



IGAN Insider

Issue 02

January 2017

Fundraisers/Events

Follow us through this past year and join us in welcoming the new year and our future plans.

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Research

Updates on ongoing research and what we contributed. Aiming to contribute more in 2017.

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Save the Dates

Exciting new events as well as the return of our favorites in 2017. Don't miss out!

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A message from the Founder

Dear friends and IGAN family,

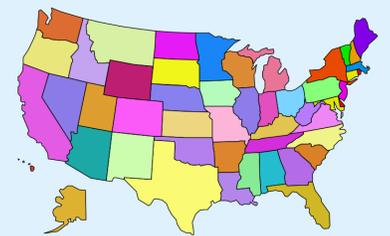
I would like to start off by saying *Happy New Year!* We wish you good health and blessings in the coming year.

2016 was a great year for the foundation. We raised close to \$1,000,000 for research, strengthened our Board of Directors, established area representatives in 14 states, became well known in the kidney research community, and aligned ourselves with other organizations that can help us move forward towards our goal. All of this would not have been possible without your ongoing support.

As you read on, we will share with you our vision for the coming year as well as our 2016 recap. We have many goals for 2017 and we anticipate another great year.

On behalf of our Board of Directors and myself, we would like to thank you for being a part of our family.

Bonnie Schneider



Help Needed!

If you are up for the challenge and would like to become an area representative please reach out to me. We desperately need active people who would like to help us move forward in 2017.

Help us fundraise! We are getting very close with our research but need more research dollars. Please help us fundraise in your community. We have all the how-to's and we will work with you every step of the way.

Call 732-770-7377 or email me at bonnie@igan.org

FUNDRAISERS AND EVENTS

1st Annual IGAN/DDI Golf Outing Friday, July 15th, 2016

Thank you to Karl Ramjeet and John Marsala for putting on one amazing golf outing. Over 100 golfers participated and the weather was with us, perhaps a little too much (it was very hot). Nonetheless, everyone gathered for the cause. The auction was loaded with great gifts and prizes were awarded in all categories. Please save the date, golfers, for July 14th, 2017 at the same place. We need you!

Participants at the Pine Ridge Golf Course



2nd Annual Tennis Outing

A big thank you to our Arkansas friends and the Moisson Family for spearheading their second annual tennis fundraiser. They raffled off great wines and competed in an all day tournament at their club. We appreciate your efforts and are so happy to have your team along with us! The Moisson family will be conducting another fundraiser TBA.

Art for Kidneys

Thank you to Dr. Margaret Warner who held her Art for Kidneys event in November. There were over 18 attendees that made beautiful scarves while spreading awareness for IGAN. Wine and appetizers were served and everyone had an amazing time.

2018 SOUTHERN IGAN CONFERENCE

We are extremely excited to announce an important event in the works. It is our Southern IGAN Family Conference to be held in early 2018 down in Birmingham, Alabama. Why did we choose Alabama? I am sure you can guess it is due to the incredible research ongoing at UAB.

We knew spearheading an event like this, we would need someone like Ann Marie Boyd who is highly qualified and has plenty of experience in event planning. Ann also has a personal connection to the foundation as her 10-year old daughter has IGAN.

This 24-hour period would consist of a casual evening meet and greet upon arrival for those coming from out of town. (Hotel options TBA). The next day would consist of breakfast & lunch with a line up of several speakers (Ds, dialysis techs, etc.) on IGAN. We will learn about IGAN and the many great things happening in research together. The day will come to a close with a Q&A session to answer many of our questions.

We will keep you up to date as we progress. Our goal is to eventually hold these very important conferences around the US.

Jersey Shore 5K for Kidneys

The 12th Annual Jersey Shore 5K for Kidneys in action

Again, the sun was out for our annual 5K. Over 300 attendees were there and we had so much fun. Our attendees rallied to the Columbia U tent to donate blood for the ongoing IGAN study. The Columbia team was able to gather hundreds of samples and they were very grateful for such a great response. Thank you all our volunteers who donated their time and energy to set up and break down the event. Thank you to our community who generously donated food and gift auction items and to Mike Kirby who volunteered to be our DJ for all 12 years. A big thank you to WAWA, Inc. our official sponsor and the Perricone Family Trust. We are so blessed to have your support.

Please save the date for Sunday, June 11th, 2017 at the Wall Municipal Complex. Times TBA. Please note that runners and walkers will have different routes this year!



Initial's Inc. Party

Thank you to Margie Wold who had her fundraiser through Initial's Inc. Everyone had a great time shopping and eating appetizers while learning about IGAN. We appreciate all those who attended.

Capitol Hill

For two years, members of our foundation have visited Capitol Hill with the American Society of Nephrology (ASN) and the National Kidney Foundation (NKF). Our focus was on both the "Chronic Kidney Improvement in Research Act" (H.R. 1130) and the "Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act" (H.R. 1428).

I am happy to report that the first bill has been passed! We are beyond pleased that more money will be allocated to kidney research. This research is desperately needed because 13 people with kidney disease die everyday while waiting for a kidney transplant. We are going back to the Hill in September this year to continue this fight for all kidney patients.

Continued...

