



IBM Research Program Updates

In partnership with Myositis Support & Understanding

December 2020

Agenda

- Introductions
 - ◆ Myositis Support & Understanding
 - ◆ AllStripes Team
- Update on our name
- AllStripes research updates
- AllStripes sign-up demo and platform updates
- What's next for IBM at AllStripes
- How you can continue to help the myositis community
- Q&A



Update on our new name: it's official, RDMD is now AllStripes!

We chose the name AllStripes to honor rare disease patients and caregivers. The zebra is the global symbol for the rare disease community – the name AllStripes represents the collective strength and impact of patients coming together and sharing their experiences.

Did the company change ownership?

No, we did not change ownership or company structure. The same dedicated team is at work behind the scenes. We changed our name, because we are in this fight for the long haul. We wanted a name that honors the strength of rare disease patients and reflects our commitment to the community.

Read more via: <https://www.allstripes.com/blog/new-name-all-stripes>

Our mission is to unlock new treatments for people with rare disease.

AllStripes works with patients, doctors, advocacy groups, and drug companies to find treatments for Manuel and the millions of rare disease patients like him.

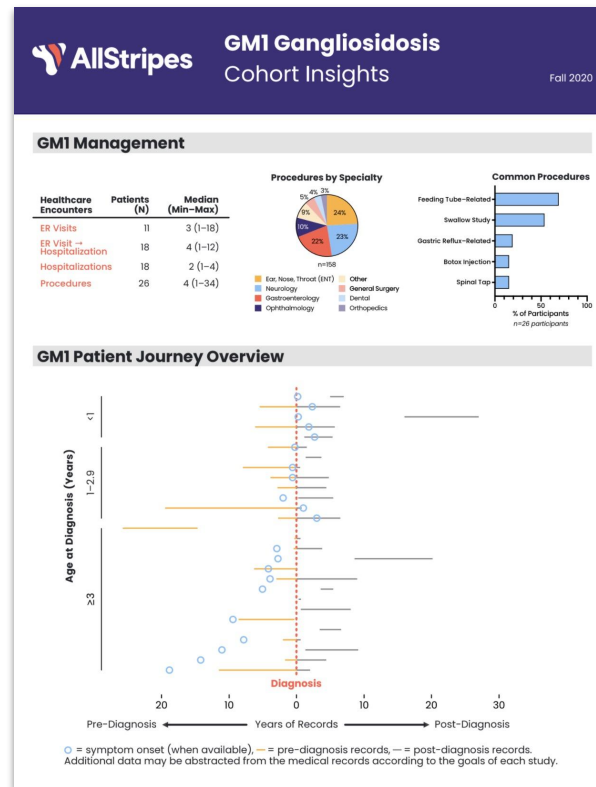
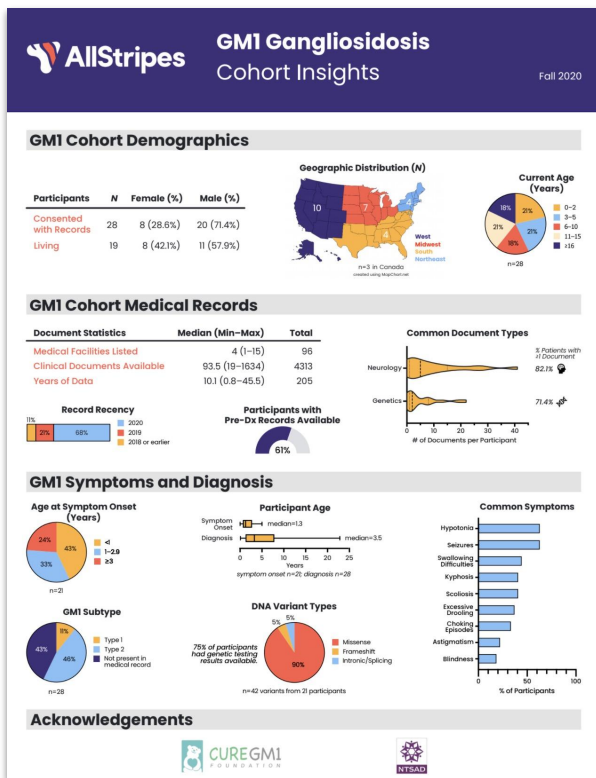


