



# IGAN INSIDER

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## IMPORTANT DATES

See what events are coming up! For more information go to [www.igan.org/events](http://www.igan.org/events)

## Help Needed!

We are still looking for volunteers. 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 2018.

We also are looking for help with fundraising. We are getting very close with our research but need more research dollars. Please help us fundraise in your community. We have all of 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](mailto:bonnie@igan.org)

## A Message from the Founder

I would like to start off by wishing you a happy and healthy new year. Looking back on 2017, I realize what a very busy and exciting year it was for the foundation. As we continue to strengthen our relationships in the kidney world, we have also aligned ourselves with new friends.

*“Looking back on 2017, I realize what a very busy and exciting year it was for the foundation.”*

In the 14 years since we started the foundation, we have had little contact or recognition from pharmaceutical companies and in 2017, that has changed. IgA Nephropathy has become of great interest to many companies in the pharmaceutical industry and is now on the map next to other kidney diseases.

As we enter into 2018, I am hopeful that all of the contacts we have made this past year will lead us to better treatment for all of those affected by this chronic kidney disease.

As you read our newsletter, I want you to know how important you have been on this journey. We could not do this without your continued support.

May God bless you and your family!

Always,

*Bonnie Schneider*



Founder and director, Bonnie, pictured with her husband, Ed.

## Fundraisers and Events

### 13th Annual Jersey Shore 5K for Kidneys Run/2-mile Walk

Over 350 walkers and runners came out to help raise awareness for IgA Nephropathy. It was a beautiful day filled with fun for all. We went over the top for our donors starting with breakfast and ended with lunch donated by our biggest sponsor, WAWA, Inc. In between, there was face painting, the tot trot, prizes, awards, DJ Mike and an incredible gift auction. We are so grateful to all who helped us make this annual event a huge success.



Walk participants at this past year's Jersey Shore 5K for Kidneys

### 2nd Annual IGAN/DDI Golf Outing

A big thank you to John Marsala and Karl Ramjeet for putting on another amazing event in Coram, NY. Over \$30,000 was raised for both IGAN and DDI (Development Disorders Institute); two very worthy causes. 92 golfers registered for this great day. Lunch and dinner was provided along with awards and a great gift auction.



John Marsala speaking at the IGAN/DDI Golf Outing

### 3rd Annual Arkansas Tennis Tournament

The Moisson family hosted their 3rd annual tennis tournament this year at their club. Many of their

friends and club members joined in to help them in honor of their son, who has IGAN. They raffled off great wines and enjoyed an awesome day together. Thank you for helping us every year to keep our research ongoing!

**“No one has ever become poor by giving” - Anne Frank**

### Giving Tuesday

This year, we decided to give FaceBook’s “Giving Tuesday Challenge” a try and I am so happy we did. We were able to raise \$8,000 within a three-week period. The support we received along with the messages of inspiration from everyone made this a very special fundraiser. Thank you to all who helped us reach our goal of \$10,000 which we did with a matching gift.

### DAVE SCROGGINS' 55 AT 55

Yes, 55 miles on his 55th birthday! That’s what one of our IGAN Family members did for his son and daughter in December. Dave Scroggins’ daughter suffers from Tuberosus Sclerosis and his son has IGAN. Without any training, Dave went for a long walk to complete about 55 miles in 15 hours (5 AM to 8 PM). Dave’s mission was not only to raise money for both diseases, but to create awareness. Thank you, Dave, for braving the elements (19°F!) and coming up with an amazing fundraiser.



Dave Scroggins (right) with his friend, John Dixon (left), who joined him at hour 12 of his walk.

# Research

## NIDDK/NIH

Our annual trip to the National Institutes of Health took place in April. We always anticipate a great meeting and again it was. Dr.

Robert Starr has been a NIDDK (National Institute of Diabetes and Digestive and Kidney Diseases) coordinator for years and we consider him not only a friend but a mentor in our journey. We updated the team on our progress in research and stated how important it is for future funding for IGAN research. We are hopeful that they will continue to keep IGAN research in their allocation of funding.

## UAB (University of Alabama-Birmingham)

As you know, UAB has been our main focus in our funding research. This year we were able to donate \$45,000 to the university. We visit the UAB team annually and continue to be pleased with their progress. The gifts from our foundation in 2017 provided funding for research concerning the causes of IgA Nephropathy and assessment of approaches for treatment of the disease (see blue column to the right).