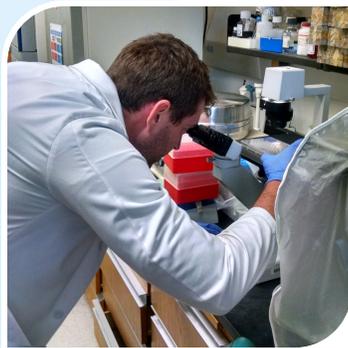


An ASN Convention presentation



MUSIC IS MEDICINE

On Wednesday, November 2nd, 2016 we were honored to attend the Music Is Medicine event at Columbia University. The event's purpose was to bring together education (five distinguished speakers) and music (performances by the Chamber Players International) providing a fun and entertaining environment to have a panel discussion on the new frontiers in nephrology and how diagnosis and treatment has changed in recent years at the Columbia University Medical Center (CUMC). CUMC's division of nephrology is one of the best in the nation (ranked in the top 5) and we are grateful to be involved in research there. Dr. Gerald Appel and Dr. Ali Gharavi, who are both involved with our IGAN research, were two of the five speakers at this amazing event. We congratulate the two of them and thank them for having us.



Observing research at UAB

NIDDK

In April, we had our annual visit with the NIDDK (National Institutes of Digestive Disorders of the Kidneys) at the NIH (National Institutes of Health) in Bethesda, MD. A few of our board members and I attended this meeting. We shared our year recap with them and they were very excited about our growth.

One of the discussions at the meeting was the CURE GN study (more info soon) ongoing at the 50 sites and sub sites around the country. IGAN is one of the four kidney diseases under the microscope in this study. We are pleased to report that our IGAN patients rallied to the cause and were number one in patient registration. Thank you to all of those who took the time to get involved in this study. We will be collaborating with the NIDDK this year on other projects as well.

Cure Glomerulonephropathy

Cure GN is a multi-center 5-year cohort study funded by the NIH, NIDDK. The study includes 2,400 children and adults with four unique Kidney diseases (IGAN being one of them). The research will be followed to better understand the causes of the disease, response to therapy and disease progression, with the ultimate objective to cure GN.

There is still space for patients and we need your help. It is a simple process to start participating. If you would like to become involved, log onto our website at www.igan.org and click on the Cure GN link.

GIGA KIDS

In 2016, we met with Dr. Kiryluk and Dr. Gharavi for our annual meeting at Columbia University in NYC. The Giga Kids study is moving along nicely. Due to the support of our friends and community, we were able to donate \$12,500 to the study this year. The study focuses on children 25 years and younger who have been biopsied positive for IGAN and the genetic factors of the disease.

This study is critical for future families with IGAN history. If you would like to become involved please log onto our website at www.igan.org and click on the Giga Kids link. we need you here as well!

University of Alabama-Birmingham

This has been an incredible year for research at UAB. We had our annual visit with Dr. Novak and Julian, whom head the research for IGA Nephropathy at the University, and awarded them with a check for \$30,000. UAB continues to match our donations dollar for dollar each year.

It is a comfort and a blessing to know we are at the right place for research. UAB is leading the world in IGA Nephropathy research. Besides setting biomarkers

for IGAN, they have been working extremely hard at two very promising treatments. We had a tour of the lab and were able to see first hand the data on their projects. We are working with them on other projects that we will share with you in the future.

Ms. Bonnie Schneider
Executive Director and Founder
IGA Nephropathy Foundation of America, Inc.
Post Office Box 1322
Wall Township, New Jersey 07719

Dear Ms. Schneider,

It is an honor to provide the IGA Nephropathy Foundation of America, Inc. with an update on the progress that the Foundation's support of research on IGA nephropathy at UAB has made possible. Philanthropy is a living tribute that helps UAB fulfill its best and highest purpose as a university every day, supporting students in search of an outstanding education, patients in search of compassionate and effective care, and researchers in search of breakthroughs that will change lives.

The Foundation's generosity is touching countless lives at UAB, and it will for generations. Thank you for partnership in our vision for UAB as a leader in our community, in our nation, and in our world.

Sincerely,

Tom Brannan
Tom Brannan
Interim Vice President for
Development and Alumni

Letter of gratitude presented to us while visiting UAB

SAVE THE DATES

- Sunday, June 11th, 2017 - The 13th Annual Jersey Shore 5K for Kidneys in Wall, NJ
- Friday, July 14th, 2017 - The 2nd Annual Golf Outing at the Pine Ridge Golf Club in NY
- September 2017 - Laser Clay Shoot Competition in Houston, TX
- 2018 (Date TBD) - The Southern Family IGAN Conference in Birmingham, AL

For more information, please visit us at

www.igan.org

Thank you for your support!



Illustration by Dr. Margaret Warner

“The greatest healing therapy is friendship and love.”

-Hubert H. Humphrey



IGA NEPHROPATHY
FOUNDATION OF AMERICA, INC.

Dedicated to finding a cure.

Now Embracing HSP Patients Worldwide

P.O Box 1322
Wall, NJ 07719



[Recipient]

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IgA Nephropathy Foundation of America, INC. is a 501©(3) non-profit, public health organization.

All donations are tax-deductible to the limit of the law.