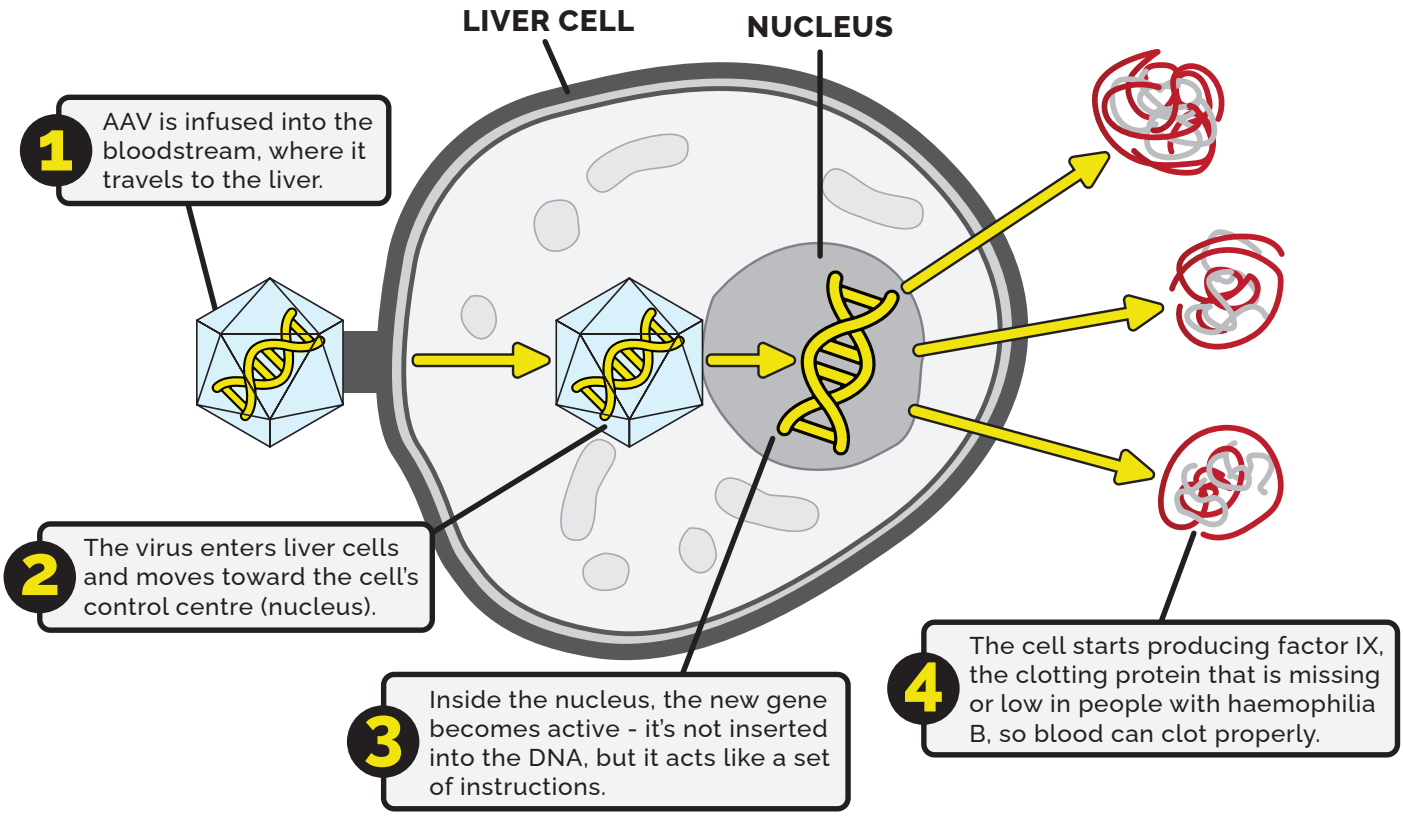
Gene therapy development for haemophilia B has progressed rapidly, with multiple therapies in various stages of development and clinical use. [45]

- Hemgenix® (etranacogene dezaparvovec) has received regulatory approval in several countries, including approval by the Therapeutic Goods Administration (TGA) in 2024. [46] In July 2025, Hemgenix® received a positive funding recommendation by MSAC. [16]
- China approved BBM-H901 (dalnacogene ponparvovec) in 2025, the first gene therapy for haemophilia B authorised in the country. [47]
- Over a dozen other therapies are in development, including FLT180a and AskBio009. [45, 48]
- Some alternative delivery platforms are being explored, such as lentiviral vectors or lipid nanoparticles (such as YUVA GT F901). [49]
- Research is also underway into gene editing approaches that aim to repair the underlying mutation at the DNA level. [49]

Together, these efforts represent a strong and diverse pipeline of gene therapy innovation for the haemophilia B community.

It's important to note that gene therapy may not be suitable for everyone. Individuals with liver disease or pre-existing antibodies to AAV can be excluded from eligibility, while others may not respond as expected. [1, 50]

Figure 6 Process of gene therapy



Source: Evohealth, adapted from [4]

A positive recommendation from MSAC, or from other HTA bodies overseas, is only the first step toward accessing this therapy. For Australians, gene therapy will remain out of reach until funding and delivery arrangements are in place. Past experience with rare disease gene therapies illustrates the risk of delays:

- Spinal muscular atrophy is a rare genetic condition that causes progressive muscle wasting and, if untreated, is the leading genetic cause of death in children aged two and under. Zolgensma® (onasemnogene abeparvovec) received a positive PBAC recommendation in September 2021 and was listed on the Pharmaceutical Benefits Scheme (PBS) nine months later, in May 2022. [51, 52]
- Inherited retinal disease is a condition linked to over 300 genes that results in progressive loss of vision. Luxturna® (voretigene neparvovec-rzyl) was recommended by MSAC for joint Federal and State/Territory funding in November 2020, but the funding agreement only came into effect in March 2022. [53, 54]

Although Hemgenix® has now received a positive MSAC recommendation, imminent access is not guaranteed. [16] Coordinated action is needed to ensure this therapy reaches the people who can benefit from it. Australians living with haemophilia B carry a unique, lifelong burden and deserve timely, equitable access to transformative treatments.

