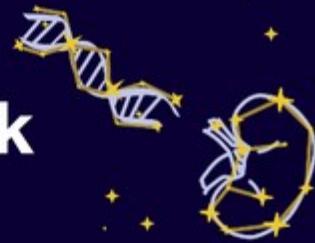




# The APOLLO Network Newsletter



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

**Spring 2022**  
Edition 1

## THANK YOU!

The APOLLO study could not happen without your participation! Thank you, thank you, for agreeing to take part in this very important observational research project! Currently, the study is still enrolling kidney transplant donors (both living and deceased) and kidney transplant recipients. Since we are still enrolling, we do not have study results to report but we can share our recruitment progress. As of February 17, 2022, we have enrolled 1,841 recipients which is 70% of our study goal of 2,614 recipients. When recruitment is complete and the analyses are finished, study participants will be informed of the results and will be given the option to request their individual genetic results.

## A Reminder: What is the APOLLO Study?

The APOL1 Long-term Kidney Transplantation Outcomes Network (APOLLO) is an observational study looking at kidney transplant outcomes based on the APOL1\* gene. There has been observational data and data from small studies that suggest that individuals with two risk copies of the APOL1 gene experience faster rates of kidney failure. By following and collecting data from eligible kidney donors and their recipients and testing their DNA for the APOL1 gene, the study investigators hope to determine the effect of the APOL1 gene on kidney transplantation. Discovering its impact (or lack of impact) will hopefully allow us to make kidney transplantation safer for living donors and all recipients and increase the number of kidneys available for donation by reducing the number of kidneys deemed ineligible for transplantation.



## Who Are the Organizations that Make-up the APOLLO Study?

The APOLLO study is a nation-wide collaborative research study, funded by the NIH. It includes the coordination and cooperation of multiple organizations and funding groups. Beginning with funding from three NIH institutes (NIDDK, NIAID and NIMHD), APOLLO added involvement of transplant programs from across the United States, including Puerto Rico. Study investigators also enlisted the involvement of OPOs, the parent organization AOPO, and HLA labs. APOLLO divided transplant programs across the US into one of thirteen groups called Clinical Centers (CC). Within a CC, there is study leadership working directly with a group of transplant programs. APOLLO also includes patient voices through its Community Advisory Council (CAC). The CAC is made of living kidney donors, kidney transplant recipients and patients with chronic kidney disease or end stage renal disease. Organizing all of these groups into a cohesive research unit took planning, cooperation and a lot of communication. Supervising the overall study is the SDRC; which is located within the Wake Forest University School of Medicine in Winston-Salem, NC.

\*please refer to page 3 for a glossary of abbreviated and study terms.



## APOLLO is a Key NIH Study Including Patient Voices

The APOLLO CAC is a group of individuals with self-reported recent African ancestry, organized to advise the APOLLO SC on policy and practice matters related to the APOLLO research study. CAC members represent much of the study population and include living kidney donors, kidney transplant recipients and patients with chronic kidney disease or end stage renal disease. The CAC actively participates in study-related calls and attends in-person SC meetings. They have been instrumental in providing input and feedback to all parts of the APOLLO research study. This input and involvement has allowed patient voices, including the patients' needs, priorities, concerns and preferences, to be heard as part of the entire research study process.

**CAC members, APOLLO Steering Committee meeting, NIH Campus—March 2020.**

CAC recommendations have had an impact in the development of the MOP, study-related information to prospective participants, future information about study results and much more.

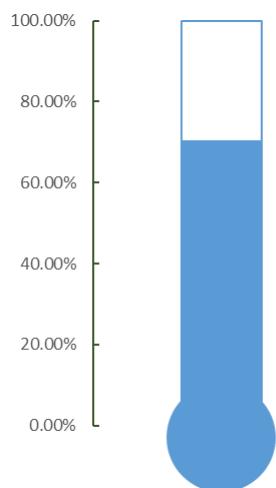
The CAC co-authored a manuscript published in the American Journal of Kidney Disease. *Improving Kidney Disease Research in the Black Community: The Essential Role of Black Voices in the APOLLO Study.*

### What It's Like to Serve as a CAC Member

As a Living Kidney Donor, when asked to participate in this research program as an advisor, I had no idea what I was in for. But since becoming a part of this elite team, I have learned so much. I am a part of a team that has taught me the meaning of standing up for what is right for all people, no matter the color of your skin. But even greater, that it is imperative that I stand up for the people that I'm there to represent, the Black Community. Helping our research team to understand what we as a people expect and look for when being addressed concerning participation in anything as daunting as research, has been an honor and a true learning experience thus far.



**Angenetta "Angie" Smith**



### APOLLO Recruitment

It took 15 months, to identify and organize the various collaborating organizations, write the study protocol and receive IRB approval to begin recruitment. We were not a year into recruitment, when the country shut down because of the meteoric rise of COVID infections. During the shutdown, elective surgeries were cancelled (including some kidney transplants) and APOLLO study staff at transplant programs were not allowed into clinics. Even as the country opened, we continued to experience disruptions in recruitment and bio-sample collection.

APOLLO study investigators were quick to adjust to the challenges presented by COVID and worked together to adjust recruitment parameters to include the largest number of potential participants possible.

## **APOLLO Study Glossary**

**AOPO** - Association of Organ Procurement Organizations

**CAC** - Community Advisory Council; patient voice that helps bridge the participant community and the APOLLO investigators

**CC** - Clinical Center, there are 13 located throughout the US and are responsible for the direction and supervision of the recruitment at US transplant centers.

**DNA** - deoxyribonucleic acid is the material [in the body] that carries all the information about how a living thing will look and function. For instance, DNA in humans determines such things as what color the eyes are and how the lungs work. Each piece of information is carried on a different section of the DNA. These sections are called genes.

**HLA lab** - participant biosamples, collected by OPOs, are processed and stored by the HLA labs and later shipped to the SDRC.

**IRB** - Institutional Review Board is an administrative body established to protect the rights and welfare of human research subjects.

**MOP** - Manual of Procedures, operations procedures to guide the conduct of the study

**NIAID** - National Institute of Allergy and Infectious Diseases

**NIDDK** - National Institute of Diabetes and Digestive and Kidney Diseases

**NIH** - National Institutes of Health

**NIMHD** - National Institute on Minority Health and Health Disparities

**OPO** - Organ Procurement Organizations; responsible for recovering organs from deceased donors for transplantation in the U.S

**SC** - Steering Committee; comprised of APOLLO investigators from each of the 13 CCs, NIH, SDRC, UNOS, AOPO, and a CAC representative. The SC is responsible for the development of the protocol and all other study documents and study direction.

**SDRC** - Scientific and Data Research Center, located at Wake Forest University School of Medicine in Winston-Salem, NC, is responsible for the overall direction and supervision of the study.

