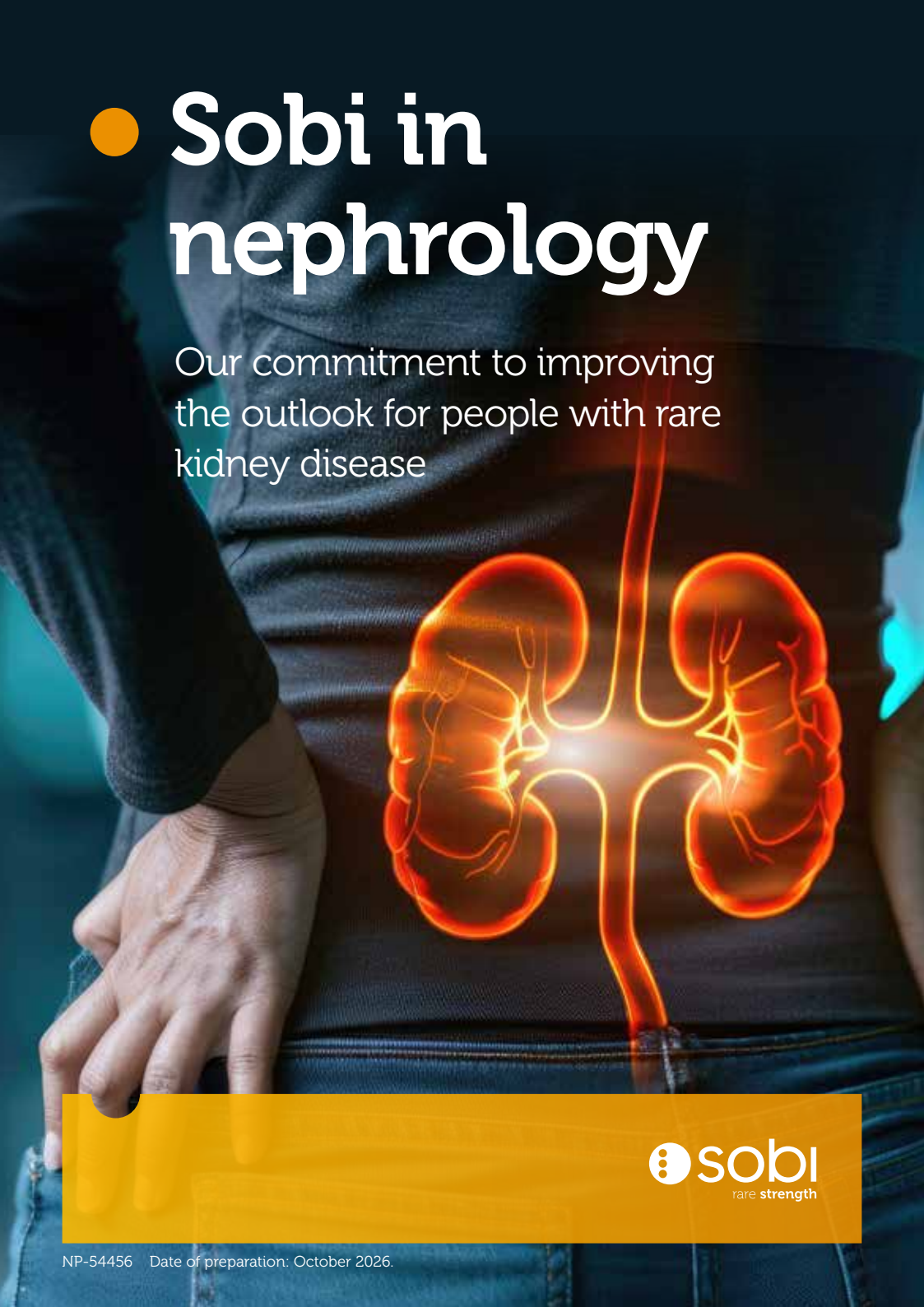
Sobi in nephrology

Our commitment to improving the outlook for people with rare kidney disease



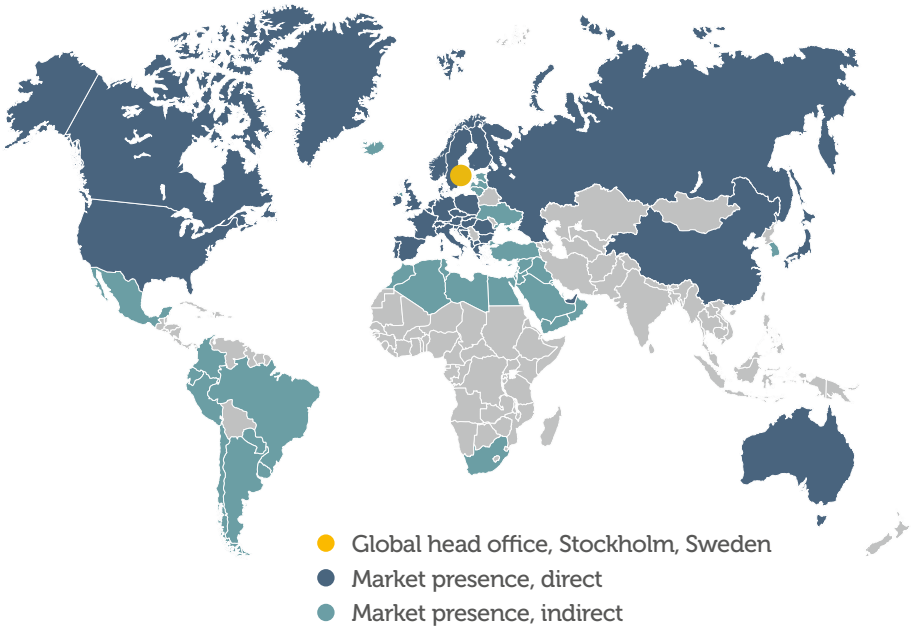
sobi
rare strength

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Who is Sobi?

Inspired by caring, powered by science

Sobi is a global biopharma company with extensive reach and a long heritage, tracing its origins to the 1930s. With headquarters in Stockholm, Sweden, Sobi has ~2,000 employees in 30 countries across Europe, North America, the Middle East, Asia, and Australia.



Committed to innovation

Providing reliable access to innovative medicines is central to our vision. We continually reinvest in research and development, providing innovative treatments, creating new evidence, and expanding the use of our medicines. A strong pipeline and expanded access are key elements of our commitment to patients.

Rare disease today

A considerable need for innovation

Despite recent advances in medicine, rare diseases continue to represent a huge unmet medical need and a significant public health challenge.

Only 5% of the estimated **>10,000 rare diseases** globally have approved medicines[1,2]

~50% of those affected by rare diseases are children[3]

400 million people worldwide are affected by rare diseases[3]

If everyone with a rare disease lived in one country, it would be the world's 3rd most populous country, after China and India[4]

1. National Human Genome Research Institute. genome.gov/dna-day/15-ways/rare-genetic-diseases. Accessed October 2026.
2. National Organizations for Rare Disorders. rarediseases.org/understanding-rare-disease/rare-disease-facts-and-statistics/. Accessed October 2026.