The value of implementing gene therapy in Australia

For people living with the condition, the value of gene therapy lies not only in fewer bleeds but in greater freedom, improved physical health, and the chance to live without constantly managing or thinking about their haemophilia B. [5]

Fewer bleeds, better protection

One of the clearest benefits of gene therapy is the dramatic reduction in bleeding episodes. [55] Across multiple long-term studies, gene therapy led to a substantial drop in annual bleeding rates, from around four bleeds per year before treatment to fewer than two after. [24] Even more profound were results collected in a 13-year follow-up, which saw the median bleeding episodes fall from 14 to just 1.5 per year, with some participants reporting no bleeds at all. [15]

Gene therapy **can reduce annual bleeds by up to 90 per cent**, turning a life of repeated bleeding into just one or even zero bleeds a year. [15, 24, 56]

The long-term benefits of a reduction in bleeds are significant. Fewer joint bleeds mean less pain, less joint damage, and a reduced risk of permanent mobility issues. For many, it unlocks the ability to return to physical activities they previously avoided due to fear of injury. [55]

Sustained factor IX levels

Unlike traditional treatments that offer only temporary increases in clotting factor, gene therapy supports the body to produce its own clotting factor IX. Most recipients, typically 80-90 per cent, reach and maintain near-normal factor IX levels, with some studies showing averages around 45 per cent five years after treatment. [15, 56, 57] For many, this transforms haemophilia B from severe to mild, or in some cases, near-normal levels. [56]

> *It is a 'treatment-free haemophilia' - the therapy is so effective that the patient is free of both the disease and their treatment.*
>
> **– Professor Huyen Tran, Haematologist**

Freedom from routine infusions

Gene therapy replaces the burden of weekly factor infusions with a single treatment that delivers lasting effects. In one study, over 90 per cent of participants were able to stop their regular prophylaxis infusions altogether, avoiding more than 249,000 units of factor IX per person each year. [24] This estimated reduction equates to an average cost saving of around $323,700 per person annually. [24]

This change represents not only a seismic shift in routine treatment requirements, but also greater independence and flexibility in daily life.

> *A one-time treatment would be life changing, for him and for us. A world where we don't have to go to the hospital every week is so foreign – it wouldn't be as traumatic for him. It would be amazing.*
>
> **– Mark and Kara, parents of son with severe haemophilia B**

An improved quality of life

Quality of life improvements enabled by gene therapy are profound. As the daily demands of managing the condition ease, so too does the emotional and mental burden on individuals and families.

> *The biggest difference I've seen in our patients on trial is their improvement in quality of life - they're off treatment entirely, even with minor bleeds. That shift from severe to mild is hard to grasp from a government point of view, but it's vastly different in terms of burden of disease and treatment.*
>
> **– Dr Stephanie P'Ng, Haematologist**

In a follow-up of the multi-national Health Outcomes with Padua Gene; Evaluation in Haemophilia B (HOPE-B) study, people with haemophilia B reported meaningful gains across key areas of wellbeing, including energy levels, participation in work and school, emotional resilience, and confidence for the future. [58] Without the constant planning around infusions or fear of spontaneous bleeds, life becomes less restrictive and more spontaneous. [58]

Gene therapy marks a profound psychological shift for individuals with haemophilia B. It's more than a treatment, it's a chance to live with fewer limitations, to think beyond the condition, and to experience what has been described as a "haemophilia-free mind". [5]

Tom's story: life after gene therapy for haemophilia

I was diagnosed with severe haemophilia before my first birthday, with no family history. I spent lots of time in hospital as a kid, often three times a week for treatment with overnight stays. My childhood was disjointed, and I missed a lot of school. When I was eight, home treatment was a big improvement, but I still had two to three bleeds per week. I went onto prophylactic [treatment] in my early 20s, but most joint damage had already been done. Arthritis in my knees and ankles was very painful and some days I couldn't walk. In my 40s, I had both knee joints replaced, and ankles fused. Getting vein access became more difficult with age and caused me stress for some years. Hospital was my second home for most of my life.

Since my late childhood I had heard there would be a 'cure' for haemophilia in the next few years. To see gene therapy become reality when I was 50 was pretty surreal. Deciding to join a gene therapy trial was a big decision, with lots to consider. I was excited by the thought of no more bleeds or IVs, but I had to consider how safe and effective it would be as a trial. There was uncertainty, and no guarantee of a sustained response. It was a long-term commitment with five years of monitoring, particularly intensive in the first year. I did my own research, but mostly spoke with my haematologist about the process, risks and side effects. In the end, I made an informed choice to have gene therapy.

Over five years later, the result is that gene therapy has been life-changing for me. I am in a great window of my life. My health is significantly improved, as has my day-to-day lifestyle. My life is more stable. Though it wasn't all rosy. My liver enzyme levels became elevated after the infusion, and I was prescribed steroids. I struggled with the effect of the steroids on my mood and sleep. This coincided with the COVID-19 pandemic, which was a testing time for me, given I had become immunocompromised.

