

# GRNDaD and CoUSIN: Investigator-initiated collaborations to improve care in Sickle Cell Disease

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**Table 1A. US & UK Study sites**

**Study site: US**

1	All Children's-JHU St Petersburg, Children
2	Case Western Reserve University-Cleveland, Adults and Children
3	CHORI-Oakland, Adults and Children
4	Christiana Care-Delaware, Adults and Children
5	Duke-Durham, Adults and Children
6	Einstein-Bronx, Adults and Children
7	JHMI-Baltimore, Adults and Children
8	MCW-Milwaukee, Adults
9	NBIMC-Newark, Adults
10	The Ohio State-Columbus, Adults
11	OHSU-Portland, Adults
12	University of Alabama –Birmingham, Adults and Children
13	University of North Carolina-Chapel Hill, Adults and Children
14	Washington University, St Louis, Adults and Children

**Study site: UK**

1	Guy's & St Thomas-London, Adults
2	King's College Hospital-London, Adults

and SCD Internationally)

**Table 1B. US & UK Study sites**

**Study sites: US**

**N=2160, adults and children**

**Study sites: UK**

**N=192, adults**

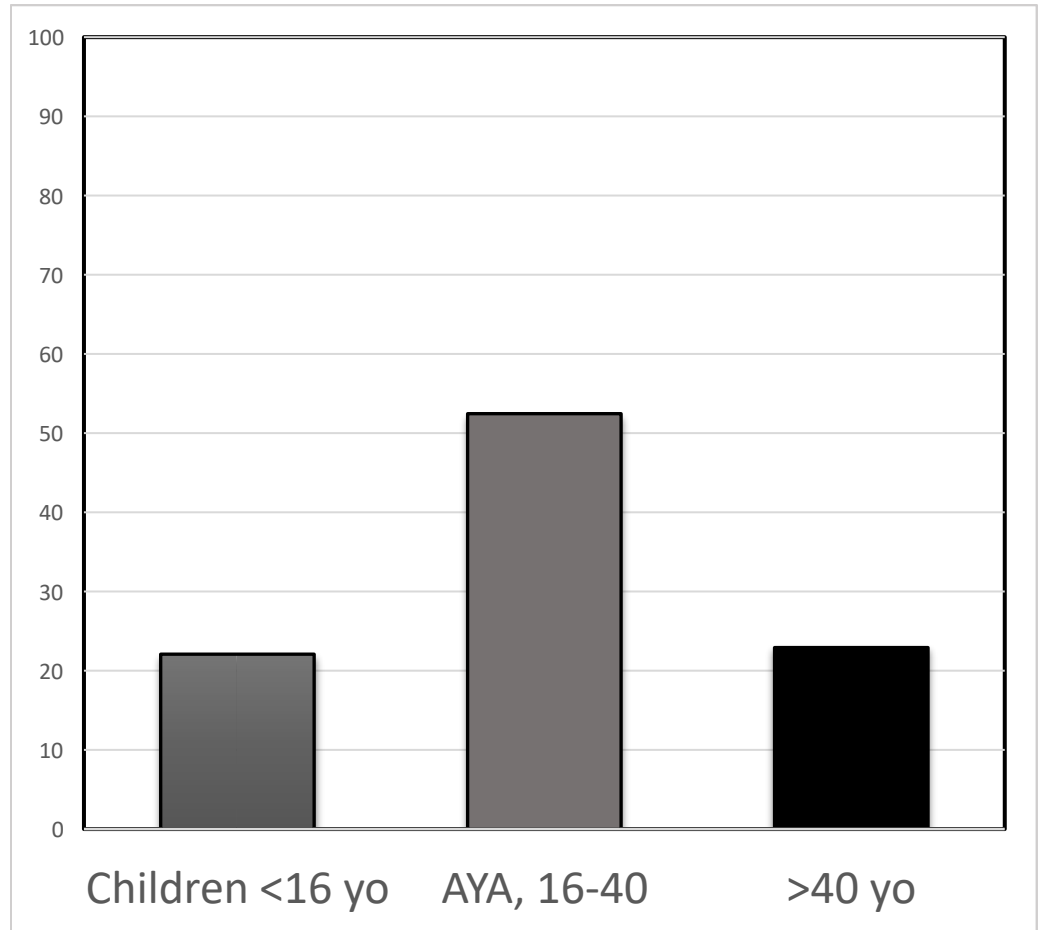


# The GRNDaD Family (GRNDaD & CoUSIn) are prospective deidentified registries

- IRB
  - (US)-reliant mechanism in which all updates are approved through a single IRB (at Johns Hopkins Medical Institute)
  - (UK) National IRB
- >300 individual data elements for each person with SCD, entered into REDCap
  - (US) **All subjects:** Data remain visible and accessible only to individual sites' team, for quality improvement and local care.
  - (US) **Fully Consented:** All data are deidentified and sent to a single repository at JHMI.
  - (UK) Harmonized data elements with GRNDaD, fully consented, and entered into UK REDCap

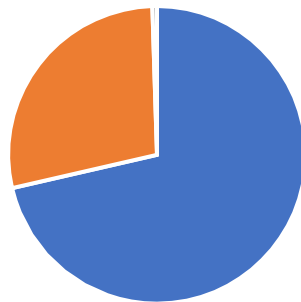
What does GRNDaD look like right now?

A snapshot of  
the GRNDaD  
Family, age  
distribution  
(US)



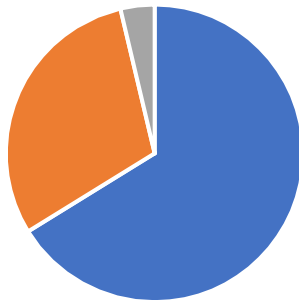
A snapshot of  
the GRNDaD  
Family,  
Disease type-  
mostly SCA