3. Global Genes. globalgenes.org/rare-disease-facts/. Accessed October 2026.
4. Sobi.com. sobi.com/en/focus-rare-diseases. Accessed October 2026.

Sobi rare strength

We specialise in rare disease, with therapies concentrated in haematology, immunology, and specialty care. Our mission is to transform the lives of people with rare and debilitating diseases.

17 medicines

11 major ongoing clinical studies and medicines in registration

19 indications across:

Haematology Haemophilia (A, B), ITP, DLBCL, PNH, HGBL
Immunology FMF, CAPS, DIRA, HLH, RSV, RA, sJIA, Still's Disease
Nephrology C3G, primary IC-MPGN
Specialty care HT-1, AKU, hATTR, FCS

Elevating the standard of care in haematology

From our pioneering days producing blood products in the mid-20th century, to today offering products that improve health and quality of life for people with haemophilia, haematology holds a special place in our legacy. Our products have consistently set new standards of care, benefiting patients around the world.

AKU: Alkaptonuria, **C3G:** C3 glomerulopathy, **CAPS:** Cryopyrin-associated periodic syndromes, **DIRA:** deficiency of interleukin-1 receptor antagonist, **DLBCL:** Diffuse large B-cell lymphoma, **FCS:** Familial chylomicronaemia syndrome, **FMF:** Familial Mediterranean fever, **hATTR:** Hereditary transthyretin amyloidosis, **HGBL:** high-grade B-cell lymphoma, **HLH:** Hemophagocytic lympho-histiocytosis, **HT-1:** Hereditary Tyrosinaemia Type 1, **IC-MPGN:** immune complex membranoproliferative glomerulonephritis, **ITP:** Immune thrombocytopenia, **PNH:** Paroxysmal nocturnal haemoglobinuria, **RA:** rheumatoid arthritis, **RSV:** Respiratory syncytial virus, **sJIA:** Systemic juvenile idiopathic arthritis.