I had great support from my haematologist and the [HTC] staff. Their support was very reassuring and I felt they were always looking out for me, especially when my liver results went wobbly. I also struggled with how to disclose to friends and colleague that I was going through this life-changing process. The haemophilia social worker gave me advice, which provided me with the clarity I needed.

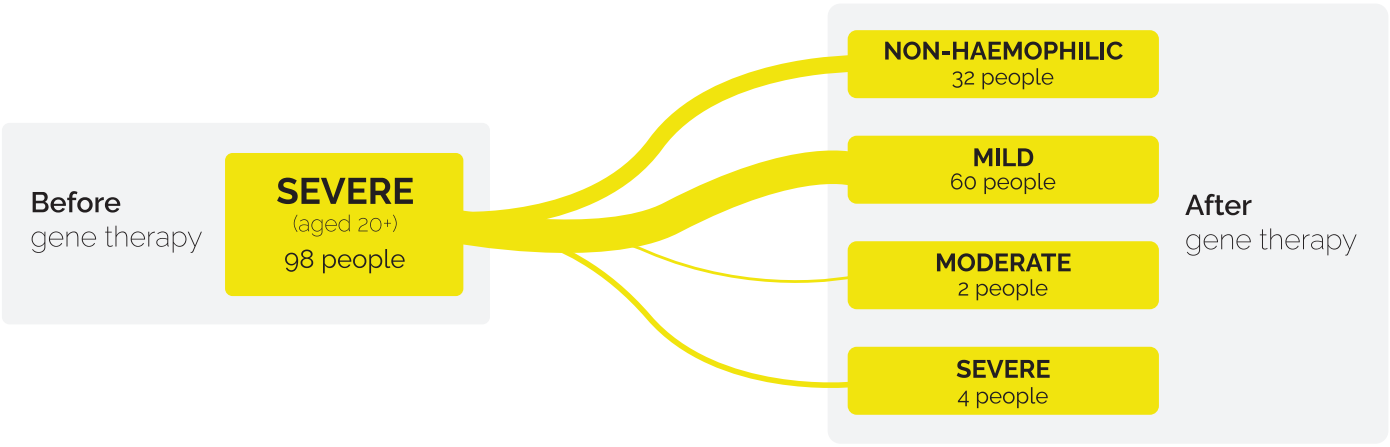
I've gone from having severe haemophilia for 50 years, to now mild. I'm not having breakthrough bleeds or thinking about how to manage my haemophilia. I don't need regular treatments. I experience way less pain than before. I'm not missing work and social events. I'm about to travel to Europe which is my first trip in 25 years – without an esky full of treatment. To be clear, I do not consider gene therapy to be a cure for haemophilia. However, gene therapy has been positively life-changing for me.

Unlocking economic benefit for individuals, the healthcare system and Australia

If all adult Australians living with severe haemophilia B received gene therapy, the impact would be substantial across clinical, financial, and social domains.

Evohealth modelling shows that gene therapy significantly shifts the national severity profile. Of the 98 adults living with severe haemophilia B in 2025, around 61 per cent would move to mild disease, 33 per cent would transition to a non-haemophilic state, two per cent would shift to moderate, and just four per cent would remain severe, equivalent to just four individuals. This change is depicted in Figure 7.[2] [6]

Figure 7 Shift in haemophilia B severity cohort with gene therapy



Source: Evohealth [6]

[2] The HOPE-B trial included only adults aged 18 and over. However, the ABDR segments individuals aged 0–19 as a single group. This segmentation results in the exclusion of a slightly broader age range (0–19 rather than just 0–17).

These clinical improvements translate directly into economic benefits. For adults with severe haemophilia B, the total cost of disease would fall from $31.1 million per year to $1.2 million following gene therapy. Across all Australians with haemophilia B, this would reduce the national cost by $27.1 million annually, equivalent to a 33 per cent reduction in the economic burden of the condition. [6] The cost of delivering gene therapy was not included in this scenario to enable isolated assessment of the economic benefit of improved clinical outcomes. These findings highlight the dual value of gene therapy. It offers life-changing improvements for individuals and delivers a long-term opportunity to ease the burden on Australia's healthcare and disability systems.

Out of 98 adults, only four would remain in the severe category after gene therapy. [6]

Gene therapy could reduce national costs by **$27.1 million per year**, equivalent to a **33 per cent reduction** in the economic burden of haemophilia B. [6]

Total disease cost of severe haemophilia B in adults would fall from $31.1 million to **$1.2 million annually.** [6]

What else is on the horizon for haemophilia B?

Alongside gene therapy, several other innovative treatments are in development for haemophilia B in Australia and globally. Non-factor therapies, including rebalancing agents and monoclonal antibodies, are designed to adjust the body's natural clotting pathways rather than replace missing factor IX. [3, 59] These are often delivered via subcutaneous injection and may benefit people with or without inhibitors. One emerging class, anti-tissue factor pathway inhibitors (anti-TFPIs), works by targeting the body's natural anticoagulants to help restore clotting balance. Anti-TFPIs are now registered for clinical use in some countries, including Australia, however require regular administration. [59]

MAKING GENE THERAPY **A REALITY IN AUSTRALIA**

Gene therapy represents a transformative opportunity to reduce the lifelong burden of haemophilia B and deliver lasting value for individuals, families, and the health system. After decades of navigating the demands of regular treatment, planning, and uncertainty, Australians now have a clear path to a therapy that could fundamentally change their lives.

