

Scout | Clinical

CASE STUDY:

Duchenne Muscular Dystrophy Trial in China

Expanding access and overcoming barriers in an underserved patient population



BACKGROUND

A global pharmaceutical sponsor was running a Duchenne Muscular Dystrophy (DMD) trial in China, one of the few of its kind in the country. Children living with DMD often lose mobility at a young age, making weekly infusion visits physically and emotionally difficult. Many families lived in rural areas, requiring repeated long trips or temporary relocation to urban sites.

At the time, there was broad skepticism about whether patient services could be delivered reliably in China, with concerns around culture, language, and technology.

CHALLENGES

- Pediatric rare disease population with severe mobility needs
- Weekly infusion schedule with no room for missed visits
- Long distances requiring multiple modes of transportation
- Holiday travel surges creating capacity and cost barriers
- Hesitancy to use a foreign vendor due to cultural concerns
- Industry focus on data privacy while families faced practical barriers of distance, language, and trust

SCOUT'S APPROACH

1. China-based Patient Liaison team serving as a direct bridge between families, sites, vendors, and sponsor
2. Partnerships with local vendors to arrange complex, multi-leg travel and lodging
3. Scout Portal proven to operate smoothly in China, with site staff trained step by step on what information to collect
4. 24/7 support for families, resolving urgent issues when sites were unavailable
5. Direct sponsor communication to secure approvals when sites were uncertain about policies or special requests

SCOPE

Provide travel logistics and patient liaison services for children with DMD. Families faced weekly infusion visits requiring extensive travel by car, train, plane, and ferry. Support included relocation assistance, coordination with local vendors, and communication with sites and sponsors.

SPECIALIZED SOLUTIONS

Families traveled weekly from remote provinces into major cities. Scout supported relocations to site cities when travel was too burdensome and secured transportation during Chinese New Year, when holiday travel surges made tickets scarce and expensive.

Local communication was essential. Families could interact with Scout staff in Chinese and coordinate with vendors through familiar channels. The Scout Portal operated reliably in China and supported local language needs, with translation available in multiple dialects to ensure patients and sites could access information clearly. Banking hurdles were eased with clear site instructions for international wire transfers, reducing reimbursement worries.

The impact was felt directly by families and sites. Parents shared that Scout made their journeys smoother and gave them meaningful support. One parent wrote,

"You have made this journey no longer lonely and given our family tremendous support."

Sites benefited from reduced administrative burden, while the sponsor saw continuity of care without interruption. The experience confirmed that with the right support, complex studies in China stay on track and keep patients engaged.