**ACCELERATE**: A Global Patient Registry/Natural History Study of Castleman Disease

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ACCELERATE: Accelerating Castleman Care with Electronic Longitudinal registry, E-Repository, And Treatment/Effectiveness research

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**WHY BUILD A REGISTRY FOR MCD?**

- Multicentric Castleman disease (MCD) is a deadly, hyperinflammatory disorder
- Natural history, epidemiology, and survival outcomes not well understood
- No diagnostic criteria; difficult to diagnose because overlap with other diseases
- Limited tissue samples available for research
- Significant off-label use of therapies, including cytotoxic chemo, anti-cytokine, and immunomodulators
- First FDA-approved treatment, Siltuximab (anti-IL-6 mAb), needs to be evaluated

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**OBJECTIVES**

- Improve understanding of natural history, pathogenesis, and treatment of CD
- Build research infrastructure by collecting clinical data & tissue samples
- Inventory & track “real world” effectiveness and safety profiles of available therapies
- Establish a model for other rare disease registries

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**FEATURES OF REGISTRY**

- Observational, web-based, real-world study
- Integration of patient-reported, physician-reported, EMR, and clinical note data
- Patient-powered => greater enrollment
- Physician-sourced, high-quality data
- Data graded by experts, curated by manager
- Virtual tracking of tissue samples
- Single IRB required in US

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**NEXT STEPS & CONCLUSION**

- Finalize contracts with partners, IT vendor
- Hire/train staff
- Submit IRB
- Enroll first patient (2016Q1)

New registry design involving patients contributing medical record data decreases cost, improves quality, and increases enrollment via direct-to-patient outreach.

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**DATA FLOW MAP**

- **(A) Enrollment / (C) Prospective Data Collection (ongoing)**
- **(B) Data Verification**
- **(D) Data Storage/Access/Analysis**

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**References:**


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**REFERENCES**

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