Humanitarian aid program

WFH
WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

More than 75% of people with haemophilia around the world have limited or no access to diagnosis and treatment.[1] Sobi is a key sponsor of the WFH Humanitarian Aid Program, which helps address the lack of access to care and treatment by providing much-needed support for people with inherited bleeding disorders in developing countries.

Over a decade of humanitarian support in haematology

From 2014 to 2024, Sanofi and Sobi together donated one billion IUs of clotting factor through the World Federation of Hemophilia Humanitarian Aid Program, helping treat 22,219 people with inherited bleeding disorders.

This collaboration was renewed in 2025, committing support for up to five further years.[1]

Over 22,000 people reported treated since programme began[2]

Over 17,000 acute bleeds treated in 2024[2]

Over 1,300 surgeries in 2024[2]

1. Sobi.com. sobi.com/en/humanitarian-aid. Accessed October 2026.
2. Sobi annual and sustainability report 2024. Available at sobi.com/sites/sobi/files/pr/202503277259-1-1.pdf. Accessed October 2026.

Rare disease

Focus on nephrology

Rare kidney diseases are a group of conditions with a collectively significant impact.[1] Although rare kidney diseases account for 5–10% of people with chronic kidney disease, they constitute over a quarter of those on dialysis or with a kidney transplant, globally.[2] Focusing on rare conditions could significantly reduce the burden of kidney disease on both patients and health services.[2]

Sustained collaboration across research, clinical care, and industry is essential to further advance treatment and improve outcomes for people affected by rare kidney diseases.[2]

Sobi's commitment to nephrology

To focus on improving lives for people with rare kidney disease, with urgency and purpose



1. Halfon M, et al. Kidney Int Rep. 2024;10(1):75-86
2. UKKA Urgent Need for Rare Disease Treatments to Combat Kidney Failure. March 2024. ukkidney.org/about-us/news/urgent-need-rare-disease-treatments-combat-kidney-failure. Accessed October 2026.

Sobi in rare kidney disease

A clear continuation

With our long-standing commitment to haematology, immunology, and rare metabolic diseases, our expansion into nephrology is a natural next step, given the inextricable link between these disease areas.

For instance, the kidney is particularly vulnerable to immune system dysregulation, often seen as 'the innocent bystander' in conditions involving the immune system.

"Clinical research in rare renal diseases has increased significantly over the past decade.

But continued commitment is critical because, without effective intervention, kidney disease can progress and ultimately lead to the failure of this vital organ."