Children, US



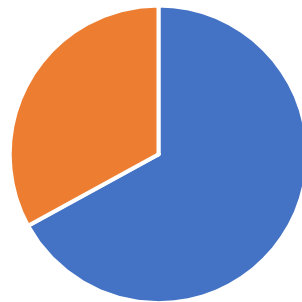
■ SCA ■ Variant ■ Other

Adults US



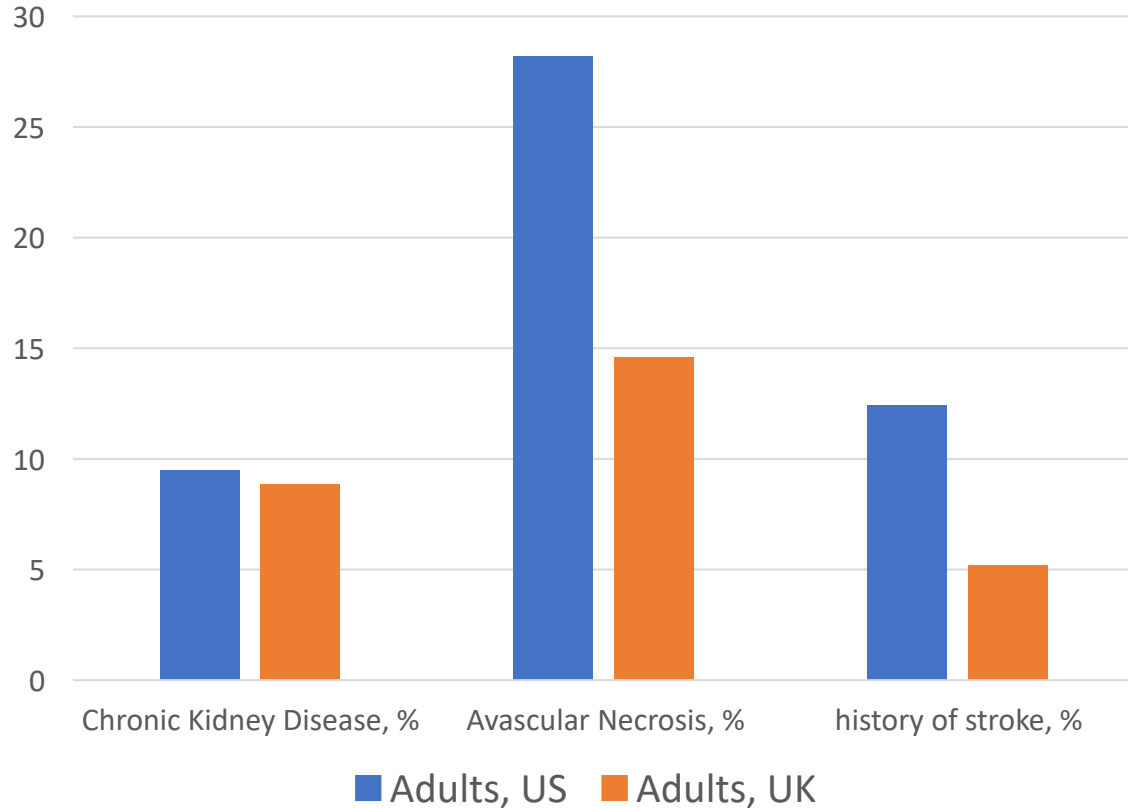
