

GIGA Kids News & Updates

Fall 2024 Update

"Autumn, the year's last, loveliest smile."

- William Cullen Bryant

Hello GIGA Kids PIs, Coordinators & Friends,

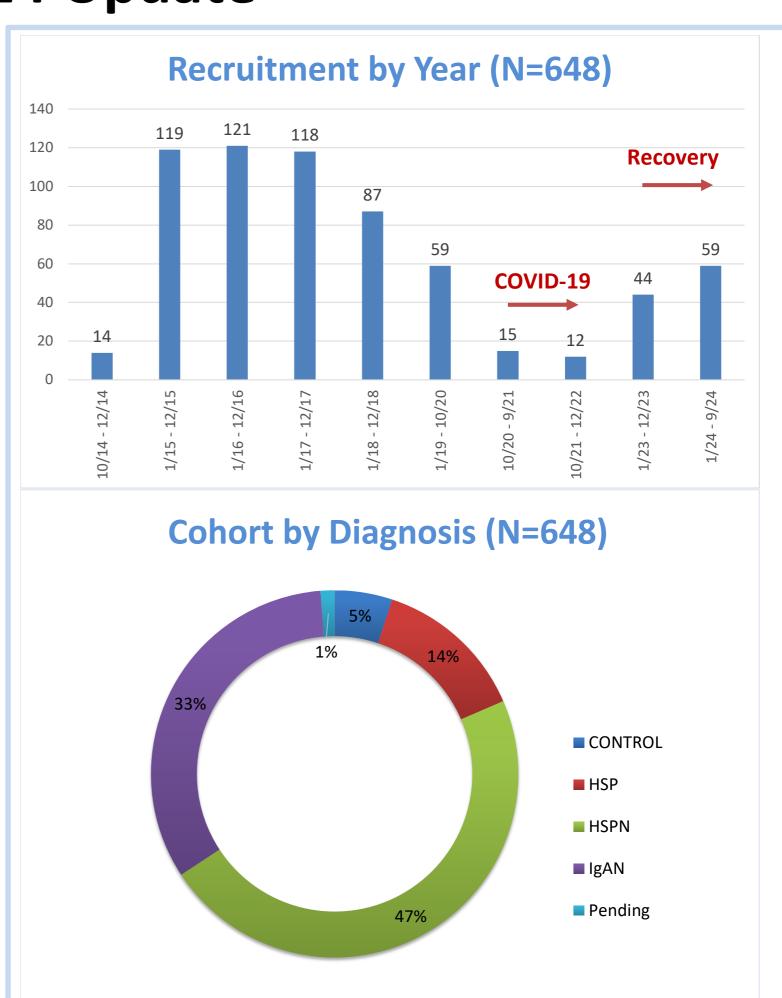
First of all, we want to **Thank You** all for your patience and your commitment to GIGA Kids – we look forward to continue working with you!

