

Breaking Barriers: A Model for Rare Disease



BREAKING BARRIERS

for black health empowerment

The Problem: Largest CCM Patient Databases in the US

Institution/Project	Total US Adult Registrants	Total Black Registrants	% Black Registrants
Angioma Alliance	914	16	1.75%
U of Chicago	512	45	8.8%
BVMC	537	2	0.4%
Mayo Clinic	282	5	1.8%
Total	2245	68	3.0%

What the numbers should be

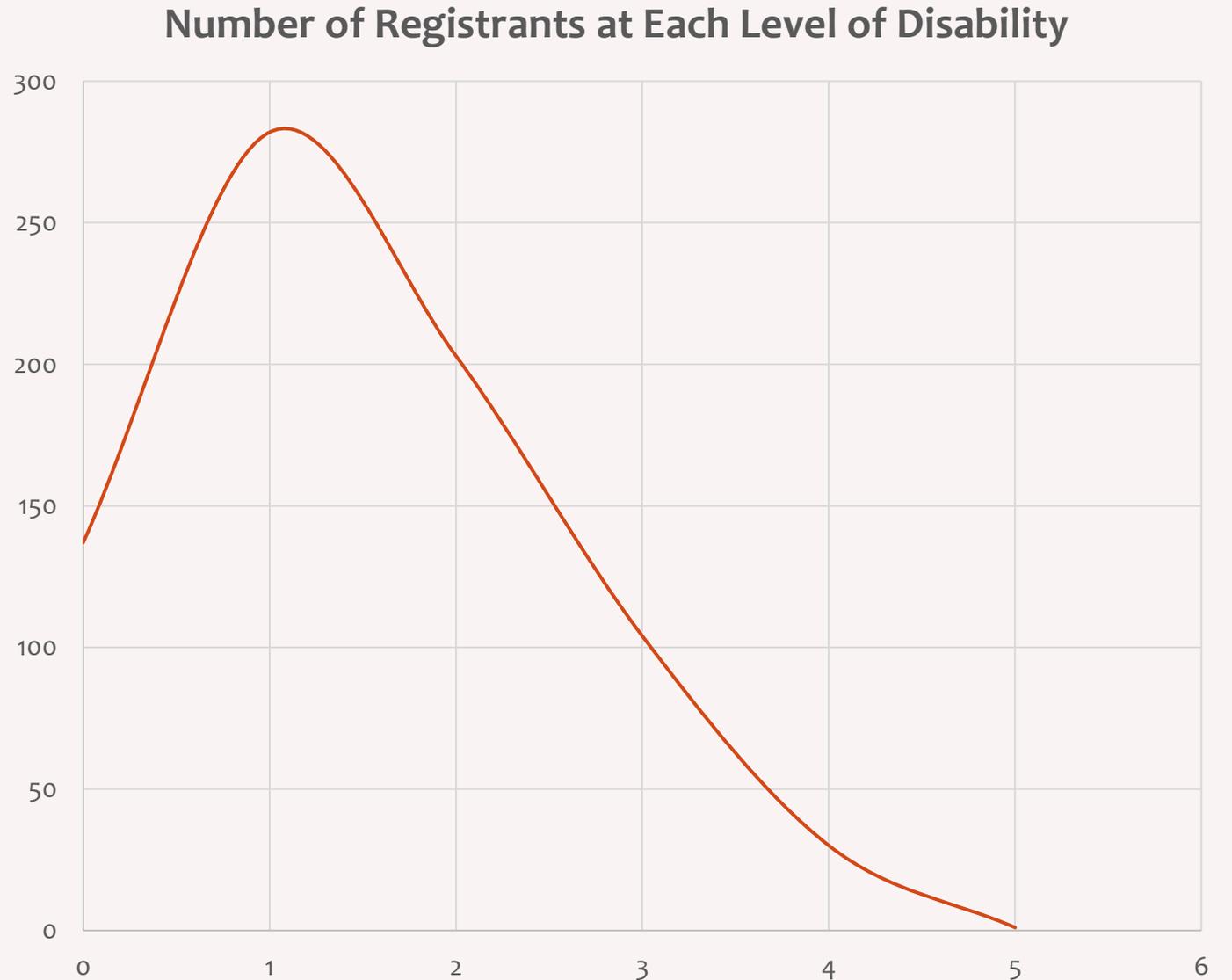
Based on epidemiology, there are approximately 80,000 Black Americans with a cavernous angioma lesion in the US

If diagnostic rates were consistent with other races, **there should be about 20,000 Black Americans who are symptomatic and diagnosed.**

We know 68 of these patients. The remainder who are diagnosed are missing critical information for healthcare.

