

GIGA-kids News & Updates

Upcoming IgAN Race - New Jersey

If you happen to find yourself in the Tri-State area this June 14, 2015 then join us for the 11th Annual IgA Nephropathy Foundation 5k Run/2 mile Walk.

The event will take place at the Wall Township Municipal Complex in Wall, NJ and registration begins at 8:30 am. Registration fees are \$25 for adults and \$12 for twelve and under. Pre-registration is available at a reduced rate online or by May 30th and includes a free t-shirt. There will be water stations available along the course. Breakfast and lunch buffets will be available.

For more information, donations and volunteer inquiries, visit www.iganephropathy.org.

Welcome to the First Edition of Our Newsletter

Welcome to the first issue of the *GIGA-kids Newsletter*, a monthly continuum that will highlight our progress as a team and encourage the exchange of information among the distance sites. This newsletter along with those that proceed will also be available on the GIGA Kids website (www.gigakids.org).

The purpose of this newsletter is to provide all our Co-Investigators and prospective sites with the most up-to-date news and interests. This would

include the usual recruitment updates such as the number of patients enrolled as well as anything from the welcoming of new IRB approved sites, upcoming events and featured articles.

We hope that you enjoy reading each issue of the *GIGA Kids Newsletter*. This publication is for you. Lastly, a many thanks for all of those who are making this study possible.

Patient Recruitment and New Sites

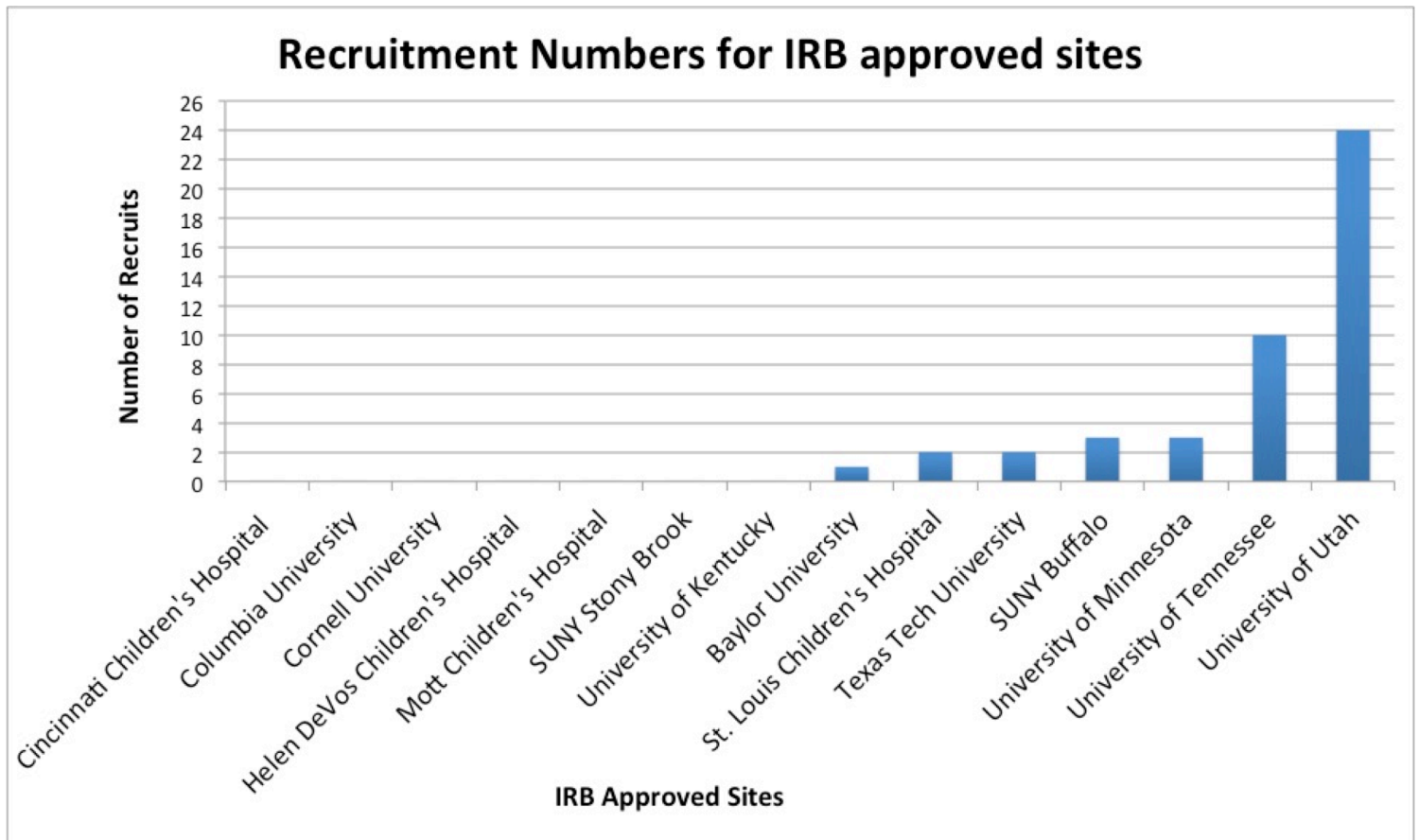
The latter part of April was a great time for us in terms of IRB approval. In a span of just two week, we had four new sites approved for recruitment. Of all the sites that have confirmed participation in *GIGA-kids* study this puts us at 14 out of 24 sites that can now recruit. Getting us to more than half the sites enrolling patients. See figure 2 (page 2).

From our last update we have also had an increase in our recruitment numbers as well. We went up from 31 patients in March to 45 as of the beginning of May. Figure 1 (below) shows

this progress in relation to each site that is already IRB approved. Utah has really excelled and is clearly leading these efforts.

Since the presentation given at the last MWPNC meeting, we have also had a few more sites show interest in joining our efforts and some even beginning the application process. We look forward to growing with you all in this national collaboration. Thanks for those of you just pledging to this study and should you need any help please reach out to our clinical coordinator, Drew Bradbury.

Figure 1: Total Recruitment Numbers for GIGA Kids – as of May 08, 2015



DUA & MTA – Sharing Between Institutions

As a friendly reminder, each site will need to be sure they execute a Material Transfer Agreement (MTA) with Columbia and a Data Use Agreement (DUA) with Nationwide.

These are standard forms that allow the sharing of specimen and data between institutions, respectively. Templates have been made available for your convenience. They should be reviewed and signed by your institution's legal representatives. You can begin this paperwork

alongside with your IRB application to expedite enrollment.

Some CTO's may prefer to use their own forms and this is quite all right. They will just need to be forwarded to the appropriate contact (located on the right hand side) so that they can be reviewed and signed.

There have been a few sites that are having issues with either the DUA and/or online database registry. If this is you, please contact Drew Bradbury. We want to get you all utilizing the online registry as soon as possible.

If you are eager to begin recruitment and still waiting for the DUA to be approved, in the meantime you can use the local clinical data paper forms. These will be made available to you through our clinical coordinator.

And as far as the MTA goes, if you are still waiting, you will not be able to ship any materials to CUMC yet. However, if you have access to a centrifuge and an -80C freezer then you can store the samples locally in the meantime.

Contact Information:

DUA – Nationwide

Corinna Bowers
Corinna.Bowers@nationwidechildrens.org

MTA – CUMC

Melanie Foley
mf2162@cumc.columbia.edu

Interested in participating in the GIGA Kids Study?

Our clinical coordinator can help and support you along the IRB application process.

Contact Drew Bradbury,
dab2213@cumc.columbia.edu

Figure 2: Progress Report on all confirmed sites– as of May 08, 2015