AllStripes Updates on our Research

→ AllStripes Insights Program

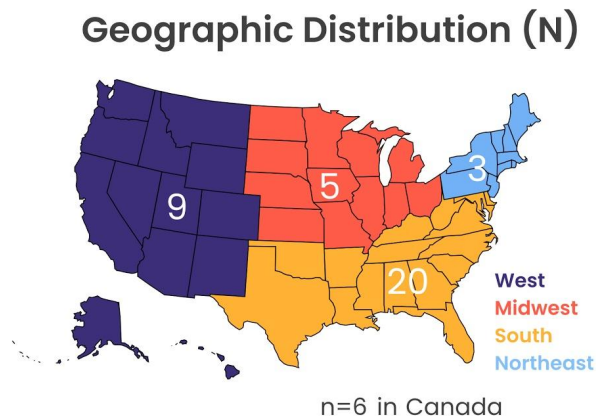
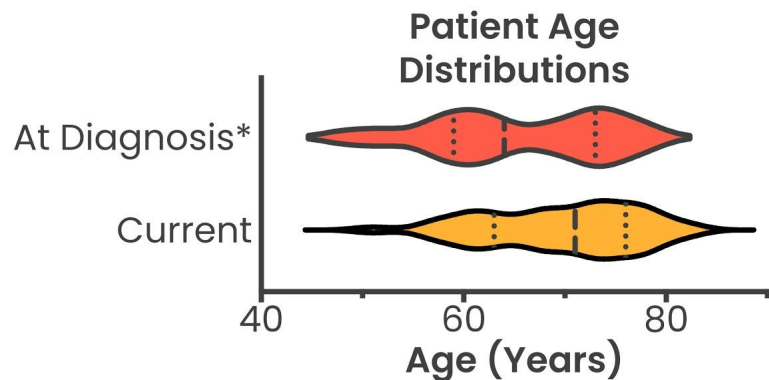
- ◆ Our team will generate high-level insights for every condition on the AllStripes Platform based on participant medical records.
- ◆ AllStripes Insights include topics like the following:
 - Demographics
 - Diagnosis
 - ER visits & hospitalizations
 - Symptoms
 - Medications
- ◆ De-identified insights are summarized and shared back to the community.
- ◆ Researchers can request access to de-identified Insights data for non-commercial studies.