> *Gene therapy has held out the promise of a near cure for haemophilia for more than 25 years. For the haemophilia community, gene therapy offers a longer-term solution, greater productivity, and as several community members have said recently, 'a normal life'.*
>
> **- Natashia Coco, Executive Director, Haemophilia Foundation Australia**

It is time to move from possibility to implementation. Realising the benefits of gene therapy requires thoughtful, coordinated action across the healthcare system, addressing the practical, psychological, and system-level considerations outlined in Table 2.

Table 2 Patient- and system-level considerations

Patient-level considerations

Navigating safety concerns

Gene therapy is generally well tolerated, but as with all treatments, there are risks:

- Common side effects include fatigue, flu-like symptoms, and infusion-related reactions. [55]
- Around 20 to 40 per cent of people experience temporary increases in liver enzymes post-treatment, typically managed with corticosteroids. [55]
- Adverse effects are usually reversible, and long-term follow-up data is reassuring, with no serious adverse events reported in trials up to 15 years. [60, 61]

Individuals need to feel confident they are well informed about the safety profile, short- and long-term risks, and what to expect during follow-up.

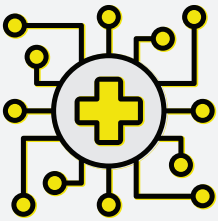
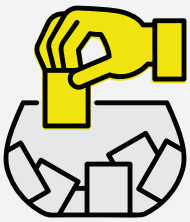
Table 2 Patient- and system-level considerations (continued)

 **Making an irreversible, long-term decision**	Gene therapy is a one-time treatment that cannot be reversed: • Modified genetic material remains in the body long term after the infusion. [62] • Additional management is required following treatment, such as avoiding alcohol for at least 12 months to support liver recovery. [55, 60] • The permanence can be daunting for some. Individuals must work closely with their healthcare teams and HTCs to assess how gene therapy aligns with their medical history, lifestyle, and personal goals. [55, 62]
 **Psychosocial support at every stage**	Gene therapy brings a shift not just in treatment, but in identity: • It can stir up a range of emotions - hope, excitement, anxiety, and uncertainty. [63] This can occur whether the treatment is successful, or if the desired outcomes aren't achieved. • Support via psychologists and social workers aids in coping with transitions, routine changes, and post-treatment challenges, helping people feel comfortable with their decision. [63, 64] Psychosocial support is essential before, during and after treatment to help individuals prepare, manage expectations, and adjust to life changes. [64]
 **Unfamiliarity with gene therapy**	Gene therapy can feel unfamiliar, or difficult to understand: • People may be unsure how it works or what it will mean for them in the long term. [64] • Access to education is essential to support understanding and informed decision-making. Education needs to be embedded across the full care continuum, from early conversations through to post-treatment follow-up. [64]

> *Individuals with haemophilia B deserve to have the choice to undertake this treatment, and the resources to make an informed decision. This includes better access to allied health care workers (social work and counsellors) across all HTCs, and equitable access to the information available on gene therapy.*
>
> **- Robyn Shoemark, Clinical Nurse Consultant – Haemophilia/Haematology**

Table 2 Patient- and system-level considerations (continued)

System-level considerations

 **Equitable access and sustainable funding**	Establishing clear funding and delivery pathways is now the priority. Ensuring the healthcare system is ready to support implementation is essential to turn the promise of gene therapy into real-world benefit for all Australians living with haemophilia B.
 **Health system capacity**	Gene therapy requires a specialised model of care, delivered through a hub-and-spoke approach: • Expertise is concentrated in a small number of 'hub' centres that administer treatment, while 'spoke' centres provide pre- and post-treatment support to ensure continuity of care. [19] • The HTCs and AHCDO have conducted significant planning and preparation to prepare the system for gene therapy is already underway. This includes the clinical implementation plan, led by Evohealth and co-designed with clinicians from AHCDO. This shaped the service delivery model, model of care and stakeholder engagement approach to support gene therapy in Australia. [19] • Many HTCs face workforce shortages, particularly in psychosocial care, and staffing remains inconsistent. Further support is needed to bolster the resources to deliver gene therapy.
 **Postcode lottery**	Access to gene therapy must not depend on where someone lives. Currently, most treatment centres are located in major cities, creating potential barriers for people in regional and remote areas. [36] Mechanisms to extend access and support ongoing monitoring outside metropolitan centres, whist ensuring high quality care, are needed to ensure equitable implementation.

Source: Evohealth [6]

A coordinated, national response is needed

The haemophilia community is already preparing for implementation, with organisations such as HFA and AHCDO developing national protocols and standard operating procedures. Ensuring timely and equitable access will require a whole-of-system effort, bringing together individuals, clinicians, researchers, funders, and policymakers. Australia can also draw on lessons from countries where gene therapy is already being delivered.

Learning from global progress in gene therapy

Gene therapy for haemophilia B is currently approved and funded in several countries, including the United Kingdom, Denmark, Switzerland, Spain and Austria. [65] Innovative reimbursement approaches, such as outcomes-based agreements, link funding to treatment efficacy. [65]

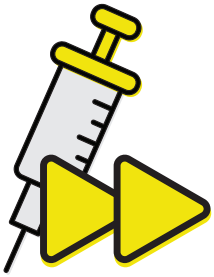
Denmark implemented the first European outcomes-based agreement in 2024, monitoring bleed rates, factor IX levels, and adverse events, with Germany following in early 2025 under a similar model. [65-67] In 2024, the United Kingdom funded gene therapy via a managed access agreement through the Innovative Medicines Fund, collecting additional evidence during delivery to inform long-term funding decisions. [68, 69]

These examples show that sustainable, equitable access is achievable. Australia is well-positioned to adopt similar approaches, aligning with the 2024 HTA Review, which emphasises strengthened pathways for innovative treatments. [18] With the groundwork prepared, the priority is clear: coordinated, timely action to deliver gene therapy to Australians living with haemophilia B.

