RECORDATI
RARE DISEASES

PATIENT COMMUNITY CHARTER

UNLOCKING THE FULL POTENTIAL OF LIFE

OUR PROMISE TO KEEP THE PATIENT COMMUNITY AT THE HEART OF ALL WE DO.

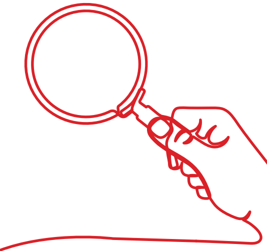
At Recordati Rare Diseases, patients with rare diseases are our top priority. They are at the core of our planning, our thinking and our actions. This Charter embodies our commitment to the patient community; it guides how we act and understand and respond to their needs. It helps us to uphold our promise to always behave ethically and act responsibly.

Scott Pescatore
Executive Vice President, Rare Diseases

THE PATIENT COMMUNITY CHARTER:

Embodies a core set of principles and behaviours guiding our interactions with patients and the healthcare community.

Formalises our commitment to the patient and caregiver communities through systematic engagement at every stage of the medicine development lifecycle.



Is backed by robust measurements to **hold us accountable** to our goal of putting patients at the heart of everything we do.

Is aligned with our commitments to society and highlights our **unique and special relationship** with rare disease **patient communities**.

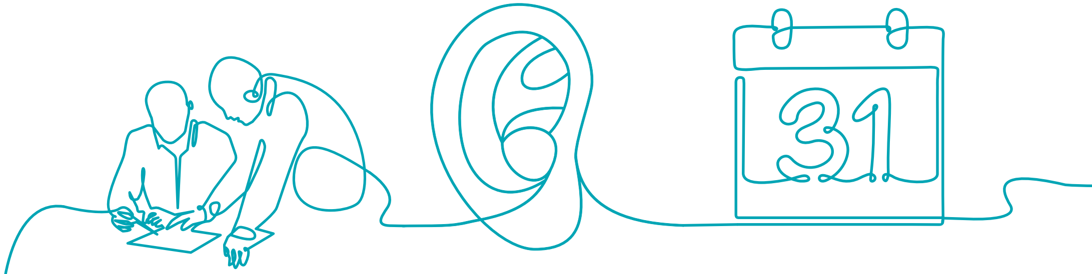
OUR AMBITION...

01

TO BECOME A **TRUSTED PARTNER**

We listen to the patient community, value their insights, and treat them as equal partners. We create opportunities for patients to share their stories and experiences with us and the broader community.

To achieve our ambition, we:



Have established a Patient Community Council and participate in various patient forums, allowing us to continually listen and learn from the patient community.

We listen to the patient community, and have open, honest and transparent communication. We agree actions together and are clear about mutual expectations.

Co-create mutually beneficial programmes of activity that have a shared purpose, with clearly defined roles and responsibilities.

Engage and involve the patient community early in all aspects of the product life cycle process, from early clinical development to post-marketing authorisation activities, ensuring our work always focuses on their needs.

> “I would prefer the approach to be that **we can be part of the solution together** rather than coming to us at a late stage and asking to check something.”

Solving Kids' Cancer,
A UK patient organisation
for neuroblastoma

> “It’s **important** to start projects, right from the early idea, with **the patient voice incorporated.**”

World Alliance of Pituitary Organizations (WAPO),
A global patient organisation
for pituitary conditions

02

TO ENSURE AN EXCEPTIONAL EXPERIENCE WHEN **COLLABORATING WITH US**

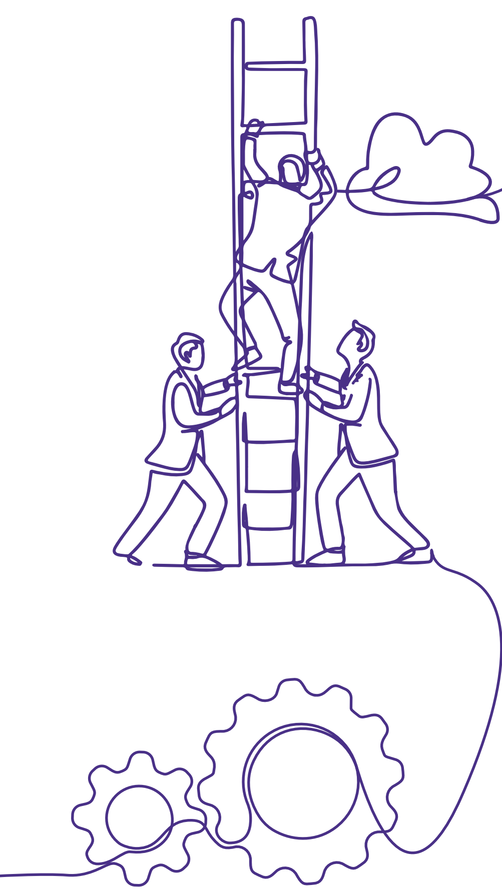
We make it easy for patients to connect and collaborate with us. We engage with the patient community thoughtfully and respectfully, considering their unique and diverse needs in all our interactions. We stay open and honest, to keep a clear balance between what our partners need and our business commitments.