In summary, the foundation's support has helped to maintain the cutting edge academic research into the causes of IGAN by the research team at UAB. Publications resulting from this research are listed on our website research page.



Bonnie Schneider, Lenny Erlanger and other board members at the NIDDK meeting.

### UAB's ongoing studies and progress:

Assessment of composition and mechanism of action in disease-inducing immune complexes

Discovery of cellular abnormalities that enhance production of Galactose-deficient GA1

Detection of IgG autoantibodies in glomerular deposits

Structural characterization of IgG autoantibodies

Assessment of the urinary proteome (proteins found in urine)

Development of a new mouse model

Testing compounds that may block activities of disease-inducing immune complexes

Studies concerning activity and composition of a Chinese traditional medicine used for the treatment of IgA Nephropathy in China.

## Capitol Hill

This was our 4th year visiting the Hill to ask for increased investment in kidney research and to co-sponsor the Living Donor Protection act of 2017 (HR 1270).

The sad news is that we spend nearly 33 billion on kidney failure and invest the equivalent of just 1% in kidney research. We conveyed our appreciation for the support Congress has historically given the NIH and hope that they continue that tradition by increasing funding for the NIH by \$2 billion for 2018 with at least proportional increase for the NIDDK.

The Living Donor Protection Act is a no cost bill. This bill protects living donors by making sure insurance companies do not deny or limit coverage and do not charge higher premiums to living organ donors for life, disability, and long term care plans. We need this bill passed. See the blue column above for the staggering statistics of a kidney patient waiting for a deceased donor.

It is up to us to bring all of this to the attention of congress and more important to continue to follow up after our visits.

## Cure GN Update

The Cure GN study has now closed all recruitment for IGAN and HSP patients. This is due to the amount of our patients supporting this study. For those of you who donated your time, we thank you! This means that any new patients who may have qualified for this study can now be recruited under the GIGA KIDS protocol.

## GIGA KIDS (Genomics of IgA-related Disorders in Kids Study)

We are pleased to announce the milestones that the GIGA KIDS study has seen in 2017. A poster was presented at the ASN (American Society of Nephrology) conference this year. The study's total recruitment is almost 400 participants. The GIGA Kids web page link is on our website for any patients under the age of 26 that would like to participate. There are 50 sites and subsides around the country. To find out a site closest to you, a site map is available. Due to the expense of these studies we were able to help defray costs by donating \$12,500 to show our support.

**Every 14 minutes**  
a patient is added to the kidney wait list.

**13 Americans**  
die every day waiting for a kidney transplant.

**100,000 plus Americans**  
are on the transplant wait list today.



Meeting with UAB in New Orleans

## Save the Dates

**Monday, May 14th, 2018 - The 1st Annual IGAN Golf Outing (SC)**

@ The River Club in North Augusta, South Carolina  
- hosted by the Almond Family

**Sunday, June 10th, 2018 - The 14th Annual Jersey Shore 5K for Kidneys and 2-mile Walk**

@ Wall Municipal Complex in Wall, NJ  
hosted by our Board of Directors

**Friday, July 13th, 2018 - The 3rd Annual IGAN/DDI Golf Outing (NY)**

@ Pine Ridge Golf Club in Coram, New York  
- hosted by John Marsala and Karl Ramjeet

Honest  
tea

Best Provision  
Co. Inc.

Coast  
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Entenmann's

  
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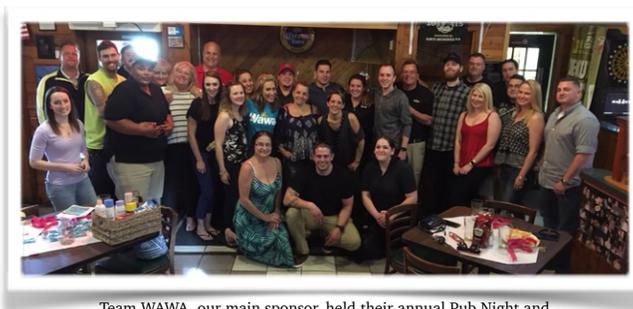
UOA

Perricone Family  
Trust

E Street  
Bagels

WALL  
STORAGE

Wawa



Team WAWA, our main sponsor, held their annual Pub Night and donated \$9,000+ to the Foundation. THANK YOU, WAWA!



IGA NEPHROPATHY  
FOUNDATION OF AMERICA, INC.

P.O. BOX 1322  
WALL, NJ 07719  
[www.igan.org](http://www.igan.org)