



*Chicago Alliance to Fund Retinal Research*

**SIGHT QUEST NEWSLETTER  
SUMMER 2016**

A publication of SEARCH FOR VISION  
1011 S. Waiola Avenue, LaGrange, IL 60525 - 847-673-0017 Marla Chorney  
(Information)  
Co-Editors: Lorraine & Jay Popek Advisor: Dr. I. Martin Grais

**What Are You Doing?**

As we know from attending lectures by researchers, discussions with our personal ophthalmologists and our own personal readings that advancements are being made in the treatments and cures of retinal maladies that we share. Our approaches and experiences to overcome these diseases are varied and wide ranging and many of these procedures are experimental.

The all-encompassing phrase “Retinitis pigmentosa” originally meant an inflamed retina and the early attempts to cure it were made on that basis. We know now that is not true.

Since we are not alone in these endeavors that occupy a sizable part of our lives sharing them could enlighten and guide the readers of this newsletter. If you would like to have your experiences appear in future issues of Sight Quest please send them to:  
Jay and Lorraine Popek [popek@att.net](mailto:popek@att.net).

Anonymity will be maintained.

**PARENT PETROLEUM 19<sup>TH</sup> ANNUAL GOLF CLASSIC**  
**ST. ANDREWS GOLF & COUNTRY CLUB**  
**2241 RT. 59, WEST CHICAGO, IL 60185**  
**AUGUST 25<sup>TH</sup>, 2016**

It is our sincere pleasure to invite you to participate in the Parent Petroleum 19<sup>th</sup> Annual Golf Classic to benefit Blindness Disease Research. By aligning ourselves with Search for Vision and the Retina Chemical Genomics Laboratory (RCGL), together, we are dedicated to raising awareness of retinal degenerative and other blindness diseases. Our aim is to provide information and community tools to help those coping with vision loss; and to develop the tools required to support a grass roots movement to raise funding for scientific research.

Search for Vision was founded in 2014 by a group of volunteers interested in consciously allocating hard-earned funds to reputable institutions where common goals and treatments are shared in finding a cure for blindness diseases. In our community, this event helps fund the research team of Dr. Michael Grassi, a dedicated clinical ophthalmologist and researcher at the RCGL of the University of Illinois. The aim of Dr. Grassi's research program is to use genomics in a multi-faceted and interdisciplinary, systems-oriented approach to further drug discovery for common blinding retinal conditions like retinitis pigmentosa. An estimated 93% of all dollars raised go directly to fund laboratory research. This work has significant implications for not only improving the current understanding of the molecular basis of retinal disease, but also for providing critical insights into its treatment.

Millions of Americans are losing their vision facing ultimate blindness. They are our friends, relatives, neighbor and colleagues. This event will help individuals like you to come together and share a common interest in this cause. Please join us this year as a sponsor, individual golfer, or financial contributor even if you can't attend.



Chicago Bear talk will be hosted by our celebrity guests Ed O'Bradovich former Chicago Bears defensive end and Steve McMichael former Chicago Bears probowler.

Co-Sponsors – BP Fuels BP Castrol

For reservation and details please contact:

Joe Alperta  
Parent Petroleum  
3340 W. Main St.  
St. Charles IL 60175  
1-630-584-2505  
jaliperta@parentpetroleum.com

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**\$5,000 Raffle**

**Search for Vision & Parent Petroleum Presents A \$5000 Raffle**

\$20.00 per ticket or (6) for \$100  
Drawing held Thursday, August 25, 2016  
At the Parent Petroleum 19<sup>th</sup>  
Annual Golf Classic  
St. Andrews Country Club  
West Chicago, IL 60185

- First Prize \$2000
- Second Prize \$1000
- Third Prize \$550
- Fourth & Fifth Prizes \$250
- Sixth, seventh & eighth Prizes \$150

(Winner need not be present)

To order tickets:

Make check payable to SEARCH FOR VISION

Mail to

Search for Vision  
1011 South Waiola Avenue  
La Grange, Illinois 60525

Or Contact: Ann Rasch

Arasch1761@aol.com or 708.354.4620

## **Silent Auction at Golf Classic**

The Parent Golf Classic, along with the silent auction, is getting nearer. SFV continues to need good prize donations from all of us. SFV has only two fundraising events each year we need to do well in both of them.