■ SCA ■ Variant ■ Other

Adults UK

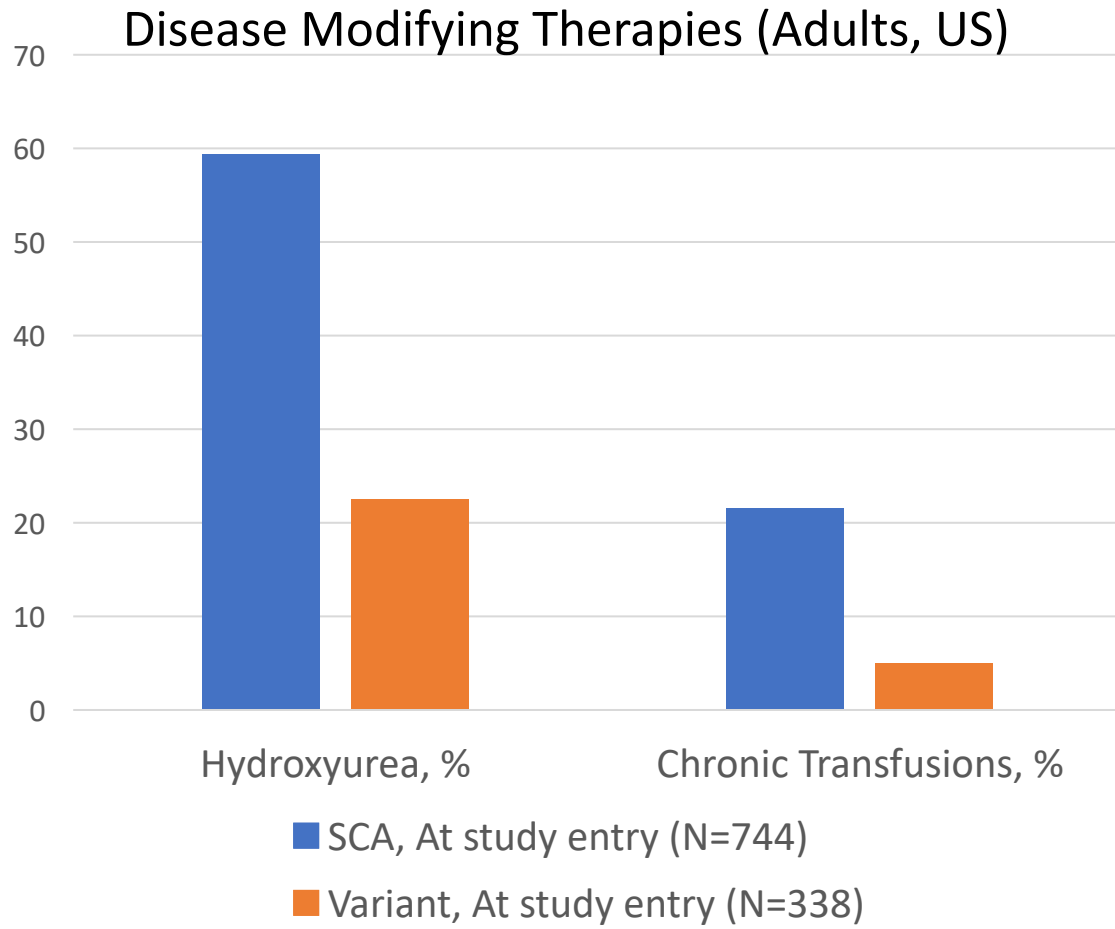


■ SCA ■ Variant

An EARLY  
snapshot of  
the GRNDaD  
Family,  