To achieve our ambition, we:

Seek to constantly improve our collaborations and co-create innovative solutions through our membership in Patient Focused Medicine Development (PFMD) and the development of training programmes and materials.

Created a dedicated patient community section on our website with clear and easy-to-access contact information.

Always strive to identify opportunities to provide broader support and capacity building for patient groups and meet the needs of diverse patient communities.



Developed patient-friendly contracting and payment processes along with a fair market value tool to ensure appropriate compensation, in line with The European Federation of Pharmaceutical Industries and Associations (EFPIA) Code of Practice.

"**Collaboration** between pharmaceutical companies, researchers and patient organisations is essential for **advancing treatment options.**"

Cystinosis Support Network Europe (CNE), A European patient organisation for cystinosis

"It's so important for us to really **build a strong relationship** and for it to develop into more of a strategic partnership."

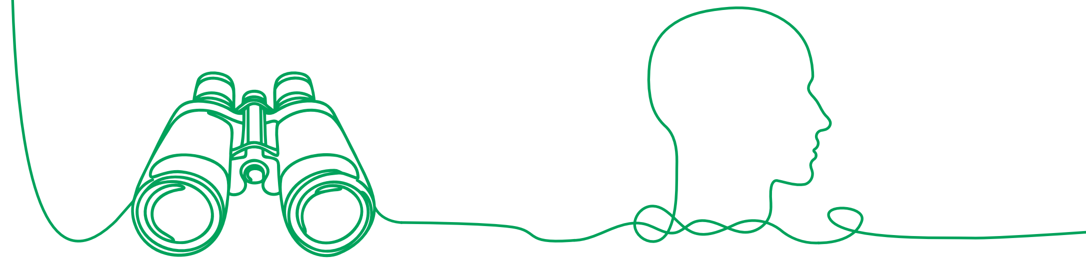
Cutaneous Lymphoma Foundation (CLF), A US patient organisation for cutaneous lymphoma

03

TO ENSURE WE BRING **VALUE TO BOTH THE PATIENT COMMUNITY** AND OUR BUSINESS

We build genuine partnerships to create lasting solutions for patients and ensure our projects provide mutual benefits and value. We support and encourage our teams to learn about patient engagement, the rare disease community and our role in improving quality of life, to make sure we keep the patient at the centre of all our business decisions.

To achieve our ambition, we:



Engage the patient community continuously across our business, to fully understand the patient journey and identify long term needs where we can add mutual value.

Foster a patient-focused mindset, communicating the importance and impact of patient engagement internally, with the help of our Patient Council and Patient Ambassadors.

Provide education and training to help our teams meet our Charter commitments.

> "**We strive to bring added value for patients by working with patient groups and seeing where we can co-create win-win scenarios.** We can only do that by listening to patients and focusing on their needs."

Lise De Strooper,
Medical Affairs Manager Benelux, and Recordati Rare Disease Patient Ambassador

04 TO DEMONSTRATE THE **IMPACT OF OUR COLLABORATIONS**

We set clear goals when collaborating with the patient community and track our progress. We ask for feedback and find ways to measure the long-term impact of our work, using what we learn to improve future activities.

To achieve our ambition, we:

Set clear goals and metrics for patient engagement and regularly measure and report on these.

Publish annual updates on our work with the patient community, including outcomes and future plans.

Offer opportunities to provide feedback on the outcomes and impact in all projects involving the patient community.

“**Setting goals, tracking progress, seeking feedback and measuring impact** are not just actions—they are our **commitment to understanding the needs of the rare disease community.** By embracing these practices, we ensure that our efforts create meaningful, positive outcomes for all stakeholders.”

Glenn Darley,
EMEA Patients Engagement Lead,
Recordati Rare Diseases

The Patient Community Charter was created using feedback and insights from the following patient organisations, together with a team of Patient Ambassadors at Recordati Rare Diseases

- Beacon: For Rare Diseases
- Cystinosis Support Network Europe (CNE)
- World Alliance of Pituitary Organizations (WAPO)
- Lymfklierkanker Vereniging Vlaanderen (LVV)
- Cutaneous Lymphoma Foundation (CLF)
- Associazione Malati Italiani Castleman – Odv (AMICa Odv)
- Castleman Disease Collaborative Network (CDCN)
- European Organisation for Rare Diseases (EURORDIS)
- Solving Kids' Cancer
- Hypofyse- og binyreforeningen (HYBI)
- Asociación Española de Afectados por Acromegalia
- Leukämiehilfe Rhein-Main (LHRM)

WE SINCERELY THANK EVERYONE INVOLVED FOR THEIR CONTRIBUTIONS IN BRINGING THE CHARTER TO LIFE

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