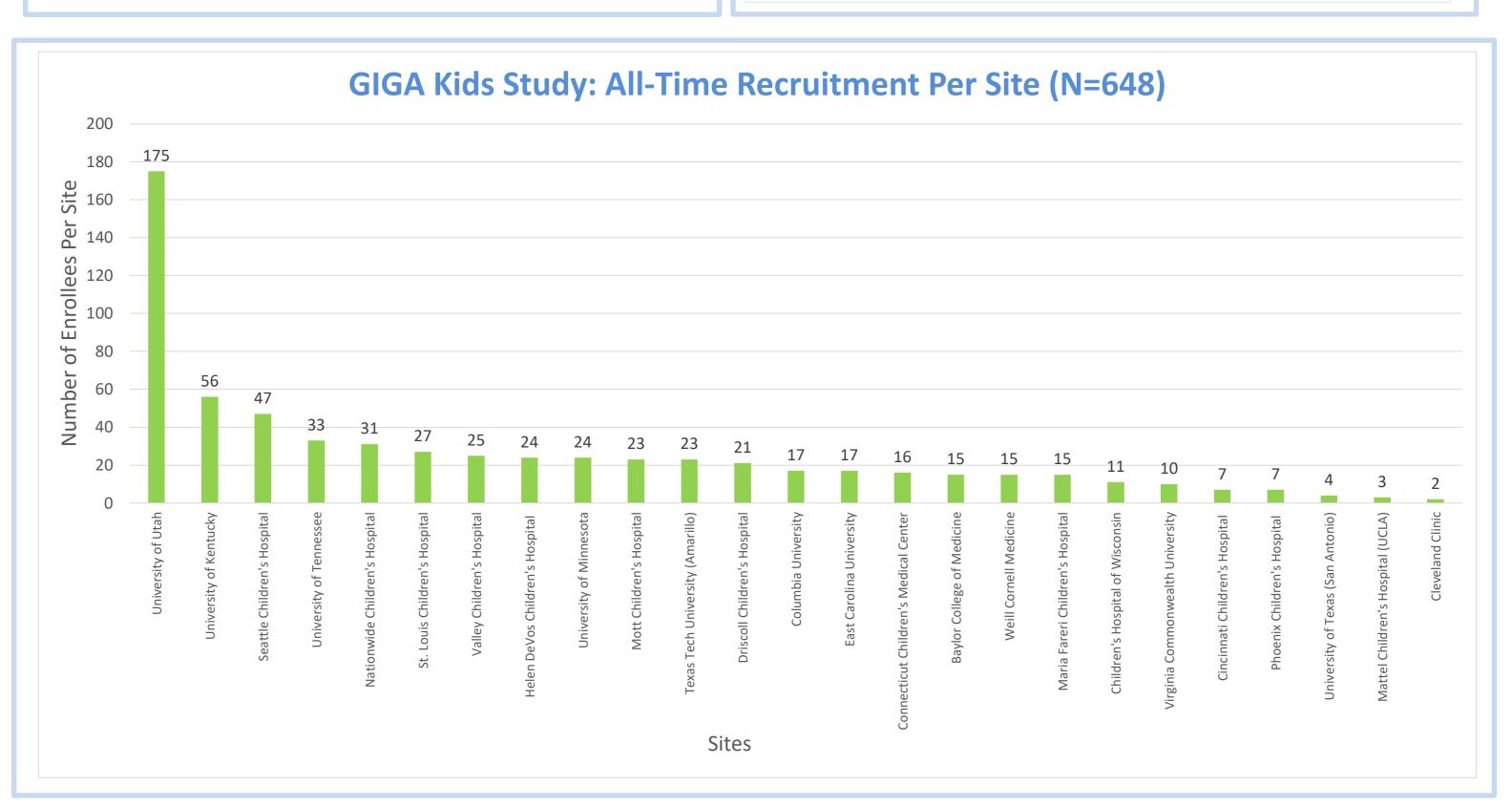
As of September 1st, 2024, there are **12 actively recruiting GIGA sites**. Total recruitment is presently at **N=648 participants!** This includes 615 cases and 33 healthy controls. This already puts us at 65% of our overall goal, however, we still need your help to bring back our initial recruitment rate of ~100 cases per year.

Please note that we are still accepting new recruitment sites, and we are actively enrolling the following:

- IgA nephropathy cases (biopsy-diagnosed)
- IgA vasculitis cases (with and without nephritis, biopsy not required)
- Healthy pediatric controls (without active infections, autoimmune disease, or liver disease)

As always, please let us know how we can best support your recruitment efforts, and do not hesitate to reach out to **Cecilia Berrouet** (ccb2184@cumc.columbia.edu) with questions, concerns, or suggestions.





Reminders

- We would like to highlight the continued need for more **HEALTHY CONTROLS**
- Currently, we have 33 healthy controls (up from 12), but our study target is at 100...
- The recruitment of healthy children for study controls has always been challenging, but here are some ideas on who is eligible:
 - 1. Unrelated friends of patients and their families (note that blood relatives, e.g., siblings, are not qualified to be controls)
 - 2. Children with vesicoureteral reflux or kidney malformations (but with no evidence of active urinary infection)
 - 3. Children with injuries presenting to the emergency room or seen by orthopedic surgery
- Any other suggestions for control recruitment are welcome, so please let us know what works well at your site...

The IgA Nephropathy Foundation 2024 SPARK Conference

The IgA Nephropathy Foundation hosted its 5th annual SPARK conference in Austin, Texas on July 26-28, 2024 for patients and their caregivers to learn about the disease, living with the disease, and being a caregiver for those with the disease.

The Columbia University team went to the conference to recruit participants for our research and was truly speechless and overwhelmed with gratitude for the success of our research effort - we were able to recruit more than 100 individuals for genetic studies!

We would like to thank Bonnie Schneider, the founder of the Foundation, and her team again for this opportunity and for their incredible hospitality – we were so impressed by the kindness, cooperation, enthusiasm, and support you have built within the IgAN community!





Important Contact Information:

DUA/OpenClinica – Nationwide: Corinna Bowers Corinna.Bowers@nationwidechildrens.org

IRB/MTA – CUMC: Melanie Foley mf2162@cumc.columbia.edu

Interested in participating in the GIGA Kids Study?

Our Coordinator for the GIGA Kids study, Cecilia Berrouet, can guide you through the IRB application process, and help to answer any questions you may have regarding study protocol, or recruitment.

Email: ccb2184@cumc.columbia.edu Tel: (212) 851-5216