Insights Example

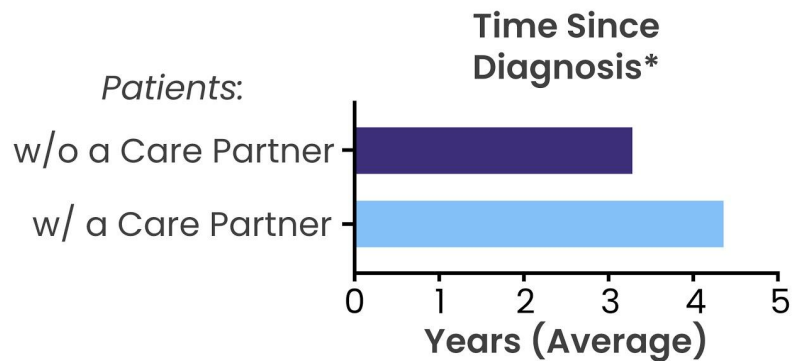


Insights Example: Demographics of Progressive Supranuclear Palsy

- 43 participants: 24 male and 19 female



Insights Example: Care Partners in Progressive Supranuclear Palsy

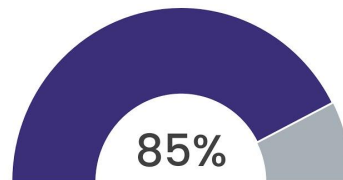


Insights Example: Medical Records in CIDP

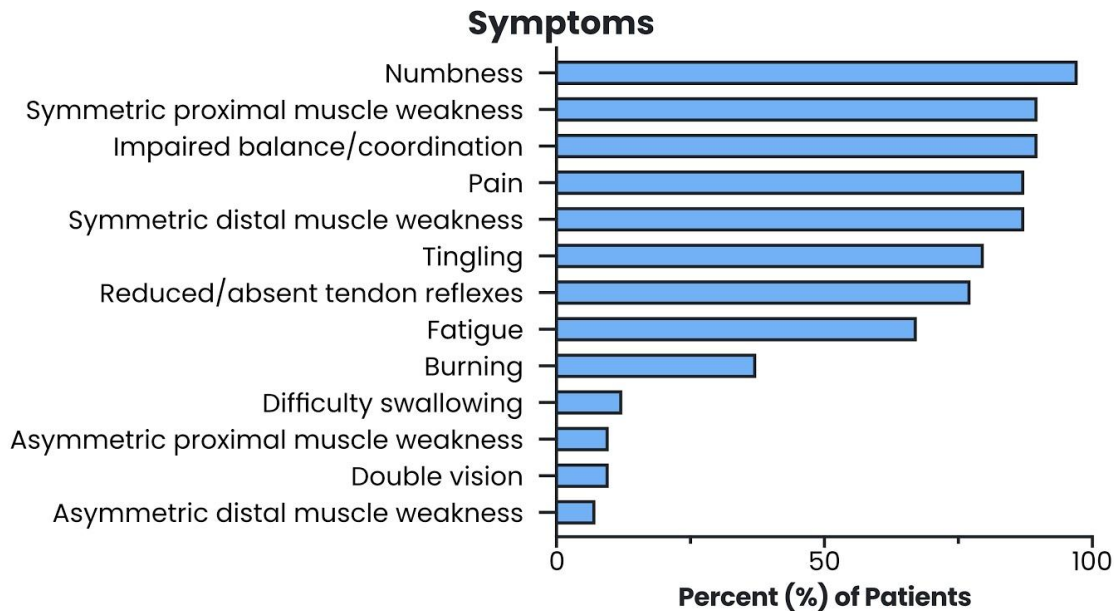
- 40 participants: 20 male and 20 female

Document Statistics	Per Patient Median (Min–Max)
Medical Facilities Listed	4 (1–22)
Clinical Documents Available	59 (18–781)
Neurology Notes	13.5 (3–73)
Years of Data	5.8 (1.3–23.7)

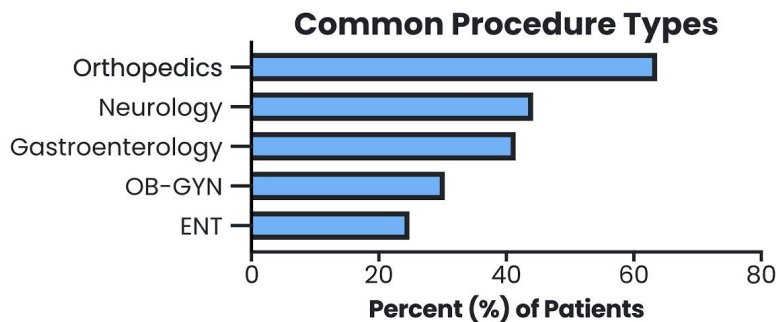
**Patients with
Pre-Dx
Records
Available**