Lydia Abad-Franch

Head of R&D and Medical Affairs and Chief Medical Officer at Sobi

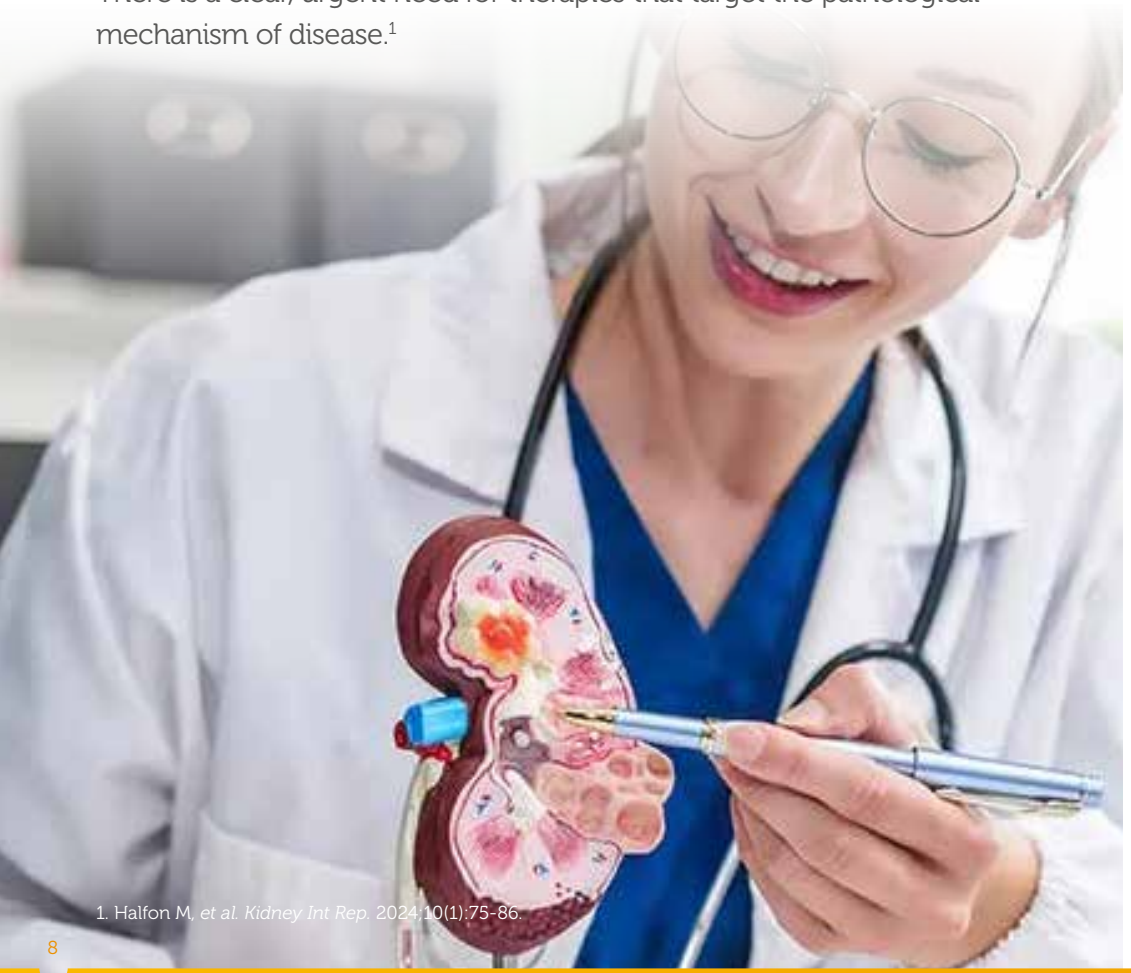


Sobi nephrology in focus

C3G & primary IC-MPGN

Complement 3 glomerulopathy (C3G) and primary immune-complex membranoproliferative glomerulonephritis (IC-MPGN) are ultra-rare chronic kidney diseases.[1]

They have an overall poor prognosis, with ~50% of patients progressing to kidney failure within 10 years of diagnosis, despite available therapies.[1] There is a clear, urgent need for therapies that target the pathological mechanism of disease.[1]



1. Halfon M, *et al. Kidney Int Rep.* 2024;10(1):75-86.

Unite4Rare

Our commitment to the rare disease community

Meaningful patient engagement in rare diseases is inherent to Sobi's DNA. We have a long history in ensuring people living with rare diseases, and their families, can receive the life-saving care and therapies they need, and that their voices are heard.

Unite4Rare is Sobi's long-standing commitment to the patient and caregiver community, outlining all of our responsibilities, what has been done so far and how we will measure progress into the future.

Co-created by internationally renowned patient community leaders and senior leadership within Sobi, Unite4Rare builds on Sobi's history of specialised expertise in rare diseases and patient engagement, taking it to the next level. It demonstrates our dedication to making a positive impact by clearly outlining what patients and caregivers can expect from us.

Unite 4 Rare



www.sobi.com/en/focus-rare-disease

Patient partnership

Our committment to nephrology

Sobi's five core values

These values reflect our approach to meeting the needs of people living with rare diseases, who are otherwise often overlooked. They are inherent to our pursuit of creating a patient-partnered culture across the company.

1. Care
2. Ambition
3. Ownership
4. Urgency
5. Partnership

Sobi-supported organisations:

- Compcure
- European Kidney Health Alliance (EKHA)
- European Kidney Patients' Federation (EKPF)
- European Renal Association (ERA)
- European Society for Paediatric Nephrology (ESPN)
- International Pediatric Nephrology Association (IPNA)
- International Society of Nephrology (ISN)
- International Society of Glomerular Disease (ISGD)
- Kidney Disease: Improving Global Outcomes (KDIGO)
- World Kidney Day (WKD)

Get in touch to learn more about how we can collaborate to improve outcomes in rare kidney disease:
www.sobi.com/contacts

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