Clinical Trial Information

Nat'l Eye Institute
800-411-1222 or www.nei.nih.gov

Clinical trials have guidelines called “inclusion” and “exclusion” criteria. These criteria (age, gender, type and stage of disease, etc.) keep participants safe and ensure researchers will be able to answer the questions they plan to study.

C3 Gene Variant Linked To Macular Degeneration

Researchers report that a change in the C3 gene, which plays a role in inflammation and in the body’s immune response, also contributes to macular degeneration.

After sequencing DNA from 10 regions of the genome that had been previously linked to AMD in previous genetic studies, the researchers turned up two gene variants: one in the C3 complement gene, and an alteration that had been identified in previous studies of macular degeneration. The two gene variants together contribute to a three-fold increased risk for macular degeneration by interfering with inactivation of inflammation in the retina.

The study was carried about by an international team at The Genome Institute at Washington University School of Medicine in St. Louis and the University of Michigan School of Public Health in Ann Arbor. The results were published online Sept. 15 in the journal Nature Genetics.

Free DVD

Hallucinations: Am I going Crazy?
AMD and Charles Bonnet Syndrome.
DVD available on request with detailed information! Call: 888-633-3937

Smart Contact Lenses for the Blind

Google has taken their new Google Glass technology a step further with an idea that could have significant benefits for the blind.

The company has applied for a patent for a contact lens containing a built-in camera. With this, a blind person would be able, for example, to receive an audible signal warning of an approaching car at an intersection.

The lens would process the image and communicate with a remote device such as a smart phone carried by the wearer. The system, according to Google, would also be able to detect and describe faces; and, by extension, it should be able to act as a text reader (optical character recognition).

Both of these capacities would be of enormous benefit to people with impaired central vision, as with macular degeneration. The user will be able to control the camera by way of different blinking patterns. The technology for this product is in place, but development and marketing are still further down the road.
Where Can I Go To Get Help Paying for My Medical Costs?

Founded in 2004, the Patient Access Network (PAN) is a nationwide, non-profit dedicated to providing financial assistance to underinsured patients or patients who have insurance but still face financial hardships for the treatment of complex specialty conditions.

PAN provides grants to qualifying patients to help pay for the out-of-pocket portions of their qualifying medication costs. Once a patient is approved, PAN allocates a certain amount of money that patients have access to for 12 months. When a patient receives a treatment or medication, their healthcare provider or specialty pharmacy submits a claim to PAN for the co-pay or coinsurance amount not covered by the patient’s insurance.

PAN also features what they call a 90-day look-back, which means if a patient has incurred qualifying expenses at any time during the 90-days prior to their grant approval, PAN will reimburse them directly through their grant.

PAN has developed multiple application routes.

* Visit PANfoundation.org and select “Online Application”.
* Call 866-316-PANF (7263).
* Physicians and Specialty Pharmacists have access to online portals where they may apply on behalf of patients and manage their grant and claims electronically.

Questions to Liz

Liz Trauernicht - CEO
MD Foundation

Where Can I Go To Get Help Paying for My Medical Costs?

Dr. David Seftel, Director of Research Development for the Macular Degeneration Foundation, is interviewing the world’s foremost scientists and medical practitioners who are actively investigating cures and treatments for Macular Degeneration and related eye diseases.

Visit MacularNews.org for the latest news and register to receive an email notice when new videos are first posted.

Donations

The Macular Degeneration Foundation, Inc. is a tax-exempt, non-profit organization.

Please visit our website at eyesight.org to make a tax deductible donation.

Checks may be mailed to: Macular Degeneration Foundation, Inc., P.O. Box 531313, Henderson, NV 89053

Call: 888-633-3937 (USA) Call: 702-450-2908 (Intl)
Email: liz@eyesight.org

Exclusive Online Videos Featuring World’s Leading Eye Researchers

DISCLAIMER - Articles in the Magnifier are for information only and are not an endorsement by the Macular Degeneration Foundation editorial staff.
Low Vision Conferences Becoming High-Tech Accessible

Organizations for the blind and visually impaired will soon be able to provide indoor navigation technology at their national conferences.

The service, called “Audio Guide”, is being offered free to charitable organizations by Macular Degeneration Support, with financial backing by Macular Degeneration Foundation.

Beginning in 2015, conference attendees will be able to more easily navigate meeting venues without depending upon sighted human guides. Location information will be transmitted by electronic beacons placed at registration tables, concession areas, exhibit areas, meeting rooms, restrooms, escalators, and elevators.

An application specially designed by Indoo.rs will then identify the locations vocally through the user’s device or Android phone. The system will be customized to the specific services of the host organizations.

Audio Guide is modeled after a system being tested at the San Francisco International Airport. It will be the first time the new technology has been used at low vision conferences, which hundreds of people attend for educational and social purposes.

The new technology will give the blind and those with low vision improved security and independence.

Several national organizations are already on board with the project, but opportunities are still available. For information about how to receive the free service, email Dan Roberts at director@mdsupport.org.

In The News

Lutein & Zeaxanthin Rich Marigold Extract

Stanford Chemicals of Irvine, CA has created a Lutein/Zeaxanthin extract that can be added to foods and cosmetics. It is currently in the process of developing a water soluable version for drink companies.