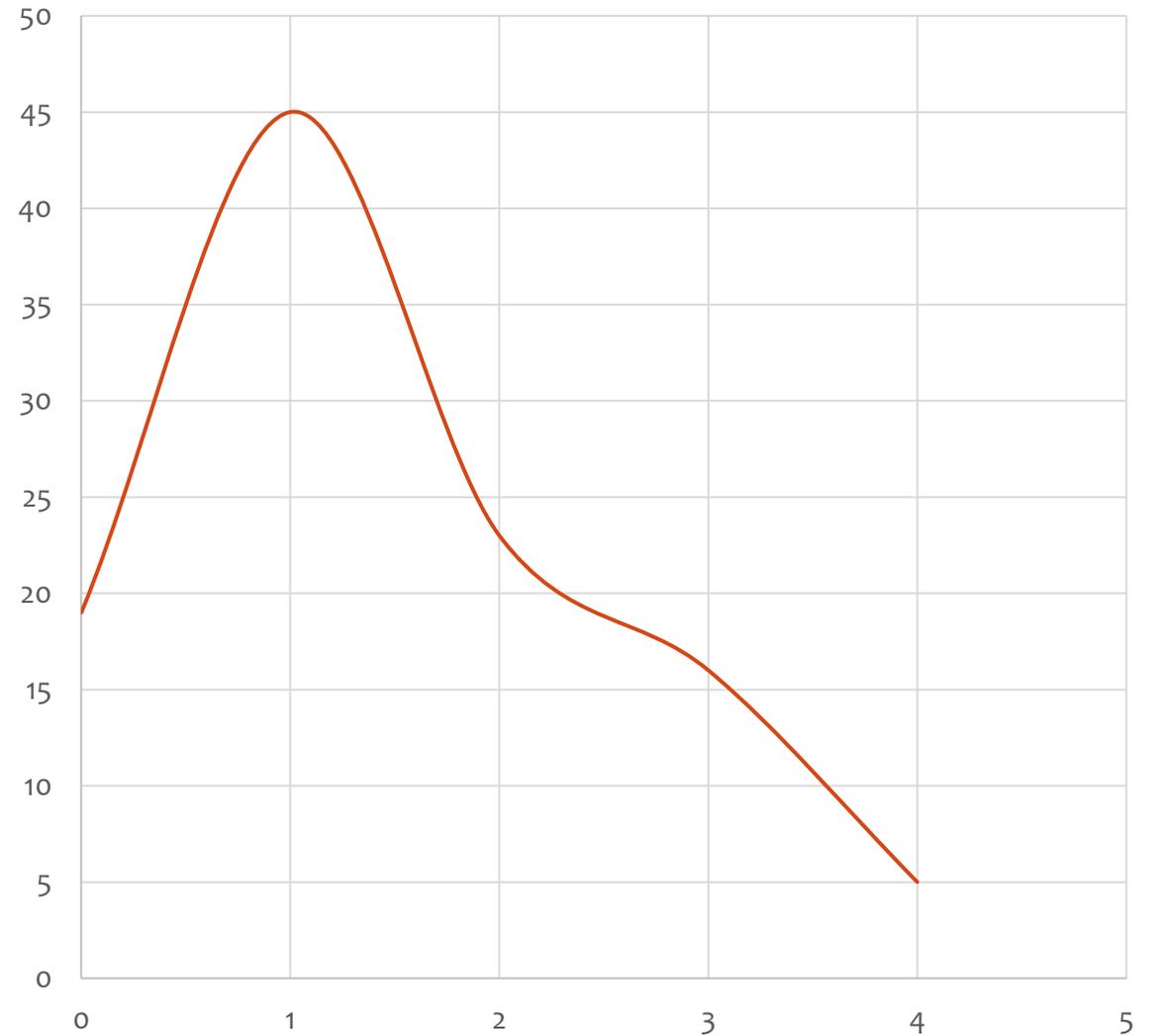
Lower CCM
Diagnostic
Rates? A
Clue: Level
of Disability

