

Patient Crossroads™



WHAT WE DO EXACTLY

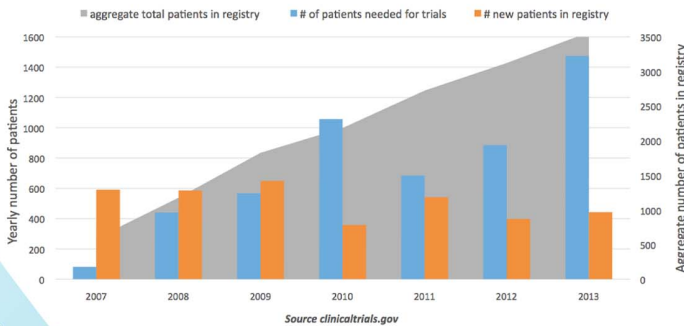
We're Patient Crossroads, a place where people can share and access medical data to hasten the search for cures.



We've pioneered the CONNECT registry platform, which allows patients around the world to join others in reporting their own experience of disease. We collect and safeguard the data to protect patients' privacy. We then upload the de-identified data to a common hub and share it with researchers and advocates.

Our system helps researchers unlock more effective treatments. It helps care providers better understand diseases. It makes organizing patient communities easier for advocacy groups. And it lets patients see how other people are managing illness.

WHY WE'RE HERE



Challenge

Challenge: As research activity on Duchenne-Becker muscular dystrophy surged in the last decade, investigators needed a platform to communicate with a global patient base. DuchenneConnect proved to be a reliable source of patients.

Every disease community should have a common, accessible patient registry.

We've heard over and over that creating a shared registry of patients is one of the most valuable things a disease community can do. A registry puts critical information about a disease all in one place. This makes it easier for researchers to study the disease, for patients to learn about front-line treatments and for advocates to speak on behalf of the disease community.

But registries are hard to maintain.

Registries are expensive. They need constant upkeep — usually by people with a lot of expertise in disease and data management. Often there are multiple competing registries for one disease, which leads to siloed, dead-end data that nobody can use.

Patient Crossroads is here to fix all of that.

Our CONNECT platform enables anyone—from individual patients to global research organizations—to collect and share disease data in a way that's controlled, transparent and centered on patients' best interests.

SUBSCRIPTION PROGRAM

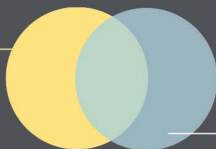


Interested organizations can subscribe to **CONNECT** disease areas. We work closely with clients to craft the program to meet your specific requirements. We are experts in patient registries and will ensure your goals are met. Our annual subscription includes:

- Recognition and branding as a supporter of the community
- Ask up to 100 disease specific survey questions
- Key medical and diagnostic reports can be submitted by patients
- Access our data analytics portal to view aggregated, real-time patient data
- Our medical staff will review patient medical surveys for accuracy and completeness
- Receive reports and analysis of collected data
- Ability to send clinical trial study notices to pre-screened participants and their physicians

AUDIENCES WE SERVE

DOWN SYNDROME



ALZHEIMER

WHAT CAN DOWN SYNDROME TELL US ABOUT ALZHEIMER'S?

By age 40, a full 40 percent of people with Down Syndrome will also develop Alzheimer's. We're helping researchers understand why. Because we collect consistent pan-disease data, we've created new opportunities to study how conditions interact.

Industry

Industry organizations join **CONNECT** by subscribing to patient registries for disease communities. In return, they have access to all de-identified data to better understand disease baselines and qualify populations for clinical trials. We also help recruit patients for trials—at a fraction of the ordinary cost.

Patients and Families

Patients and families can join a registry to submit their own data. After taking web-based surveys, they can explore public data we've collected. The more surveys they complete, the more they can view. Patients always retain ownership of their data and can opt in or out any time.

Advocates

Disease organizations and patient advocacy groups can join the program as partners at no charge. They control the branding of their customized registry homepage and get a unique URL. Partners educate the community on the importance of participating in the registry. In return, they get access to de-identified data and tools for organizing the patient community.



RECOGNITION & AWARDS

Founded in 2004, PatientCrossroads is the leader in building patient-entered registries collecting data on over 250 diseases. Dedicated to openly accessible and patient-centric registry programs, PatientCrossroads has been recognized globally for their innovative programs:

- | National Institutes of Health Merit Group Award, National Down Syndrome registry
- | Patient-Centered Outcomes Research Institute (PCORI) grant recipient
- | RD-CONNECT European Union FP7 grant partner
- | NIH Office of Rare Diseases Research, Global Rare Disease Registry program

Patient Crossroads™

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