Complications  
may vary  
internationally



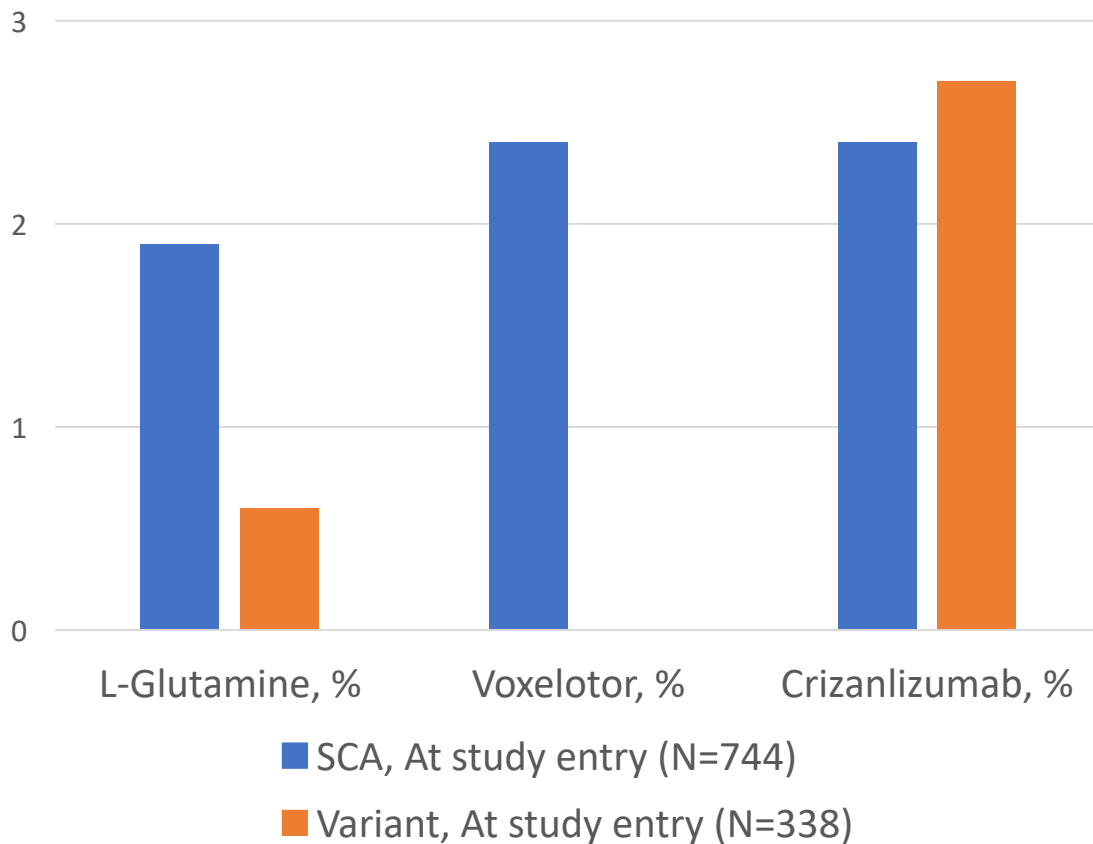
GRNDaD will allow us to track Disease Modifying Therapies.