TRANSFORMING LIVES AND RESHAPING CARE: **THREE RECOMMENDATIONS TO HARNESS GENE THERAPY IN AUSTRALIA**

With gene therapy now within reach for haemophilia B in Australia, we stand at a pivotal moment. This breakthrough can transform lives. Realising these benefits will depend on how well we prepare our systems, policies, and care pathways for implementation. The opportunity is clear: to match scientific innovation with practical reforms that ensure safe, equitable, and person-centred access to this potentially life-changing treatment.

These three recommendations, developed with our Advisory Committee, outline the actions needed to ensure Australians with haemophilia B can access this treatment and its benefits, today and into the future.



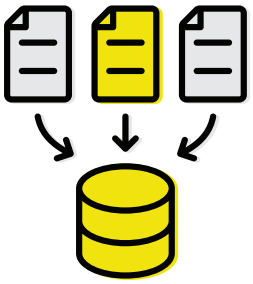
RECOMMENDATION 1

Fast-track implementation of Recommendation 16 from the HTA Review to ensure innovative therapies are accessible as soon as possible.

Australians with rare and genetic diseases need access to innovative therapies to achieve equitable treatment and quality of life outcomes. [17] Recent progress has been made with a positive funding recommendation for Hemgenix®. The challenge now is to ensure bottlenecks in negotiation and funding do not slow translation of this recommendation into access. [16]

Recommendation 16 of the HTA Review calls for a new framework to support mechanisms that facilitate timely access to high-cost, high-impact treatments. [18] This includes earlier financing and contracting negotiations, and adopting approaches beyond the traditional 'price per unit' model. Importantly, the framework would help manage the uncertainty that often surrounds innovative therapies, while ensuring Australians are not left waiting. [18]

Implementation of HTA recommendations rests with the HTA Review Implementation Advisory Group, who have been tasked by the Minister for Health and Ageing to prioritise equitable access. [70] To date, no progress toward the implementation of Recommendation 16 has been reported in the Advisory Group's meeting communiques. [71] Urgent consideration and implementation of this framework is critical to enable timely access of innovative health technologies in Australia, such that people who experience inequity through rare and genetic diseases - including haemophilia B - can achieve the same quality of life as most others.



RECOMMENDATION 2

Implement sustainable data systems to enable gene therapy monitoring and support evidence-based care.

The possibility of gene therapy in clinical care marks a significant shift in the management of haemophilia B, requiring new approaches to support long-term monitoring and evaluation. Australia's existing data infrastructure must be strengthened to collect real-world evidence, ensuring patient outcomes and treatment efficacy are tracked over time. The importance of real-world evidence was highlighted in Australia's 2024 HTA review, which identified it as critical for assessing the safety and effectiveness of innovative therapies. [18]

The ABDR is the national data system for haemophilia and other inherited bleeding disorders. It plays a central role in monitoring treatment, informing clinical care, and supporting public funding decisions. To support gene therapy, the ABDR must be updated with new fields and functions for long-term monitoring, such as factor IX levels, liver function, post-infusion safety checks, and quality of life outcomes. Updates should also reflect recommendation 27 of the HTA Review, which called for an Australian framework to oversee real-world data systems and processes. [18]

Delivering these enhancements will require dedicated resources and technical development. This presents an opportunity for the NBA, as the custodian of the ABDR, to seek additional funding and ensure the system is ready ahead of broader gene therapy roll-out. Early investment will avoid delays, enabling proactive monitoring for safety and efficacy from the outset.

Expanding the ABDR to integrate with global registries, such as the World Haemophilia Federation's World Bleeding Disorders Registry, would allow benchmarking against international data while contributing to the global evidence base. [72] Careful planning will be essential to safeguard Australian data sovereignty and security within these platforms.

A strong, future-ready ABDR is critical to support the safe and effective use of gene therapy. A system that enables high-quality data capture and real-time insights will ensure Australia's monitoring framework remains best practice and responsive to the rapidly evolving gene therapy landscape. It is also foundational to maintaining public trust, enabling evidence-based care, and collecting data that supports sustainable funding into the future.

RECOMMENDATION 3

Increase funding to deliver wraparound care for haemophilia B.

For Australians with haemophilia B, access to gene therapy must be accompanied by strong wraparound support. Without adequate psychosocial care and reliable information, patients and families may struggle to navigate the profound emotional, psychological, and practical impacts of treatment.

Tailored psychosocial support is essential to help individuals process these experiences and adjust to their new reality. Currently, access to structured psychological care within HTCs is limited and inconsistent, with psychologist and social worker positions unevenly funded across centres.

Targeted investment is needed to ensure nationally consistent, high-quality psychosocial services are available through all HTCs, including for people in rural and remote areas. Several standard operating procedures for psychosocial care are being developed by AHCDO, and a network of psychosocial care providers across Australia and New Zealand is already supporting training and collaboration. With sustained funding, HTCs can scale and embed these resources to deliver continuity of care.

At the same time, investment is also needed to develop evidence-based resources that support informed decision-making about gene therapy. Development of accessible resources that provide accurate, clear, engaging, culturally informed and accessible information on gene therapy for people with haemophilia B are needed. In addition, a centralised hub that consolidates contemporary research and education materials would support clinicians to remain up to date on the international horizon of gene therapy and ensure Australian clinical practice is best practice.