Retinal eye maladies are considered orphan diseases and public funding is difficult to come by. Therefore private funding must do all it can to keep the advancements coming.

As always, the proceeds from the Silent auction go directly to retinal eye research at the University of Illinois.

Time goes by fast and obtaining auction items takes persistence. The more and better the prizes offered the more enhanced will be the auction's results. The prizes can be merchandise, gift certificates, restaurant certificates, service certificates, etc... These auction rewards can be obtained from any business dealing with the public such as big box stores (general and home), clothing stores, restaurants, etc. Also the companies that employ us may make contributions.

The best of luck and we are working for a great cause.

Please have all donations sent to:

Search for Vision1011 S. Waiola  
LaGrange, IL 60525

***Search for Vision through The University of Illinois Foundation is a tax exempt 501 © 3 organization.*** The Tax Identification Number is 37-6006007.

## **Age-related macular degeneration before and after the era of anti-VEGF drugs**

NIH-funded study of Avastin and Lucentis examines their effects at five years.

In a study of nearly 650 people with the eye disease age-related macular degeneration (AMD), half still had vision 20/40 or better, typically good enough to drive or to read standard print, after five years of treatment with anti-VEGF drugs that are injected into the eye. The authors of the study, funded by the National Eye Institute (NEI) at the National Institutes of Health, say those outcomes would have been unimaginable about 10 years ago, prior to the drugs' availability.

The results were published in the journal *Ophthalmology* and presented May 2nd at the annual meeting of the Association for Research in Vision and Ophthalmology (ARVO) in Seattle.

“This is the most comprehensive study of anti-VEGF therapy for AMD to date,” said NEI Director Paul A. Sieving, M.D., Ph.D. “It points to the importance of long-term follow-up in studies evaluating disease treatments.”

AMD is the leading cause of vision loss among older Americans. It causes damage to the central part of the retina, the light-sensitive tissue at the back of the eye. AMD often has very few symptoms in its early stages. However, in later stages, it causes loss of the central, straight-ahead vision needed for activities like reading and driving.

There are two types of late AMD — geographic atrophy, and the more common neovascular AMD, also known as wet AMD. In neovascular AMD, fragile blood vessels grow under the retina and leak fluid. This usually starts in one eye, and is stimulated by a protein called VEGF. Just 10 years ago, people diagnosed with neovascular AMD were almost certain to develop severe vision loss in their affected eye and likely to lose vision in their other eye, too.

The new study looked at people with AMD who had regular treatment with drugs designed to block VEGF. After five years, 50 percent of those treated had 20/40 vision or better, 20 percent had 20/200 vision or worse, and the rest were in-between.

Ten years ago, the best available treatment for AMD was photodynamic therapy — in which an intravenous drug (injected into a vein) and laser are used to seal off leaking blood vessels. Past studies have found that just one year after diagnosis, less than 15 percent of patients given this therapy alone retain 20/40 vision, and up to 40 percent decline to 20/200 vision. Without any treatment, less than 10 percent of patients retain 20/40 vision at one year, and up to 75 percent of untreated patients decline to 20/200 vision. In the U.S., state drivers’ licenses generally require 20/40 vision in at least one eye. A best-corrected vision of 20/200 in both eyes is considered legally blind for the purpose of federal disability benefits.

