



# The APOLLO Network Newsletter



You are receiving this newsletter because you are participating in the APOLLO research study.

**Spring 2023**  
Edition 3

## You will be Hearing from Us in Fall 2023

The APOLLO study could not happen without your participation. Thank you! In mid 2022, APOLLO submitted a grant application in hopes of continuing the recruitment of African American Living Kidney Donors and to extend the follow-up of recruited Recipients. The COVID-19 years significantly stalled recruitment and as a result, we have not been able to follow kidney transplant recipients and living donors for as long as we hoped, when the study received NIH funding in 2017.

Beginning in the Fall of 2023, APOLLO will be reaching out to you, as APOLLO participants, to schedule a clinic appointment to collect additional biosamples, including blood and urine. You will be asked to complete a brief consent document allowing us to collect an additional biosample. We will then continue to follow your kidney transplant outcomes through your Electronic Medical Record (EMR). The additional biosample collection will allow the study to evaluate serum creatinine at an additional time point and strengthen biospecimen contribution to the National Institute of Diabetes and Digestive and Kidney Diseases' (NIDDK) Central Repository.

## NEW! Participant and Community-Focused APOLLO Website

Based on input and inspiration from APOLLO's Community Advisory Council (CAC), we developed a website for our participants and community. We hope you will visit

[www.APOLLOCommunity.net](http://www.APOLLOCommunity.net). This website is written for our patients and local communities and focuses on kidney health education and APOLLO information. Within the website, we highlight our collaborative CAC (one of the first NIH-sponsored studies to incorporate the patient's voice from the beginning). You will find links to our education videos created in collaboration with top kidney organizations, previous participant newsletters, links to scientific papers written about the APOLLO project and by APOLLO investigators, a look at our participating recruiting sites and so much more. We think it is a great resource!



## Return of APOL1 Genetic Results



When you consented to be in the APOLLO study, you were told that your APOL1 genetic results would be made available for you. The NIH is currently developing an Expert Panel to provide input on the return of genetic data to all research participants across all NIH-sponsored studies. As such, the APOLLO study will wait for guidance from this Expert Panel and will abide by their guidance. We will continue to keep you updated on the NIH's progress and its implications for you, as an APOLLO participant.

It is important to note that APOL1 genotypes will **not** be included in your EMR or any of your medical records.

When APOL1 genetic data are available, APOLLO plans to mail letters to participants who wish to receive results containing their APOL1 genotype. Again, this information will **not** be sent to hospitals, medical teams, or physicians.



## We Are Working to Enhance Our Social Media Presence and Connect With You!

APOLLO has a committee dedicated to creating educational videos for the community and working to connect the APOLLO study with the kidney disease & kidney transplant patients, families, and local communities through social media. Please help us reach and connect with more individuals and families by following our Facebook and Twitter accounts, 'liking' our social media posts and sharing our posts on your social media.

APOLLO has active Twitter and Facebook accounts as well as a YouTube channel filled with informational and educational videos about APOLLO, APOL1, kidney disease and kidney donation.

In the coming months, APOLLO will highlight World Kidney Day (March 9) and National Donate Life Month (April) and so much more!

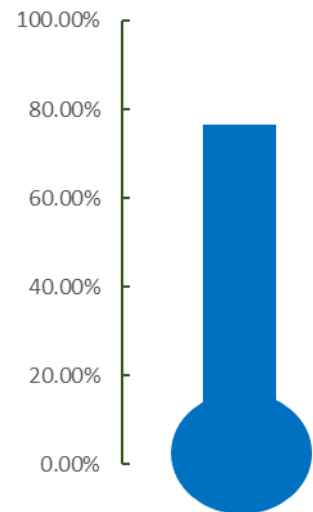


## Recruitment Update

APOLLO's recruitment goal is to recruit and create 2,614 deceased donor + recipient pairs. APOLLO leadership determined that progress towards our recruitment goals will be measured by confirmation of participant biosamples cataloged in the APOLLO Central Lab. So while APOLLO transplant programs have consented and collected biosamples on recipients that meets our recruitment goal, not all of the biosamples have been received in the Central Lab.

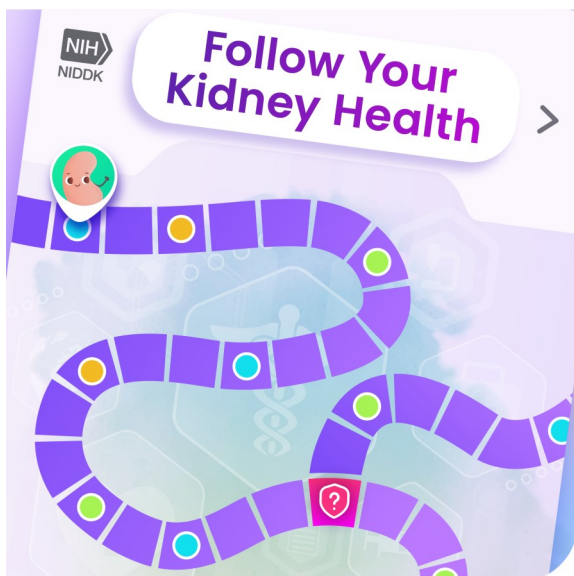
**As of February 9, 2023, we have created 2,002 deceased kidney donor + recipient pairs in the APOLLO Central Lab**, which is 76.5% of our recruitment goal. We will continue to recruit recipients until we have reached our recruitment goal of deceased donor + recipient biosamples cataloged in the Central Lab.

Within that same time frame, APOLLO transplant programs have recruited 273 living donors and created 183 living donor + recipient pairs in the Central Lab. APOLLO anticipates that living donor recruitment will continue for another 4 or more years; allowing us to create one of the largest repositories of biosamples and data on living kidney donors in the country.



## Be on the lookout for activities in your community!

**March is National Kidney Month** and March 9 is World Kidney Day! Learn how you can follow your kidney health with information from @NIDDKgov.



↑ Click for more information. ↓

## April is Donate Life Month!

Donate Life Living Donor Day: April 5  
Blue & Green Spirit Week begins: April 8  
National Donate Life Blue & Green Day: April 14  
National Pediatric Transplant Week: April 23-29

