

# Patient Crossroads™



## WHAT WE DO EXACTLY

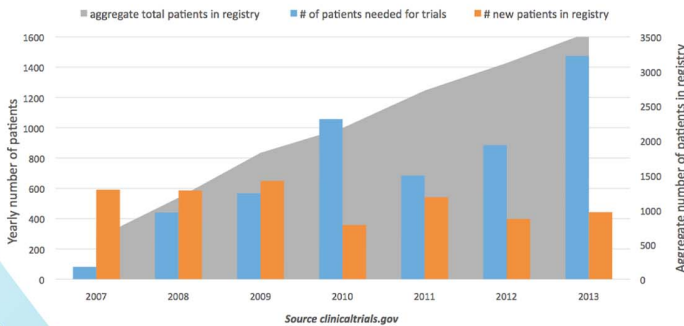
We're Patient Crossroads, a place where people can share and access medical data to hasten the search for cures.



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



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.

### 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.

## REGISTRY PARTNER PROGRAM



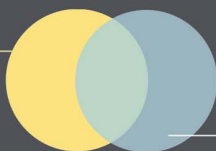
Set up a **CONNECT** registry. Brand it to your cause, and collect all the data your community needs at no cost. Then take the money you would have spent on creating a registry and go use it for research and advocacy and making people's lives better.

As Registry Partners, non-profit organizations and institutions educate the community on the importance of joining the registry through their marketing and outreach channels. In return, they receive all de-identified data and a customized registry portal.

- Start a registry TODAY in a system that protects patient privacy
- Use your branding and logo to customize the registry portal
- Collect data for pan-disease analysis and open data-sharing
- Contribute common data elements to global & NIH registry initiatives, as available
- Send educational information and newsletters to participants
- Access our data analytics portal to view aggregated, real-time patient data
- Opportunities for custom or research data collection available

## 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.

### 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.

### 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.



## RECOGNITION & AWARDS

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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

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