Translation

Help Us Find A Cure Add Your Data To Our Medical Database

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IgAN Foundation

*The **IgA Nephropathy Foundation** was started as a personal quest by me, Russ George, following my discovery that I have this condition. I am a scientist and researcher both by profession and avocation. As I worked to learn all I could about my own condition I discovered that there was a need to have this information presented on the Internet. I began by posting my information as a few web pages. Over the years the effort grew and eventually other people with the condition thought it would be good to incorporate an official charitable foundation. That was done and it has been a fair idea though in reality it has taken more effort than it has returned and has rarely provided sufficient funds to cover expenses. Never-the-less the IgA Nephropathy Foundation is alive and well. Our main purpose is to maintain this web site, collect data for research on the nature and possible treatments of the condition, and act to advocate a more thorough reading and understanding of this condition by patients and those in the medical world. To that end we measure our success and reward for this effort by the thousands of letters of interest and thanks from those we have helped.*

Please note, as you read these pages you may find unfamiliar technical and medical words. For the most part you shouldn't worry about knowing the exact meaning of these specialist words right away. You will learn most of what there is to know about IgA Nephropathy with or without a full understanding of the technical words and you'll learn their meaning as you read on.

Russ George, Founder

IgA Nephropathy or Berger's ("burrjays") disease is the most common non-diabetic kidney disease. It results when IgA, a normal component of the blood, collects in the kidney as damaging deposits. These deposits are an immune system defect, hence IgAN is considered an autoimmune disease. Just why these deposits form is not known though a variety of factors such as family genetics and coincident infections seem to play important roles.

Included in the diagnosis of IgAN is Henoch Schoenlein Purpura (HSP) where it involves the kidney and sometimes other forms of glomerulonephritis (kidney disease). Available evidence suggests that IgA nephropathy occurs from either increased production or reduced clearance of the immune protein IgA and associated antigen complexes that are ultimately deposited within the kidney.

Many sources categorize IgAN as a rare disease with some sources claiming it afflicts 1:100,000. It seems that this estimated level of incidence for IgAN is not accurate as a large proportion of patients who present with IgAN symptoms have mild disease which is not diagnosed via the accepted biopsy diagnosis. One published study showed 94 out of 100,000 military inductees were diagnosed with IgAN. Other published research of random autopsy kidney biopsies suggests IgAN may be vastly more common and may affect up to 2-4% of the human population at large. Certainly there is a dramatic variance in the prevalence of diagnosed IgAN. In Japan and France where testing for the condition is part of regular preventative medical care the disease incidence is twice that found in the USA where testing for IgAN is rarely performed as preventative medicine. Most people probably never realize they have the disease or at least do not realize it until a late stage. Amongst those diagnosed

Make a contribution to the IgA Nephropathy Foundation

Physician referrals

Understanding Medical Reports and Data

Literature and References

Fish Oil Buyers Info

Kidney Health Organizations

Personal Stories

Other Links

Coming Soon

Kids with IgAN

Diet and Exercise

Continuing Education for Physicians

Russ George Founder
IgAN Foundation

as having IgAN as many as 20%- 30% will suffer eventual kidney failure within 10-20 years. They will require life saving dialysis and/or a kidney transplant.

A Few Warning Signs of Kidney Disease

Tea colored urine
(hematuria - blood in the urine)

Very foamy urine
(proteinuria - protein in the urine)

Puffiness around the eyes, hands, or feet
(edema - fluid retention)

High blood pressure

Pain in the small of the back just below the ribs not aggravated by motion.

Frequent urge to urinate especially at night and or reduced amount of urine produced.

There are few "widely accepted" western medical treatments for IgAN save in the latest stages of the disease. There is however growing evidence that a number of therapies can be effective in delaying the deterioration of kidney function for many years. Most nephrologists with an active awareness of IgAN prescribe ACE inhibitors and fish oil at a minimum. In some cases powerful steroid treatment is utilized. For about half of those with IgAN, tonsillectomy which treats part of the underlying immune disorder, is effective. There are additional new treatments that show the promise of being a start on finding a cure for the disease.

Research is one of the most important things this internet site is able to do by collecting data from individuals with IgAN. Since this condition is somewhat rare there are very few research projects focusing attention on the disease simply because recruiting patients to participate is difficult.

Your help is needed to find treatments and cures for IgAN. If you find the information on this site of use to you or your family please make a contribution of your own personal medical data so we can learn more about this condition.

Just click on the menu item in the left hand margin. All submitted data is kept in the strictest confidence and in accordance to prevailing medical research rules. Your name will be kept secret and your data use only for medical research on IgAN and related conditions. Please help us by filling out the research questionnaire on this site and returning once or twice a year to update us on your condition.

Foundation Mission Statement

The IgAN Foundation's mission is to provide vital and the latest information on the diagnosis and treatment of IgA Nephropathy to patients, their families, and their healthcare providers. We also serve as a voice for the multitudes of IgAN patients as advocates for enlightened regulatory, research, and appropriate funding policies affecting treatment and research. Most of all we hope to inspire people to make informed choices amid uncertainty and to choose hope over despair.

This page is here to enable and encourage world wide communication and collaborative research on this common kidney disease. We are confident that the IgAN Home Page will help us all to find effective treatments and a cure for this disease.

Tell us about your interest

Do you or someone you know have IgA Nephropathy?

Self ☐ ... Spouse ☐ ... Son ☐ ... Daughter ☐

Where do you live?

North America
Europe
Asia
Africa
South America

If you are willing to give us your name and e-mail address we will send you more information as it becomes available.

Name

Email address

All information is kept private.

Submit Reset

If you are interested in adding more information on your condition to our research database don't forget to visit our IgAN Internet Research Page while you are visiting this site.

Become a member of the IgA Nephropathy Foundation

As of January 1999 we are offering memberships in the IgAN Foundation. Membership helps us help you by keeping up with emerging research and practices in this field of medicine. Starting in the spring of 1999 we will begin publishing newsletter to keep you informed on developments in this area of medicine. Members will receive the newsletter free of charge. See our **Membership/Contributions Page** for details.

Make a charitable gift to the IgAN Foundation

To make all that we do possible, the IgA Nephropathy Foundation depends on private contributions from caring individuals throughout the United States and around the world. Every year more of these contributors are discovering the benefits of supporting the IgANF. Please make the IgAN Foundation your charity of choice. See our contributions page for details on giving.
Membershi/Contributions Page

Absence of Copyright notice

> *"If you steal from one person that's called plagiarism, if you steal from everyone ... that's called research!" American folk singer Woody Guthrie.*
>
> *Everyone is free to conduct research using materials found on this page! If this material is helpful in your efforts to understand or help those who suffer from IgAN disease we pray you will put it to good use.*

Standard Disclaimer Notice

> *We've had a number of inquiries about why we don't prominently feature standard disclaimer notices and chastising us for the lack there-of.*
>
> *This "Standard Disclaimer" is for those whom the following is not apparent: Information you find on the Internet, this site included, or in any other medium for that matter is not supposed to be used as your sole source of scientific or medical knowledge. Any knowledge you gain here you ought to consider in concert with other knowledge and advice from all sources. If you have a medical condition that needs treatment it is generally considered a wise practice to seek professional help from medical practitioners when making choices as to treatment or care.*

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You are at

IgAN Foundation Home

www.iganfoundation.org

Website bits and pieces

Award of Excellence

MAJON
Majon's Web Select Award

SITE CREATED WITH Microsoft® FrontPage™

Best viewed at 800x600 resolution