Media Release

Singapore's Haemophilia Community Shows Its Resilience As It Charts the Path Towards A "Haemophilia-Free Mind"

New national study by the Haemophilia Society of Singapore (HSS) recognises the community's commitment to care, and highlights opportunities to build a more holistic, life-enabling future for patients and families.

SINGAPORE, 9 April 2026 — Singapore has made significant strides in the management of haemophilia — transforming a life-threatening condition into a treatable chronic disease, supported by strong clinical protocols, improved access to care, and recent policy enhancements to MediShield Life and MediSave.

Ahead of World Haemophilia Day (17 April), the Haemophilia Society of Singapore (HSS) has released an inaugural national study titled *Living with Haemophilia in Singapore: Care, Lived Experiences and Outcomes*. The study captures the lived realities, aspirations and daily experiences of people with haemophilia (PwH) and their caregivers across different life stages.

What emerges is a portrait of resilience — and of a community poised for the next chapter in haemophilia care. The study findings show that patient aspirations are shifting toward the goal of a **haemophilia-free mind**: a state where the condition no longer dictates every daily decision or choice.

Going Beyond the Resilience Burden

The study also recognises the **"resilience burden"** — the invisible mental and physical effort required by patients to maintain their quality of life.

"Singapore has made significant progress in haemophilia care," said Gerald Foo, President, Haemophilia Society of Singapore. "The next step is to address the daily burden of living with the condition. It's about ensuring that the logistical, mental and emotional demands don't limit how PwH and their families participate in school, work, and everyday life."

Lightening the Physical Toll

While 80% of patients report adhering to preventive treatment plans, 85% still experienced bleeding episodes in the past year, with nearly half requiring hospital care. On average, PwH reported 6 breakthrough bleeds annually despite regular preventive treatment. Furthermore, 70% live with joint-related symptoms that impair daily and long-term mobility. The community aspires to treatment options that lighten the bleed burden and better prevent cumulative joint damage.

Lifting the Psychosocial Weight

The community's resilience extends beyond the physical. The need for frequent, timely intravenous infusions — approximately 100 a year for people with Type A haemophilia on preventive treatment — contributes to a heavy mental load.[1] One in three PwH say haemophilia impacts their mental well-being, daily activities, and work lives. Of the latter, 33% say their work performance has suffered or that they have had to stop working altogether. Alongside career concerns, 30% of all respondents fear long-term dependence on subsidies. This creates a sustained mental and emotional load — one where greater psychosocial support could make a meaningful difference.

Easing the Shared Burden

Haemophilia is a weight shared by the entire family. Nearly one third of caregivers experience chronic anxiety from worrying about their loved one. 44% also said that caregiving demands have impacted their personal and professional lives, with many forced to reduce working hours or take unpaid time off. On average, the annual cost of care per PwH was found to be S$7,004, excluding the cost of medication.* Greater support in financial planning could meaningfully ease this burden for families.

Moving Towards a Haemophilia-Free Mind

Building on Singapore's strong clinical foundations, the study points to a clear opportunity: to evolve towards a more holistic model of care that supports not just physical health, but the psychological, social and financial dimensions of living well with haemophilia. The study identifies three priorities — protecting long-term mobility, advancing psychosocial support, and easing the shared burden on caregivers and families.

HSS aims to help families move from a life of limitations to a future of possibility. By achieving a haemophilia-free mind — liberated from the physical toll and psychosocial weight of the condition — patients and their families can live with confidence and thrive.

The full study is available for download **here**.

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**Please refer to the full report for a breakdown of these costs. At the time of the study, the ongoing cost of haemophilia medication was S$6,000 per annum. As enhancements to MediShield Life and MediSave coverage have since come into effect, this number may no longer be representative and is thus excluded from the report.*

About Haemophilia

Haemophilia is a rare, lifelong genetic disorder caused by a deficiency in clotting proteins (Factor VIII in Haemophilia A; Factor IX in Haemophilia B). In Singapore, approximately 280 individuals live with the condition. It primarily affects males, and is often passed down from a

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[1] Srivastava A, et al. WFH Guidelines for the Management of Hemophilia, 3rd edition. *Haemophilia*. 2020;26(Suppl 6):1–158.

parent to a child, though 30% of cases occur spontaneously with no family history. Females with the haemophilia genes are known as carriers.

Without optimal protection, patients face prolonged spontaneous or trauma-induced bleeding. These episodes can cause cumulative joint damage and impaired mobility. Continuous, high-quality care is essential to prevent long-term disability and ensure lasting independence.

About the Report

Living with Haemophilia in Singapore: Care, Lived Experiences and Outcomes is a study led by HSS, conducted by Blackbox Research and supported by Roche. The study employed a multi-method approach to capture a broad spectrum of lived realities, combining qualitative engagements with 12 PwH and 4 caregivers (via in-depth interviews, focus groups, and paired interviews) alongside a community-wide survey of 33 HSS members. Given Singapore's haemophilia population of approximately 280 people, these findings represent a meaningful cross-section of the community.

About Haemophilia Society of Singapore

Founded in 1985, the Haemophilia Society of Singapore (HSS) is a patient-led charity dedicated to supporting individuals with bleeding disorders and their caregivers. An affiliate of the National Council of Social Service (NCSS) and the World Federation of Haemophilia (WFH), HSS provides vital peer support, education, and advocacy. Today, HSS has grown into a trusted community that connects individuals and families, providing shared experiences, peer support, and education. It champions a holistic care model that reflects the lived experiences of its members, aiming to improve long-term outcomes, and empower patients to lead fulfilling lives and contribute more fully to society.

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