HFA, in collaboration with AHCDO, is already progressing this work through the development of the Gene & Emerging Therapies Hub. [20] This is an important step forward, however additional funding support for HFA is needed to expand the depth and reach of these materials. This will also include continued collaboration with HTCs and AHCDO to ensure materials reach the individuals and clinicians who need them most.

Strengthening funding for HTCs and HFA to deliver this wraparound care is essential to ensure Australians with haemophilia B can access the person-centred, holistic and practical support they need along the treatment journey.

> *"While the physical toll of haemophilia B is readily visible with joint disease, less evident is the mental impact on our patients. What will be much appreciated by patients and clinicians alike is funding on a national level to provide dedicated mental health and psychosocial support to our haemophilia patients. The difference to the patient's wellbeing from such an initiative is indescribable."*
>
> **– Dr Chee Wee Tan, Haematologist**

Haemophilia B remains a lifelong condition with significant physical, psychosocial, and economic impacts on individuals, families, and the healthcare system. Yet a major step forward has been taken: with a positive funding recommendation, gene therapy is now within reach.

This creates a tangible pathway to reduce the daily burden of treatment, improve quality of life, and deliver lasting health benefits. The challenge now is ensuring this potential translates into real-world access for those who need it most.

By addressing the challenges outlined in this report, we can turn the promise of innovation into outcomes for people living with haemophilia B. We can ensure equitable care, and finally ease the weight of the condition of those who have carried it for too long.

ABBREVIATIONS

Abbreviation	Description
AAV	Adeno-Associated Virus
AB	Annual Bleed
ABDR	Australian Bleeding Disorders Registry
ABS	Australian Bureau of Statistics
AHCDO	Australian Haemophilia Centre Directors' Organisation
AIHW	Australian Institute of Health and Welfare
ARIMA	Autoregressive Integrated Moving Average
CADTH	Canadian Agency for Drugs and Technologies in Health
COI	Cost-of-Illness
DALYs	Disability-Adjusted Life Years
DSP	Disability Support Pension
ED	Emergency Department
EHL	Extended Half-Life
FTE	Full-Time Equivalent
GT	Gene Therapy
HCPs	Home Care Packages
HFA	Haemophilia Foundation Australia
HIV	Human Immunodeficiency Virus
HOPE-B	Health Outcomes with Padua Gene; Evaluation in Haemophilia B
HTA	Health Technology Assessment

Abbreviation	Description
HTC	Haemophilia Treatment Centre
ITI	Immune Tolerance Induction
IV	Intravenous
LGA	Local Government Area
MBS	Medicare Benefits Schedule
MSAC	Medical Services Advisory Committee
NBA	National Blood Authority
NDIS	National Disability Insurance Scheme
NHMRC	National Health and Medical Research Council
pCPA	pan-Canadian Pharmaceutical Alliance
PBS	Pharmaceutical Benefits Scheme
rFIX	Recombinant Factor IX
RACGP	Royal Australian College of General Practitioners
SHL	Standard Half-Life
SMRs	Standardised Mortality Ratios
THANZ	Thrombosis and Haemostasis Society of Australia and New Zealand
VSLY	Value of a Statistical Life Year
WPL	Work Productivity Loss
YLD	Years Lived with Disability
YLL	Years of Life Lost

APPENDIX A - **EVOHEALTH'S ECONOMIC MODEL FOR HAEMOPHILIA B**

Summary

Evohealth developed an economic model to estimate the direct, indirect, and societal costs of living with haemophilia B in Australia, and to assess how emerging technologies such as gene therapy could reshape this burden. It provides a first-of-its-kind, nationally representative estimated economic burden of haemophilia B. The findings offer new evidence to inform policy discussions, research, and health system planning.

This model uses a cost-of-illness approach, supported by a prevalence-based framework, to quantify the economic burden of the haemophilia B cohort in Australia. Economic burden was disaggregated by severity (mild, moderate, severe), age group, and geography. This includes:

- **Direct, indirect and societal costs** estimated using national datasets, registry data, published literature and structured input from clinicians and patient advocates.
- **Population forecasts applied to 2050** at the local government area level to reflect regional growth patterns and support long-term projections.
- **A technology impact scenario** based on post-treatment outcomes from the HOPE-B gene therapy trial. Adults aged 20 and over with severe disease were reclassified into new severity levels to estimate the downstream cost impacts. The cost of delivering gene therapy was not included in this scenario to enable isolated assessment of the economic benefit of improved clinical outcomes.

Key findings

- In 2025, 646 Australians are estimated to be living with haemophilia B, with 362 (56 per cent) classified as mild, 153 (24 per cent) as moderate, and 131 (20 per cent) as severe. [6]
- The total cost of haemophilia B in 2025 is estimated at $81.6 million. With no change to the standard of care, the annual cost is projected to rise to $108.5 million by 2050, driven by rising prevalence and ageing cohort. [6]
- The gene therapy technology impact scenario would result in annual savings of $27.1 million, or a 33 per cent reduction in the economic burden of haemophilia B. [6]

Further detail on the model inputs, assumptions, and analytical approach is provided in the Detailed methodology section on page 47.

Detailed methodology

1. Cost-of-Illness (COI) approach

Evohealth developed a cohort-based COI model to estimate the direct, indirect, and societal costs of living with haemophilia B in Australia. The model captures the existing economic burden of the condition using prevalence-based modelling rather than incidence. This approach provides a snapshot of cost impacts at a given time and allows for forecasting into the future. Costs are reported by disease severity (mild, moderate, severe) and by age group and state, enabling a granular view of disparities across demographic and geographic groups.

The model draws from publicly available data, clinical literature, and structured input from advisory committees and stakeholders.

