

GIGA-kids: MWPNC Spring Meeting Recap and Summer Announcements

Overall, our total number of study participants is presently at **N=311 (Figure 2)**. This includes **305 cases and 6 controls**. As always please let us know if there is anything we can do to better support your recruitment on our end. If any one has collaborators at other centers that may be interested in participating in the study please feel free to forward them this Newsletter and encourage them to contact us with any questions.

As of May 2017, two new sites have joined the GIGA-kids Network – Phoenix Children’s Hospital (Phoenix, AZ) and Driscoll Children’s Hospital (Corpus Christi, TX). The MWPNC meeting this past April afforded us the opportunity to engage with a number of additional potential new sites. If you are interested in getting involved with GIGA-kids, please contact Olivia Balderes (contact information at the bottom of the page).

IMPORTANT NEWS: The CureGN study has now closed all recruitment of IgAN and HSPN patients (total pediatric cases recruited **N=239**). This means that any new patients who may have qualified for CureGN can now be recruited under the GIGA-kids protocol. Importantly, GIGA-kids recruitment has already exceeded the CureGN study by N=72 participants (**Figure 1**), effectively making the GIGA-kids cohort the largest nationwide pediatric cohort of IgAN and HSPN!

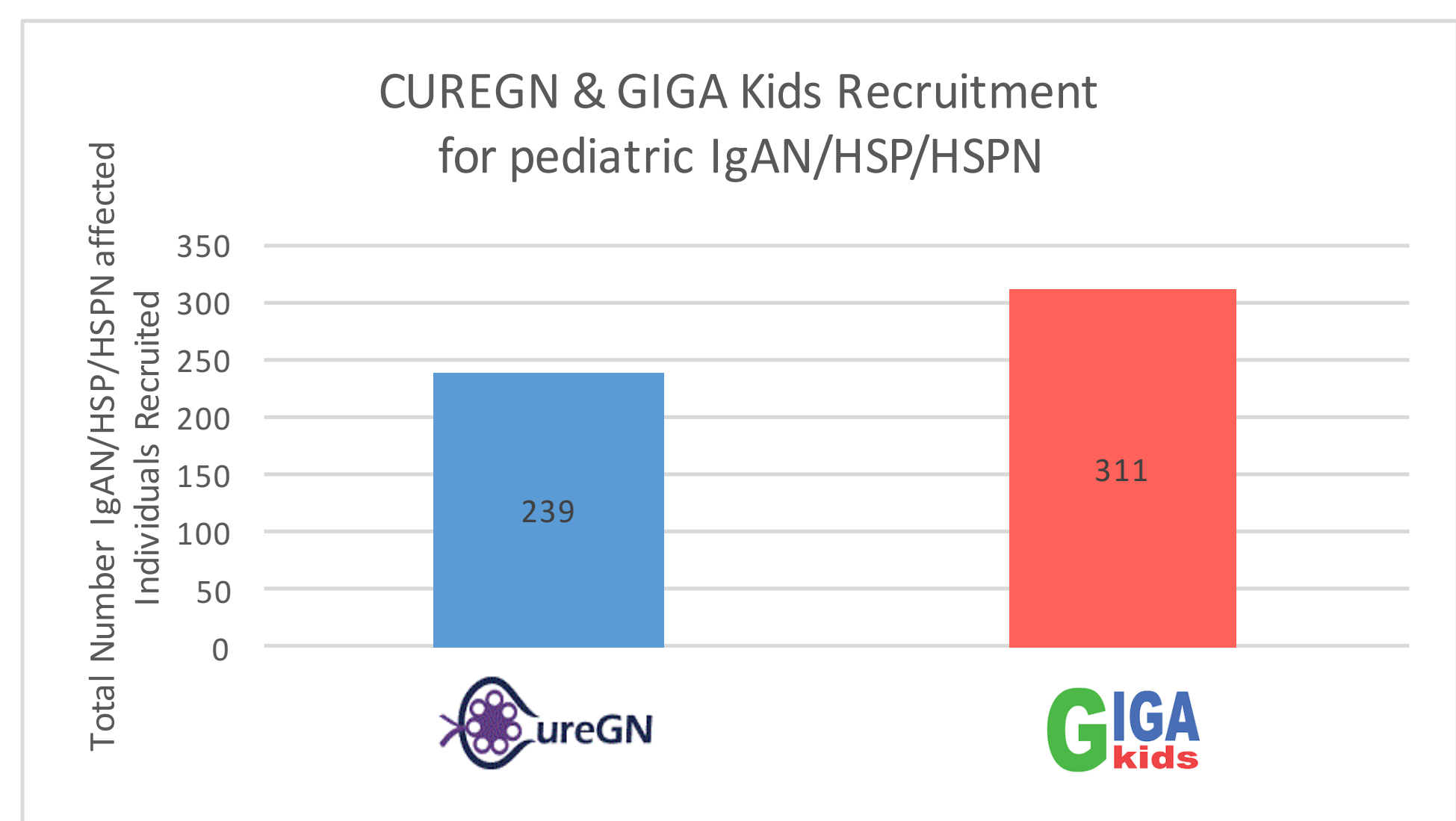


Figure 1: Total number of pediatric participants with IgAN and HSPN: CUREGN (N=239) and GIGA-kids (N=305+6 controls).