White Non-
Hispanic
Registrants



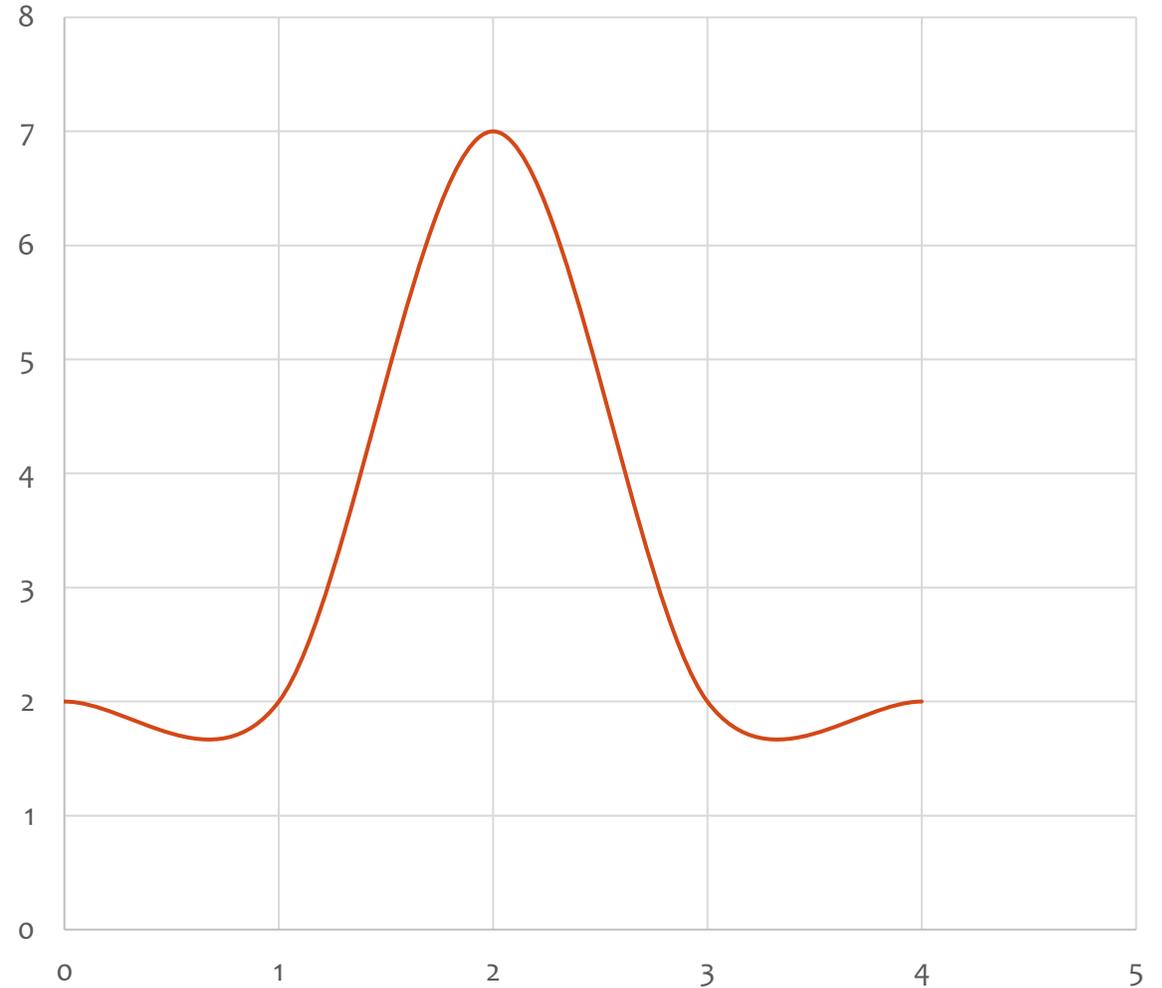
Hispanic/Latinx
Registrants
This curve is very
similar to non-
Hispanic Whites