The Comparison of AMD Treatments Trials (CATT) began in 2008 and was designed to compare the anti-VEGF drugs Avastin and Lucentis. VEGF is important in the growth and development of new blood vessels in normal and cancerous tissues. Avastin\* (bevacizumab) was approved by the Food and Drug Administration in 2004 for the treatment of metastatic colon cancer. Other drugs were later developed specifically to target blood vessels in the retina, with Lucentis (ranibizumab) coming to the market in 2006 and Eylea (aflibercept) in 2011. For treating AMD, the drugs are injected into the eye. Before Lucentis was available, many ophthalmologists began treating the disease with Avastin, which

appeared to have similar benefits, at least in the short-term. The difference in the cost of the drugs also made Avastin appealing; the approximate per-dose price was \$50 for Avastin and \$2000 for Lucentis. In the trial, more than 1200 participants with neovascular AMD were randomly assigned to receive either Lucentis or Avastin for two years, through monthly or as-needed injections. During that time, the two drugs were equally effective at preserving visual acuity. These results were later confirmed in five multicenter clinical trials around the world.

The current study followed up with CATT participants between March 2014 and 2015, an average of 5.5 years after enrollment in the trial. After two years on their assigned drug, participants were free to work with their eye care providers to choose their own course of therapy. During that 3.5-year period, more than half received at least one treatment with a drug or therapy other than the drug assigned to them. The investigators obtained visual acuity measurements for 647 of 914 participants who were still living. In addition to the overall effects of anti-VEGF therapy at five years, the investigators compared the outcomes of participants who received Avastin or Lucentis during the trial. "Some experts had speculated that two years of treatment with ranibizumab might have long-term benefits superior to bevacizumab. However, at five years, there were no differences in visual acuity between the two drugs," said Daniel F. Martin, M.D., chair of the Cleveland Clinic Cole Eye Institute and CATT study chair. The study also found that after five years, participants assigned to Lucentis during the trial had a higher rate of strokes and heart attacks (7.6 percent) than those assigned to Avastin (4.5 percent). Since most participants received treatments other than their assigned drug after the two year-trial, the investigators are cautious about attributing this difference to the study drugs.

Finally, the study provides information on the general course of AMD with treatment. It was already known that many people with neovascular AMD eventually develop geographic atrophy, which has no treatment. In the trial, participants were more likely to develop geographic atrophy when they received monthly, rather than as-needed injections of Avastin or Lucentis. After the trial, almost all participants stopped monthly injections in favor of as-needed treatment, with an average of 4-5 injections per year. By five years, the rate of geographic atrophy increased from 20 percent of participants at two years to 41 percent at five years. The fraction of participants with geographic atrophy was similar between the Avastin and Lucentis groups. "Although anti-VEGF treatment has greatly improved the prognosis for patients overall, we still need to find ways to avoid poor vision in these patients and to decrease the burden of ongoing treatment," said Maureen G. Maguire, Ph.D. For more information about AMD, please see <https://nei.nih.gov/health/maculardegen>. \* Patients and health care providers should also be aware that, in contrast to Lucentis and Eylea, Avastin has not been approved by the U.S. Food and Drug Administration to treat AMD. Avastin is a preservative-free biological product originally packaged in a single-use vial, and it is particularly susceptible to microbial proliferation if

contaminated. To be used to treat AMD, Avastin must be repackaged into syringes. FDA has investigated many serious adverse events, including infections and blindness, associated with Avastin that was contaminated by pharmacies while being repackaged.

This article was excerpted from the National Eye Institute website (<https://nei.nih.gov>).

## **Memorial**

**With regrets we report that Sandra Lee Mayer, mother of Mindy Mayer, passed away on Tuesday, June 25th at 1:00 pm.**

## **Search for Vision Disclaimer**

Information disseminated by Search for Vision is for information purposes only. Readers must discuss any intervention with their Eye Care practitioner. Information in this newsletter does not imply that Search for Vision endorses any particular therapy, intervention or medication. Search for Vision assumes no responsibility for the use made of any information provided in this newsletter.

## **NOTICE**

**Anyone wishing to receive Sight Quest Newsletter can contact Jay or Lorraine Popek at [popek@att.net](mailto:popek@att.net) or call 708-652-4614.**