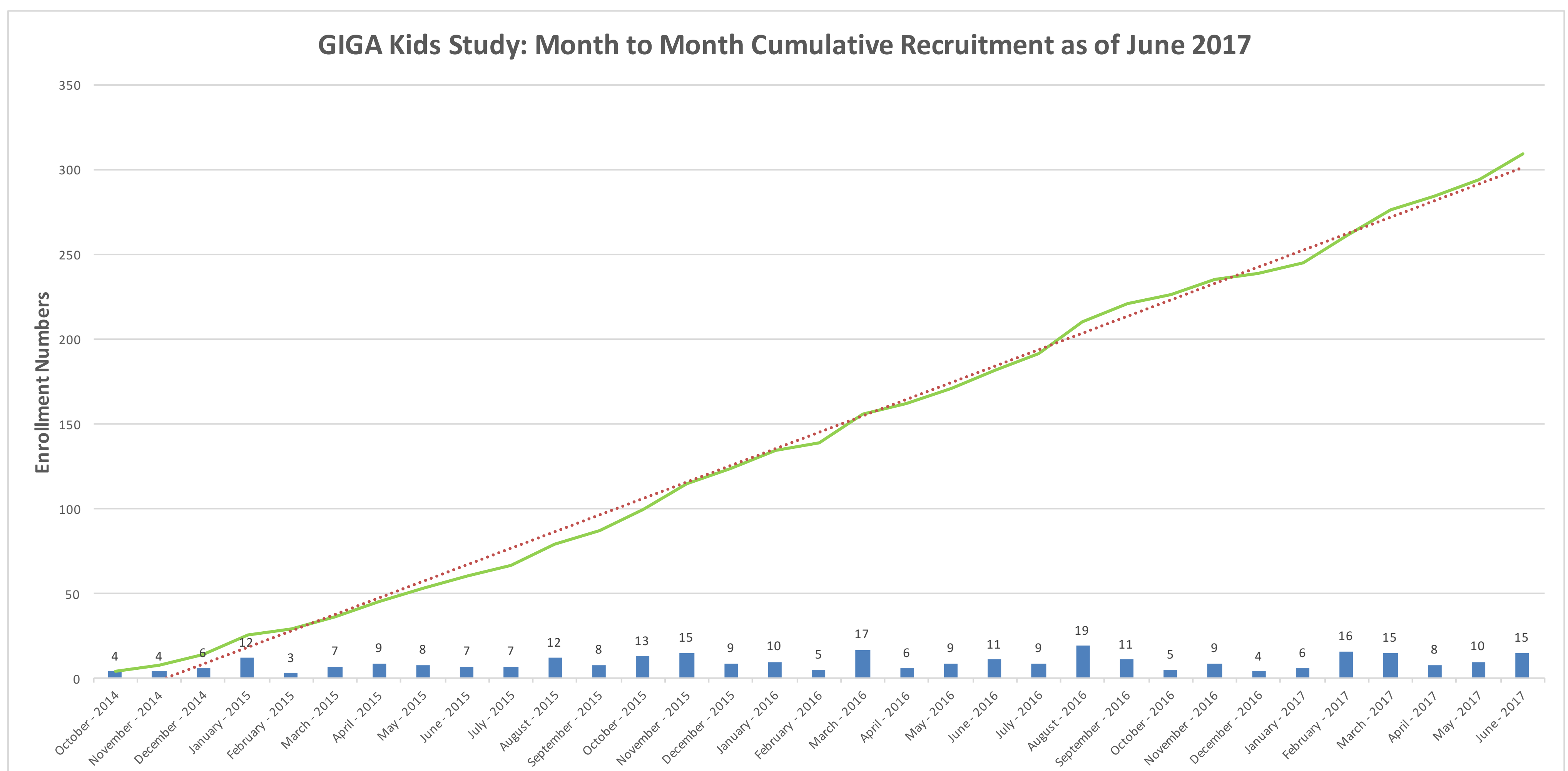


Figure 2: Cumulative Recruitment – as of June 2017.

Important Contact Information for GIGA-kids

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Interested in participating in the GIGA Kids Study?

Our Coordinator for the GIGA Kids project, Olivia Balderes, can help and support you along the IRB application process.

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Recruiting Healthy Controls

A main setback in achieving the desired recruitment goals for the GIGA Kids Study is in recruiting healthy pediatric controls. The recruitment goal for healthy age and ethnicity matched controls is 100 – as of May 2017, between the 23 actively recruiting sites the study has only 6 control subjects. Recruiting pediatric controls regardless of study criteria or size is difficult for a variety of reasons (the least of which is a lack of interest in furthering research on the part of the recruits and their parents or guardians). Siblings of affected children are generally the most willing to participate in studies, but who are, as per the exclusion criteria outlined in the GIGA Study, unable to count as healthy controls. So where does this leave us when trying to recruit a robust cohort of age and ethnicity matched healthy controls? What is the best way to meet the study's goal of 100?