2. Prevalence-based modelling

Prevalence was used to estimate the number of people living with haemophilia B, rather than incidence, to capture the total burden at a point in time.

- Primary data source: ABDR for 2021–2023.
- Sex and severity disaggregation: Prevalence was modelled separately for males and females and across severity levels, using latest available ABDR data. Projections to 2025 show a male prevalence of 3.66 per 100,000 and female prevalence of 1.08, with mild cases the most common (1.32 per 100,000).
- State-level variation: The model captures significant variation across states, e.g. Queensland at 2.82 per 100,000 versus Northern Territory at 0.40, consistent with reporting disparities in registry data.
- Age-group distribution: Prevalence across age groups was relatively stable, ranging from 2.14 (60–79 years) to 2.62 (40–59 years), with no evidence of age-specific regression effects.

3. Population forecasting

Since the ABS does not publish population projections at the local government area (LGA) level, Evohealth applied 500 tailored ARIMA forecasting models to historical population data (2001–2023) for each LGA. These forecasts extend population estimates to 2050. The resulting projections were validated against the ABS national projections and were found to closely track the high series.

This approach allowed long-range, regionally tailored population estimates that reflect local growth patterns, essential for downstream prevalence projections and cost calculations.

4. Economic analysis

a. Direct costs

Direct costs represent all healthcare and medical expenditures incurred as part of managing haemophilia B, across both acute and chronic phases of care. These include costs for therapeutic interventions (e.g. rFIX treatments), hospital admissions, outpatient care, diagnostic procedures, allied health support, and government expenditure such as research funding. Costs were disaggregated by disease severity and derived using a combination of administrative datasets, registry information, pricing schedules (MBS, PBS, NBA), and committee-validated assumptions regarding real-world treatment intensity.

i. Treatment costs

Evohealth reverse-engineered rFIX unit costs using NBA supplier-level spend and issue volumes, due to lack of publicly available prices. The following costs were utilised as part of the model:

- SHL rFIX: $0.65 per IU
- EHL rFIX: $1.30 per IU (2× multiplier from Medical Services Advisory Committee's 2019 report)
- Validation against 2019 data aligned with Medical Services Advisory Committee's SHL $0.79/IU benchmark
- MonoFIX-VF: $1.064/IU and NovoSeven: $1,250/mg from NBA product list [73]

ii. Hospital services

Costs derived from AIHW data were scaled by disease severity using a cost ratio of 1:2.22:8 for mild, moderate, and severe haemophilia B, respectively. [74]

iii. Outpatient, allied health and diagnostic

MBS/PBS data was used for unit pricing. Visit frequencies by severity (e.g. 6 physio + 6 psych for severe) were based on committee input. The total cost of running HTCs was not available. As a proxy, the model estimated allied health service use and applied MBS unit pricing and typical out-of-pocket costs. This likely underestimates the full resource requirements of delivering care through HTCs.

iv. Government-funded services

Disability Support Pension (DSP), National Disability Insurance Scheme (NDIS), carer payments, and Home Care Packages (HCPs) were excluded due to the lack of available data and the variability in service access. Stakeholder interviews suggested that only a limited number of individuals with very severe haemophilia B would likely be eligible for these supports.

v. Research expenditure

All grants were identified through a keyword-based text analysis of NHMRC grant titles and summaries, using plain-English and clinical terms related to Haemophilia B.

b. Indirect costs

Indirect costs capture the broader economic impact of living with haemophilia B, including the loss of productivity due to reduced workforce participation, absenteeism, and premature death, as well as the unpaid time and opportunity cost borne by informal carers. These costs are particularly pronounced in individuals with moderate and severe disease, where functional limitations and treatment burdens reduce employment capacity. All estimates were stratified by age and severity and monetised using national wage and employment data.

i. Patient productivity loss

Work productivity loss (WPL) was mapped to disease severity based on annual bleed (AB) frequency, using findings from the Cost of Haemophilia in Europe: a Socioeconomic Survey II (CHESS II) study: The impact of bleeding event frequency on health-related quality of life and work productivity outcomes in a European cohort of adults with haemophilia A. [75] Annual bleeds were used as a proxy to categorise severity and align with associated productivity impacts:

- Mild (0–2 ABs): ~13% WPL, corresponding to an average of 5 hours lost per week, based on CHESS II data for AB = 1.1
- Moderate (3–4 ABs): ~23% WPL, or 8.5 hours lost per week, based on CHESS II data for AB = 2.2
- Severe (5+ ABs): ~40% WPL, or 15 hours lost per week, reflecting the midpoint of the 35–48% WPL range reported in CHESS II [75]

These hours were then monetised using Australian Bureau of Statistics (ABS) wage and employment rate data. [75]

ii. Informal care productivity loss

Average hours were monetised using ABS wage and employment rate data: [76]

- Mild: 4 hrs/week
- Moderate: 10 hrs/week
- Severe: 14 hrs/week

iii. Mortality-related productivity loss

To estimate productivity lost due to premature mortality, we applied standardised mortality ratios (SMRs) to age-specific death rates from the Australian Institute of Health and Welfare (AIHW). SMRs reflect how much higher (or lower) mortality is in a specific population compared to the general population, adjusting for age and sex. [77]

Based on published literature, we used the following SMRs by haemophilia B severity:

- Mild: SMR = 1.0 (no excess mortality)
- Moderate: SMR = 1.1 (10% higher mortality)
- Severe: SMR = 2.4 (140% higher mortality)

These SMRs were applied to AIHW's baseline mortality rates to estimate the increased likelihood of death for each severity group. We then calculated working years lost by comparing the expected retirement age with the estimated age at death for each group. Finally, these lost years were monetised using average annual wages and labour force participation rates from the ABS to reflect productivity lost due to premature death.