of Registrants at Each Level of Disability



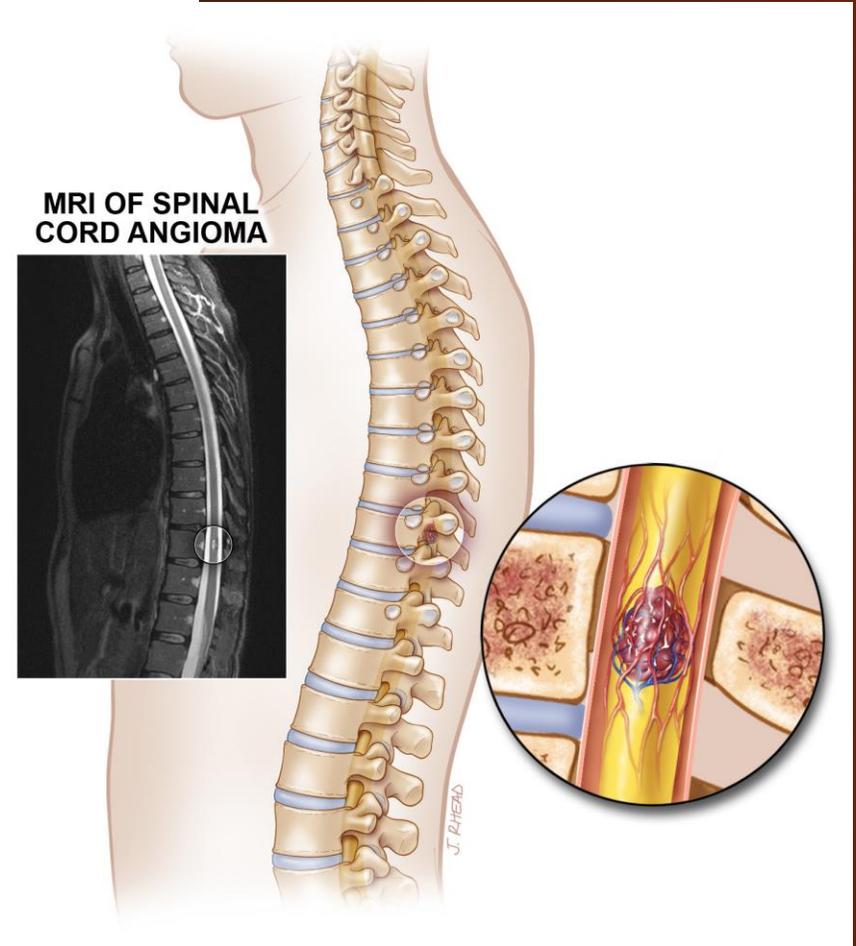
Black Registrants:
The numbers are small, but there is clearly more disability

Number of Registrants at Each Level of Disability



What else we know

- Black Americans in our database are much more likely to have a lesion in the **spine** (50% have a spinal lesion vs 10% in the rest of our registry)
- Spinal lesions can result in more obvious, disabling symptoms that are harder to ignore or misinterpret.



This Problem Crosses Rare Diseases

- There are 7000 rare diseases, affecting 10% of Americans
- 4.3 million Black Americans have a rare disease.
- Aside from a few rare diseases, such as sickle cell and lupus that disproportionately affect Black Americans, there are **no** initiatives to find, diagnose, and engage Black Americans who have rare diseases.
- Patient groups all use a one-size-fits-all engagement approach that is not working for this community.

Program Goals

Find and Engage

Find and Engage Patients

- Find and engage diagnosed Black CCM patients, particularly to convey disease mitigation information and to foster community and conversation.

Improve

Improve Diagnosis

- Improve diagnostic rates through provider education so that people come to diagnosis earlier and can benefit from known interventions.

