Enabling Real-Time Insights from Patient-Generated Registry Data

> The RUNX1 Patient Data Hub has officially launched, and we are encouraged by our participation numbers in just a few short months. Our research community is on the cusp of launching the first therapeutic trials for our rare disorder and having our patient community represented in the REDCap Cloud platform will no doubt facilitate trial recruitment in the immediate future and offer valuable data to support clinical development strategies and logistics into the future."

DR. KATRIN ERICSON
Executive Director, RUNX1 Research Program

Overview

The mission of the RUNX1 Research Program (RRP) is to prevent cancer and improve the quality of life for patients with RUNX1 Familial Platelet Disorder (RUNX1-FPD; i.e., FPD/AML, FPDMM), by promoting awareness and funding world-class collaborative research with an empowered patient community. RUNX1-FPD is a genetic disorder that causes low platelet counts, easy bruising, prolonged bleeding, and a high risk of fatal hematologic malignancies.

The RUNX1 Patient Data Hub is a critical part of RRP's mission. The hub securely collects RUNX1-FPD patient-reported health information, enabling patients, scientists, and the clinician community to glean real-time insights on the health impacts of this rare disease.

The REDCap Cloud unified data science platform helps drive RRP's mission in two key ways: 1) informing the design of both current and future research aimed at early cancer detection and prevention, and 2) generating frequent reports summarizing study results that can be shared directly with patients and their physicians, thereby supporting caregivers in delivering optimal care.

Four months after launching the hub, 40 patients were fully enrolled, with a 57% completion rate – a strong uptake rate for a rare disease patient population, and a huge first step toward the goal of enrolling 150 patients by the end of 2023, and another 100 yearly thereafter.

The RUNX1 Research Program

FEATURED SOLUTIONS

REDCap Cloud eConsent
Enable patients to consent onsite or remotely via the myREDCap Cloud portal

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REDCap Cloud Clinical Registry
Aggregate and analyze patient data in real time while building an ongoing community with patients and hospitals

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myREDCap Cloud Patient Portal
Provides patients with a single point of access to remotely engage in a clinical trial via a web browser or mobile device

Learn More about REDCap Cloud Patient Engagement

RUNX1 Research Program and REDCap Cloud

During its research into data hub hosting, RRP explored a number of platforms, keeping four main criteria in mind:

- Electronic consent and mobile accessibility capabilities
- HIPAA and GDPR-compliant security and privacy practices
- A user-friendly, intuitive interface
- A robust survey format and data access flexibility

The RUNX1 Patient Data Hub on REDCap Cloud met and, in many cases, exceeded these criteria. Although RRP learned about the daily challenges and worries facing nearly 320 patients over the past seven years through one-on-one conversations and focus groups, the advocacy organization was not able to document that information systematically and securely for the full patient population.

The new data hub allows RRP to summarize and anonymize trends and share them with patients and key stakeholders throughout the clinical research and healthcare ecosystem and helped ensure that the organization understands and considers diverse perspectives and experiences. To learn more about RUNX1 Research Program, visit **www.runx1-fpd.org**.

Business Impact

The REDCap Cloud platform helps lower the cost of operation for online patient-reported measures, compared to clinician-reported and entered data. Importantly, patients are able to participate in research from their own homes, anywhere in the world, via the myREDCap Cloud patient portal.

CROSS-SYSTEM DATA AGGREGATION POTENTIAL

RRP works with multiple clinician collaborators with existing Academic REDCap databases, conferring a built-in level of trust with the platform. The system product team aims to add the ability in the future of seamlessly connecting data across these databases - an imperative for advancing toward a treatment and cure for this rare disease community.

SECURITY

All RRP advisers can securely access the system in a way that aligns with their primary functions. For example, counselors that review genetic reports shared by patients are given access rights only to the patient information relevant to their work. Similarly, associate investigators - physician scientists - have access only to anonymized data used to identify and track trends

FLEXIBILITY

REDCap Cloud's platform enables a high degree of flexibility across several important domains, including study design (the ability to add questions and grow topic areas over time, as new learnings are applied); and accessing and exporting data (the creation of anonymized reports tailored to each audience).

HIPAA AND GDPR COMPLIANCE

It is vital that this registry is housed on a platform that is secure, private, ethically managed, and compliant with all regulations pertaining to a global community of patients

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