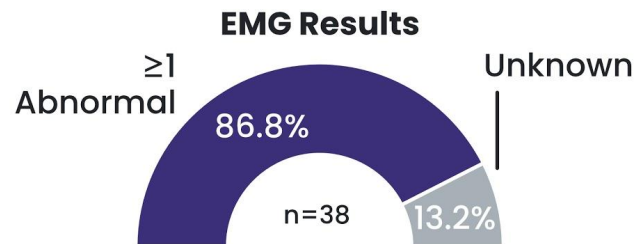
Insights Example: Symptoms in CIDP



Insights Example: Procedures in CIDP

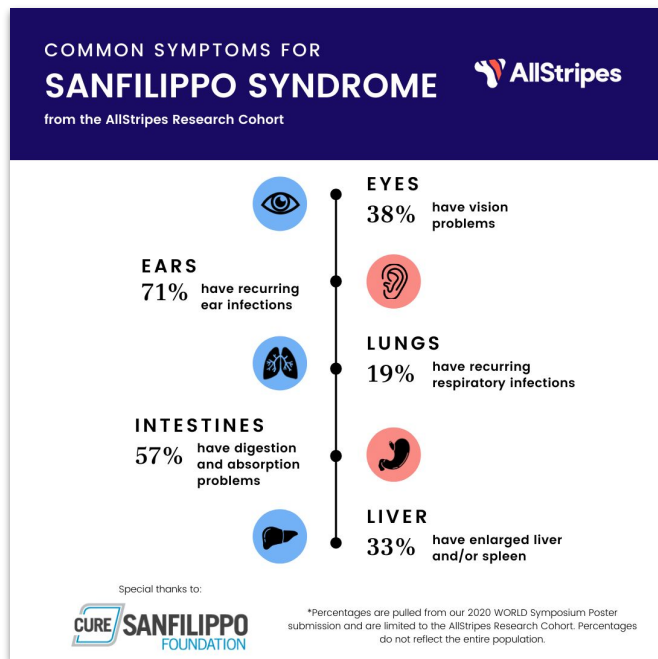


n = 36 patients with procedures. Lumbar punctures represented the most common procedure (15/136 or 11%).



0 patients with available EMG interpretations had only normal results

Research insights are shared back via social media, email, and blog posts



← Blog

Ensuring High-Quality Data for Rare Disease Research

Updated October 23, 2020



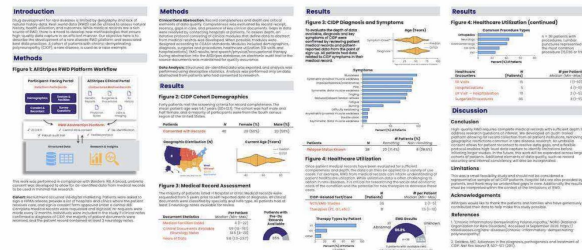
Once AllStripes collects your medical records, how do we use them for research? One important step is verifying the completeness and depth of the data from each participant.

By Caitlin Nichols, PhD

Development of a robust real-world data platform for rare diseases



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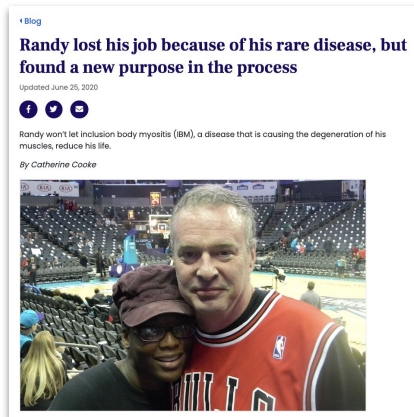
At AllStripes, our mission is to unlock new treatments for people with rare diseases. One of the ways the AllStripes research team contributes to this mission is by asking important questions about the diagnosis, symptoms, and progression of rare conditions. We do this by analyzing de-identified information extracted from participants' medical records, looking for new patterns or connections. But as with so many endeavors, the quality of our output (research findings) can only be as good as the quality of our input (medical data). So before we can begin asking new questions about the rare diseases we study, we must first ensure our starting data is as complete and deep as possible. We recently detailed this process in a research poster presented at the 2020 International Conference on Pharmacoepidemiology (ICPE), using the rare condition chronic demyelinating polyneuropathy (CIDP) as a case study.

Up next for IBM at AllStripes

- The IBM Insights Program will launch in early 2021.
- We are piloting a new approach to make the Insights even more patient-centric:
 - ◆ All participants in the AllStripes IBM Community will receive a survey about top symptoms that impact their lives.
 - ◆ That survey will provide the basis for the symptoms we analyze in the medical records.
- Insights will be available in Fall 2021.

What you can do now

- ➔ Share your myositis experience
- ➔ Join the AllStripes IBM program if you haven't via allstripes.com/IBM
- ➔ If you have, update your information:
 - ◆ New doctors or care providers
 - ◆ Verify your email and contact information
 - ◆ Add a care partner
 - ◆ Answer surveys
- ➔ Reach out to our team for feedback and suggestions (support@allstripes.com)





Thank you

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