Increase

Increase Representation in Research

- Increase Black representation in research databases.

Create

Create a Model for Rare Disease

- Create an outreach and education model that can be emulated by other rare disease groups and expanded by us.

Angioma Alliance Strengths

- We have had a **successful Hispanic outreach program** in the Southwest that incorporated creative, culturally exciting ways to engage this group.
- We are the **only patient advocacy organization** for this illness, and we are viewed as a **model for other rare disease organizations**.
- The moderately successful outreach accomplished through the **University of Chicago** gives us something to build on.
- We have **connections and partnerships in many intersecting areas** – stroke, epilepsy, health equity, research, and rare disease.

Methods



LISTENING &
CONNECTING



PARTNERSHIPS



HOSPITAL
OUTREACH



DOCUMENTATION
AND MENTORSHIP

Project

Our first-year activities include:

- Qualitative interviews
- Connecting current patients to create community
- Building partnerships
- Creating materials
- Center of Excellence criteria
- Public Awareness
- Outreach to one public hospital (pilot)

Breaking Barriers for Black Health Empowerment

Year 1

Finding and Engaging Patients

- Facebook page & private group.
- Instagram

Social Media Platforms



- BlackCCM.org provides program information, resources, & access to program events.

Website



- Materials were distributed to Angioma Alliance's Centers of Excellence to be distributed to Black CCM patients.

Printed Materials



Breaking Barriers
For Black Health Empowerment

The Need

Our Breaking Barriers program is born out of a need to connect Black patients who have cerebral cavernous malformations (CCM or cavernous angioma) with appropriate care, support, and research participation opportunities.

[Learn More](#)

Ways We Help

☆ *Second Look*
Access to quality care
This program will help connect Black CCM patients to quality care. Expert CCM healthcare providers help review patient MRIs, offer surgical recommendations, clarify medical information, and provide free genetic testing. For more information about this program, please get in touch with us.

[Get in Touch](#)

☆ *Building a Community*
Offering Support
Coping with a CCM diagnosis can be difficult. Our Black CCM patient community provides support and care resources through our Facebook and Zoom groups.

[Learn More](#)



Patient Interviews

- Have completed 10 patient interviews.
- 9 females and 1 male.
 - Ages ranging from 70 to 25.
- 8 have sporadic form of CCM.
- 2 have familial form of CCM.

Important finding

The lack of diversity in skin lesion photographs on darker skin.

Themes:

- Impact of aftercare (physical, occupational, psychological therapies) on patient's wellbeing, following initial CCM diagnosis and/or surgery. The want and need of aftercare from patients is great, however, it is lacking and not a standard of care.
- Importance of support system in transitioning into “new” lifestyle after diagnosis. This could be support from family or friends, but also the church... how does spirituality help support someone through this journey?
- Power of advocacy on better patient outcomes, throughout path to diagnosis and treatment. This could be self advocacy or having someone else advocate for them throughout this process.
- Experiences in receiving medical care differs based on race or socioeconomic status

Support Group

- The Breaking Barriers for Black Health Empowerment Support group meets via Zoom.
- Goal is to provide support to BBBHE group members and give them the space to openly discuss CCM related issues.
 - Meetings are led by Angioma Alliance Board members:
 - Dr. Kimberly Foley
 - Kandance Weems Noris
 - Group was offered twice a month.
 - Started with high group attendance but dwindled down to one member.
 - Placed group on hold to revamp group.
 - Special Guest that will further discuss group interest.





Public-Private Partnership

Partnership with Angioma Alliance's Center of Excellence and a Public Hospital.

Goal: To increase access to quality CCM care for all patients no matter the insurance coverage.

- Area of interest: Chicago
- Hospital: Stroger Community Hospital and Angioma Alliance's Center of Excellence at the University of Chicago.
- The partnership will provide a Physician training crafted from "What a Clinician Should Know", patient and provider materials, patient access to Second opinion and Genetic testing programs, and recognition from Angioma Alliance.

Keep Moving Forward

Continue to identify, engage Black CCM patients.