Injections for Macular Degeneration Could be Replaced by Eye Drops

Medications like Avastin and Lucentis used to treat age-related macular degeneration by injection could one day be replaced by eye drops.

Most medicines won’t reach the retina unless they are made of molecules small enough to bypass barriers within the eye. To overcome this, researchers from UCL Institute of Ophthalmology loaded tiny nanoparticles with an approved drug, suspended those nanoparticles in liquid and used that liquid in the form of eye drops to treat the eyes of rats and rabbits.

This new technique could be tested and available within a few years if the researchers can get funding to move things along quickly.

MAGNILINK VOICE From Low Vision International

This new text-to-speech device boasts speed, simplicity and the ability to detect and read multiple languages. See lowvision.preventblindness.org or mdsupport.org

Definitions

Ophthalmologist
a practitioner in the medical science of surgery and care of the eye and its related structures. An M.D. degree is required.

Retina specialist
a medical doctor trained as an ophthalmologist, who has received additional training in diseases and surgery of the retina and vitreous.

Optometrist
a degree (O.D.), independent, primary health care provider skilled in the co-management of eye health and vision care, including examination, diagnosis, treatment, management of diseases/disorders, prescription of eyeglasses/contact lenses, and provision of low vision aids and therapy.

Optician
a person who designs or manufactures ophthalmic appliances or optical instruments (“ophthalmic optician”) or deals in prescriptions (“dispensing optician”).
When What You See Isn’t Really There

Charles Bonnet Syndrome Revisited

by Joe Fontenot MD - Medical Directory of Community Services for Vision Rehabilitation

Many people who read The Magnifier probably already know about Charles bonnet Syndrome (CBS). CBS is visual hallucinations ... that is, seeing things that are not there such as faces, figures, animals, flowers. The exact incidence is not known with certainty, but it seems to be roughly between 10 and 20 percent of people with ARM.D.

The visual hallucinations of CBS occur in people who are completely sane but have loss of central vision. The images are not accompanied by sound, are usually of brief duration and may occur frequently. Most people are not aware of what causes them when they first begin. Many are understandably alarmed or confused by the unexpected images.

Since its first description by Charles Bonnet in 1759, CBS has been regarded as a benign, non-troublesome condition ... more of a curiosity than a problem. CBS has been likened to the “phantom limb” experienced by amputees who have feelings in a hand, for example, that no longer exits.

Mr. Bonnet’s original description was of the things seen by his 87 yr. old grandfather who had poor vision. The exact cause of his vision loss is not known. It may have been ARMD or cataracts. He was, according to Mr. Bonnet, “respectable, full of health, judgment and memory”. However, his grandfather saw men, women, carriages, and buildings that didn’t exist. Bonnet felt that these images arose in “that part of the brain that commanded the sense of vision”, which we now know to be the occipital cortex.

How to Treat CBS

The first step in treating CBS is to know that it is a normal part of vision loss. It does not mean that you are crazy, but simply that your brain does not like not getting information from the area of your blind spot. In most cases, the frequency and intensity of the images will gradually diminish and usually go away or become mild and not bothersome. Medical treatment, such as antidepressants or other psychoactive drugs, are not recommended.

A new perspective on CBS

In the May 2014 issue of the British Journal of Ophthalmolo-
yrus, authors Thomas M Cox and Dominic Ffytche reported on the largest study of people with CBS ever done.

Their findings were different from what was expected. First, CBS hallucinations lasted much longer than usually thought. Seventy-five (75) % continued to have CBS for 5 years or more. Furthermore, 1/3 of these had what the authors termed “negative outcome” CBS. By this they meant that 1/3 had bothersome symptoms. Some were fearful of the hallucinations, some felt that the images interfered with daily activities, distracting them or making some activities more difficult and less pleasurable.

They confirmed that most people (67%) did not know what CBS was when they first began to see things that were not there. Half of the people discussed it with medical personnel, but 1/3 of the medical personnel did not know what CBS was.

This study, the first of its kind, presents a different picture of CBS. It hopefully will stimulate further studies into the treat-
ment of CBS and help raise awareness of CBS among medical personnel and their patients.

The authors concluded that CBS is of longer duration than previously suspected with clinically relevant consequences in a third of those affected. Also, that Interventions that reduce the frequency, duration or fear of hallucinations may help re-
duce “negative outcomes” and that “The era of regarding CBS as an incidental curiosity has passed”.

So, if you have CBS and it has been bothersome or lasted for years, you are not alone. This study suggests that CBS is a problem to more people than previously recognized.

More Information

Go to www.ncbi.nlm.nih.gov/pubmed and enter “Negative Outcome Charles Bonnet Syndrome” in the search box.

For a full description of CBS, contact the Macular Degenera-
tion Foundation for a free DVD about it.

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When you miss out on benefits, are you or an elder relative missing out? Eldercare Locator can connect them to the needed support services that are easily accessed by them.

BenefitsCheckUp (benefitscheckup.org)

Eldercare Locator (1-800-677-1116 or eldercare.gov)