



IGA NEPHROPATHY
FOUNDATION OF AMERICA, INC.

Dedicated to finding a cure.

Now Embracing HSP Patients Worldwide

A Look Back on 2019 Our Top 5 Favorite Moments

Counting down our favorite moments of 2019. So many great things to remember and so much to look forward to in 2020!

[Visit our Website](#)

#5 - Foundation grants to UAB & Columbia Universities

The University of Alabama Birmingham & Columbia University continue being on the cutting edge of research in IgAN.

UAB continues to be on the forefront of IgAN research. For more information about UAB's research, check out this news release on information they published in the Journal of the American Society of Nephrology in 2019.

[UAB Research](#)

Columbia & their GIGA Kids study is on the forefront of pediatric IgAN research. For information on the GIGA Kids study, please check out their website

[GIGA Kids Study](#)

They are still enrolling pediatric patients so please check with your child's nephrologist to see if they can join. If your child's center doesn't participate, they can still be a part of the study through GIGA's remote recruitment program. Please contact carrie@igan.org for more info.



GIGA
kids

#4 - Kidney Community Advocacy Day

Once again, the IgAN Foundation represented in Advocacy Day. We had a great breakfast with the American Society of Nephrology updating us on all the newest and latest kidney-related legislation and how the Executive Order signed in July, 2019 has impacted kidney health regulations.

We then split up into groups from our individual states and visited our Senators and Representatives letting them know the importance of passing the proposed legislation such as the Living Donor Protection Act and the resulting legislation on the Advancing American Kidney Health Initiative born from the Executive Order.

If you are interested in joining us in 2020 please contact carrie@igan.org and Carrie will make sure to send you information when the time comes.



#3 - Phase 3 Clinical Trials

Three clinical trials are now in Phase 3. This is great news for patients! The IgAN Foundation is working with the pharmaceutical companies to get the word out and get these trials filled! As you know, there are currently no disease-specific medications on the market. These phase 3 trials are changing that! If you are interested, click on the links below. All three trials are still enrolling!

Calliditas - [NeflgArd Study](#)

Retrophin - [Protect Study](#)

Omeros - [Artemis IgAN Study](#)

#2 - President signing Executive Order on Advancing American Kidney Health

The IgAN Foundation was invited to attend the historic signing of the Executive Order – Advancing American Kidney Health – in Washington, D.C. on July 10, 2019. This Order is the first of its kind. The goals of the EO are to give more choices to patients when it comes to dialysis and have more organs available for transplant.

Some of the legislation that has arisen from this order will guarantee transplant patients access to the necessary immunosuppressant medication through Medicare for the life of the transplant (as opposed to the 3 year limit now imposed).



#1 - Externally Led-Patient Focused Drug Development Meeting

The IgAN Foundation and the National Kidney Foundation partnered to bring together patients, pharmaceutical companies and the FDA for an Externally Led-Patient Focused Drug Development Meeting.

The goal of this meeting was to have patients tell their stories and present information to the pharmaceutical companies about their side effects to current medications, day-to-day living with IgAN and the impacts on their lives.

The FDA was there to hear how new medications are needed NOW and to decide whether to include the current IgAN clinical trials for their fast-track rare disease program in getting these new medications to market.

Some of the biggest take-aways from this meeting are patients need something other than prednisone as a treatment. Fatigue and mental health were two of the biggest complications patients deal with accompanied by joint aches & pains. Patients also commented on how great it was to meet other patients and be able to have others to relate to.



Quick Look at 2020

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We are looking so forward to 2020! We are having our first annual IgANF Spark. This patient symposium promises to be jam packed with sessions on understanding and living with IgAN, information for caregivers and lots of comradery and new friends made. This event will be July 19-20 in Nashville, TN. Please be on the lookout for information!

We want to wish you & yours a wonderful New Year! May your year be filled with blessings and great health!

Much love to all of our patients!
Bonnie Schneider & Carrie Enicke