

ADVANCING CLINICAL AND SCIENTIFIC VALUE IN RARE DISEASE RESEARCH: OSTEOGENESIS IMPERFECTA ARTICLE

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EXECUTIVE SUMMARY

Osteogenesis imperfecta (OI) presents lifelong clinical challenges for patients and physicians alike – from managing fracture risk to navigating bisphosphonate therapy and surgical interventions. Yet few providers have access to longitudinal, structured outcome data to guide treatment decisions or assess long-term effectiveness.

RegenMed Circles changes that by giving physicians the tools to collect compliant, real-world data (RWD) directly from clinical care – without disrupting workflows. With Circles, OI specialists gain insights that lead to better protocols, stronger patient outcomes, and evidence-based care pathways tailored to rare bone disease. While Circles support revenue generation through data licensing, the core mission remains clinical: empowering communities of providers to advance care through shared data, shared insights, and shared impact.

www.rgnmed.com | circles@rgnmed.com



INTRODUCTION

Osteogenesis imperfecta (OI) is a rare genetic disorder characterized by increased bone fragility, which often requires a lifetime of complex care. Patients with OI may receive bisphosphonate infusions to improve bone density, undergo corrective surgeries to manage fractures or deformities, or benefit from physical therapy and emerging regenerative approaches. However, despite advancements in medical treatments, clinicians continue to face significant uncertainty in managing OI.

Questions persist about which patients respond best to bisphosphonates over time, how fracture frequency may change with growth or puberty, and what the long-term functional outcomes are of early orthopedic interventions. These critical issues are difficult to answer with certainty, and many providers must rely on fragmented notes, anecdotal recall, or small, siloed studies to inform their high-stakes decisions. In a field where treatment protocols and patient care are still evolving, it's clear that the need for better, more structured data has never been greater.

THE OPPORTUNITY: CLOSING THE OUTCOMES GAP

OI care spans years, disciplines, and interventions – but structured outcome tracking is virtually nonexistent. Physicians often struggle to:

- Standardize assessments of pain, function, and quality of life
- Track treatment response across growth stages
- Analyze long-term effects of pharmacologic and surgical interventions
- Share data or collaborate with peers on new protocols

This creates missed opportunities to learn from real-world outcomes and improve care at scale. As precision medicine advances and regulators seek more real-world evidence, longitudinal, de-identified datasets are becoming critical – not optional.

REGENMED CIRCLES: A PLATFORM FOR COLLABORATIVE CARE

RegenMed Circles are secure, physician-led networks built to collect, analyze, and share structured outcome data – designed specifically for rare and complex conditions like OI. Through Circles, OI providers can:

- Capture patient-reported outcomes and clinical events across visits
- Track response to bisphosphonate therapy, surgeries, and rehab over time
- Compare anonymized data against aggregate benchmarks
- Propose or join disease-specific registries and research cohorts

Each Circle is tailored to clinical priorities – like fracture incidence, mobility scores, or growth metrics – and can incorporate custom scoring formulas and patient-reported outcome measures (PROMs) built in collaboration with care teams.

Physicians can join existing Circles or propose new ones based on their areas of interest.

Real-world evidence is becoming essential – not optional.

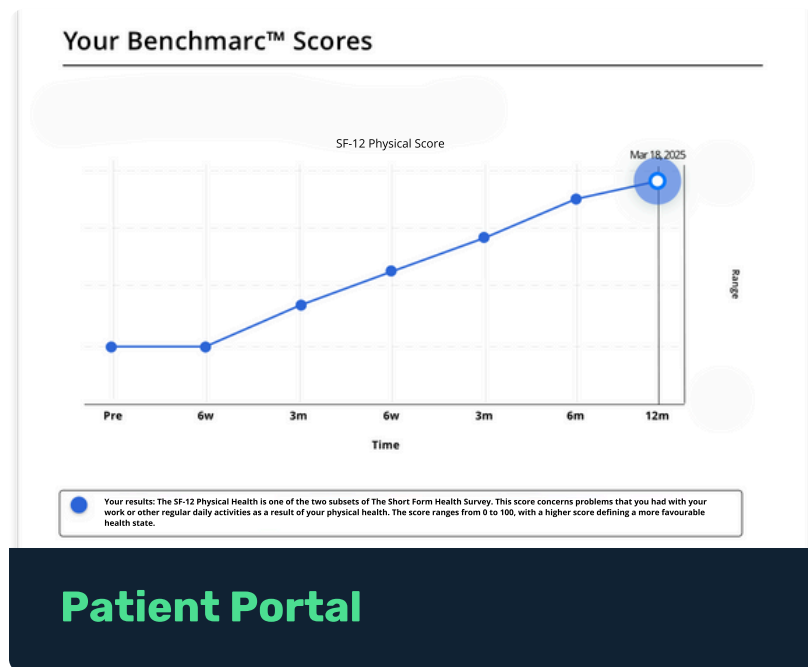
IMPROVING PATIENT OUTCOMES THROUGH REAL-WORLD EVIDENCE

By collecting outcomes data in a structured, longitudinal format, clinics gain powerful tools to improve care:

- Identify top-performing protocols and refine treatment plans
- Monitor long-term changes in mobility, function, and pain
- Detect adverse events early and respond proactively
- Share findings with peers, researchers, and families

Circle members receive interactive dashboards, cohort-level reports, and access to collaborative datasets.

These tools empower providers to continuously improve outcomes – without hiring new staff or disrupting care delivery. See below for some examples of what the platform looks like and how it can be used to assess patient outcomes.



MONETIZING YOUR REAL-WORLD DATA

In addition to improving care, RegenMed Circles create sustainable revenue through compliant, de-identified data licensing. Clinics can:

- License aggregate datasets to pharma, device, or digital health partners
- Earn up to 85% of licensing revenue
- Participate in studies that shape future treatment development

Revenue is just the beginning. Circle participation supports scientific publications, conference presentations, and national recognition for clinical leadership.

CALL TO ACTION

Whether you specialize in pediatric bone health, genetic orthopedics, or multidisciplinary rare disease care, RegenMed Circles can help you turn everyday care into evidence-based advancement.

Visit www.rgnmed.com/circles or contact us to learn how to launch or join an OI Circle tailored to your clinical priorities.

CONTACT US

RegenMed | www.rgnmed.com
circles@rgnmed.com