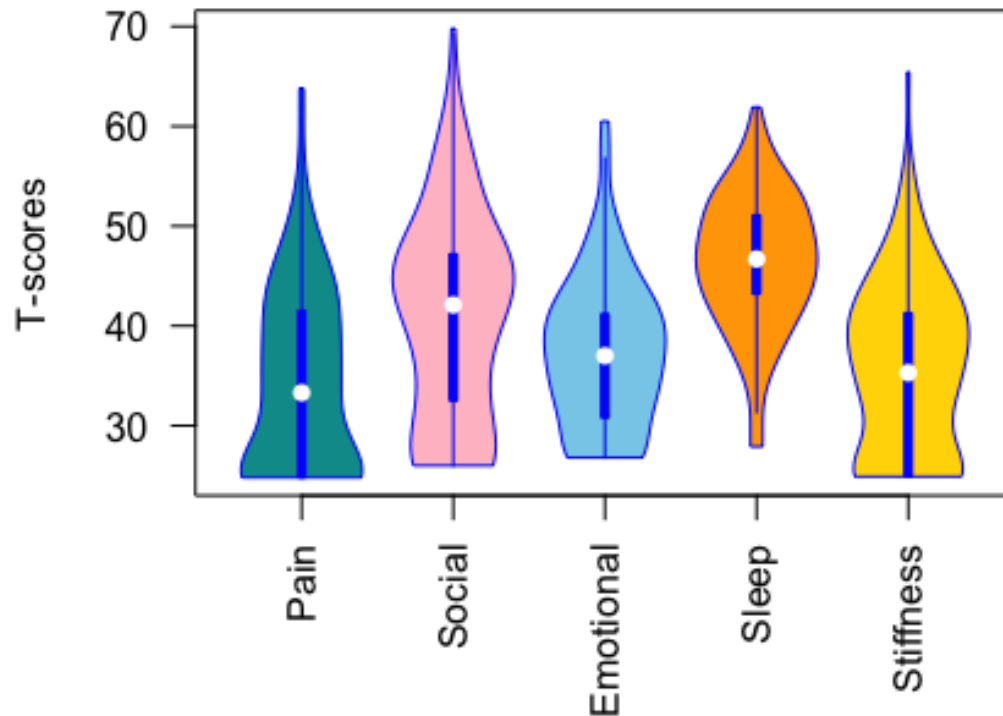
GRNDaD will allow us to track and evaluate the use emerging therapies

Emerging Therapies (Adults, US)



GRNDaD will allow us to track Patient-centered Symptom Burden

Patient Reported Outcomes  
(Adults, US, N>350)



# The GRNDaD Family



- Harmonized multi-site and **International**, patient-centered, PI-led database
- Prospective view of Disease Modifying and Emerging Therapies in the modern patient who is living with SCD
- National registry adopted by the National Alliance of Sickle Cell Centers (NASCC)
- Adopted by the US-based HRSA-funded sickle cell treatment demonstration projects (SCDTDP) as the national registry for data collection
- Quality improvement efforts
  - Iron-Overload management
  - Appropriate implementation of guideline-based care
  - Transition measures
- Join us!



SCHOOL OF MEDICINE  
Blood Research  
Center



UAB LIFESPAN COMPREHENSIVE  
SICKLE CELL CENTER  
The University of Alabama at Birmingham

King's College Hospital  
NHS Foundation Trust