After speaking with a number of coordinators here at Columbia it is apparent that recruitment of controls takes a concerted effort on the part of the coordinators who must go out of their way to track down controls. One recommendation I received was to involve the parents/guardians of the affected children by asking them to contact parents/guardians of their child's friend – a potential source of eager to participate and healthy individuals. This, of course, requires both a willingness to reach out and a full understanding of the study on the part of the parent or guardian.



Dinner at the Boettcher Memorial Tropical Conservatory (above) and Dr. Nelson's update on the GIGA Kids Study (below).



MWPNC Meeting Spring 2017

This year the spring 2017 MWPNC (March 31st - April 1st) was hosted by the Children's Hospital Colorado at the lovely Anschutz Medical Campus. The day of the 31st began at noon with project proposals from a number of sites and concluded with a tour of the facilities featuring the NICU and Dialysis Unit. Dinner was held at the Denver Botanical Gardens in the Boettcher Memorial Tropical Conservatory (pictured left), where attendees mingled and ate above and amidst orchids and Banyon trees alike.

The second day started off with updates on active studies (Dr. Nelson gave the GIGA Kids progress report – pictured left) and featured breakout sessions for Working Groups. Big thank you to the Children's Hospital of Colorado for hosting and to Corinna Bowers for all of the hard work she put into handling the logistics of the conference.

The fall 2017 MWPNC (October 20th and 21st) will be hosted by the University of Iowa in Iowa City, and will include the annual coordinator specific seminars and presentations.