c. Societal costs

Societal costs reflect the long-term burden of health loss due to Haemophilia B and were measured using disability-adjusted life years (DALYs). This includes both the years of life lost due to premature mortality (YLL) and the years lived with disability (YLD) associated with the condition's functional and quality-of-life impacts. DALYs provide a comprehensive and standardised metric to capture the non-financial consequences of disease and were monetised using the Australian Government's value of a statistical life year (VSLY) to ensure comparability with other health economic evaluations.

i. YLL: calculated as life expectancy (83) minus age at death

ii. YLD: based on disability weights sourced from literature:

- Mild: 0.054 [78]
- Moderate: 0.151 [78]
- Severe: 0.197 [78]

To ensure the robustness of the YLD estimates for Haemophilia B, values derived from literature-based disability weights were cross-checked against aggregate YLD figures for haemophilia as a whole reported by the AIHW. The Haemophilia B YLD estimates represented a proportion of total haemophilia YLD that was broadly consistent with the known prevalence ratio of Haemophilia B to Haemophilia A, providing confidence in the validity of the approach.

iii. VSLY: $245,000/year used to monetise DALYs

These estimates were sense-checked against AIHW burden of disease data for Haemophilia at the aggregated level. The resulting DALYs closely aligned with the expected share of total burden, providing external validation of the societal impact estimates.

5. Technology impact scenario

To assess the potential economic impact of gene therapy for Haemophilia B, a scenario was developed in which all adults aged 20 and over currently classified as having severe disease transition were reclassified based on post-gene therapy outcomes. This scenario was based on 24-month follow-up data from the HOPE-B trial of etranacogene dezaparvovec, a Phase 3 gene therapy study involving adults with severe or moderately severe Haemophilia B. [79]

a. Severity reclassification

In this scenario, the pre-treatment severe adult cohort was redistributed into post-treatment severity levels based on observed FIX activity at 24 months in the HOPE-B trial (n=54), as follows:

- Mild (5–40% FIX activity): 61%
- Non-haemophilic (>40% FIX activity): 33%
- Moderate (1–5% FIX activity): 2%
- Severe (<1% FIX activity due to lack of efficacy): 4%

These proportions were applied directly to the severe adult cohort in the base prevalence model, effectively shifting the distribution of severity under the gene therapy scenario. The adults in the "non-haemophilic" group were assumed to incur no ongoing direct, indirect, or societal costs associated with Haemophilia B, while those in the mild and moderate groups were costed according to their new severity classifications.

b. Assumptions

- The intervention was assumed to have occurred uniformly across the entire severe population (aged 20 and over) in the model year.
- Costs associated with the one-time administration of gene therapy were excluded from this scenario to isolate the downstream economic benefits associated with reduced disease severity.
- The shift in severity was assumed to be durable, consistent with the long-term efficacy observed in HOPE-B up to 24 months and supported by 36- and 48-month follow-up data showing sustained factor IX activity and similar clinical outcomes.

c. Purpose

This technology-level scenario does not reflect current clinical practice but serves as a forward-looking assessment of the potential economic benefit if all eligible adults with severe Haemophilia B were to receive and respond to gene therapy. It illustrates how emerging treatments could shift the burden profile of the disease and inform future investment and reimbursement decisions.

d. Limitations

Individuals aged 0–19 were excluded from this scenario. The HOPE-B trial included only adults aged 18 and over. However, the ABDR segments individuals aged 0–19 as a single group. This segmentation resulted in the exclusion of a slightly broader age range (0–19 rather than just 0–17). This likely results in a conservative estimate of cost savings.

6. Data sources

- ABDR (2021–2023) – Prevalence, severity, treatment rates
- ABS (2001–2023) – Population forecasts (LGA and national)
- NBA (2022–23, 2018–19) – Product expenditure and issue volume
- AIHW (2022–23) – Health expenditure data
- AIHW Life Tables (2020–2022) – Life expectancy and age-specific mortality rates, used for YLL calculations and to apply SMR-adjusted mortality estimate

- PBS/MBS – Pricing for outpatient and diagnostics
- NHMRC – Research funding by year
- CHESS II, literature – Productivity, YLD weights, mortality ratios

All data were processed and analysed, with calculations documented for validation and audit.

7. Assumptions

- As small number of cases were redated from the ABDR reports, we assumed that the unknown cases follow the same severity distribution as known cases.
- Recombinant Factor IX (rFIX) SHL is used for mild cases, EHL for moderate and severe.
- DALY costs are monetised using a value of a statistical life year (VSLY) of $245,000.
- Future costs are discounted at 3% annually; inflation is applied at 3.5%.
- Productivity assumptions based on CHESS II and severity-linked bleed frequency.

8. Limitations

- ABDR underreporting in smaller jurisdictions required imputation.
- Some cost components (e.g. diagnostics, community services) may be underestimated.
- Total cost of running HTCs was not available. A proxy was used based on MBS and typical out-of-pocket expenses, likely underestimating service provision costs.
- Due to variability of disability, some individuals on the very severe end may receive government supports (e.g. DSP, NDIS, aged care). A small number of people have been reported as receiving such support, but data availability limited our ability to include these costs. Therefore, modelled costs are likely an underestimate of the true financial burden.
- Research funding data excludes non-government sources.

9. Expert validation

Assumptions were reviewed and validated through structured engagement with clinicians, researchers, and advocacy groups. Key modelling inputs such as severity splits, carer burden, and treatment practices were refined through Advisory Committee feedback to ensure they reflect real-world experience.

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