



## Fuchs' Genetic Study Seeking Participants!

Our study to investigate the genetic reasons why up to 30% of cornea transplant patients have steroid-induced glaucoma a year or more after their transplant needs volunteer participants!

Participation involves submitting a saliva sample via mail or in the office. We need volunteers that have and have not experienced pressure problems after a cornea transplant.

Check out Page 7 to learn more and see if you are a candidate!

## DMEK Documentary online!

**Did you ever wonder what really goes on during a cornea transplant?** Watch the firsthand experience as patient Bob Grimm (pictured below with wife, Cindy) has DMEK surgery performed by Dr. Francis Price.

For the first time ever you can see DMEK surgery without being the patient! You'll follow Bob as though you've tagged along with him through check-in, pre-op, DMEK surgery and his second day post-op exam at Price Vision Group.

Dr. Price shares a post-op update of his complicated case which involves prior cornea transplants and glaucoma. We checked back 6 months later and Bob shares how his vision has healed since the surgery.



Watch the video at [www.youtube.com/cornearesearch](http://www.youtube.com/cornearesearch) and click on DMEK Documentary.

This video was made possible thanks to Bob Grimm and a generous gift to provide educational video content from Frank and Mary Castelnovo.



## ROCK Inhibitor Study Enrollment Complete

Our study to determine if taking the eye drop Rhopressa® can reduce the primary cornea transplant complication that up to 30% of patients experience (elevated intraocular pressure, or high pressure in the eye) has completed enrollment of 188 subjects.

If successful, we will have yet another strategy to help control pressure and maximize vision for cornea transplant patients. We look forward to sharing the findings of this study next year.



## 26th annual Focus on Education Optometry Seminar

Focus on Education, hosted by the Foundation each fall along with Dr. Kathy Kelley of Price Vision Group, has cumulatively provided more than 25,000 hours of continuing education to optometrists throughout the Midwest.

Optometrists from throughout the region look forward to attending this annual event which provides 7 quality continuing education (CE) credits while learning from contemporary industry experts. Optometrists, like all doctors, must seek continuing education to maintain their licenses which helps ensure patients are receiving the latest advances in care.

In addition to research, we provide information to patients and doctors. Optometrists are often the first line of care in eyes while ophthalmologists offer surgical care. We assist in training both types of eye doctors through directed educational initiatives. This year, the OD seminar will take place on Saturday, November 17, 2018 at the Ritz Charles in Carmel, IN. Doctors may register at [Cornea.org/CE](http://Cornea.org/CE).



Surgeons practice DMEK in wetlab at a recent Cornea Course.

### CRFA Welcomes New Research Fellow



Dr. Kavitha Subramaniam has joined us from India for a 3-month fellowship. She is evaluating the outcomes of micropulse laser treatments for glaucoma management. See "Ask the Doctor" on the last page to learn more.

## HAPPENINGS...

What's new with CRFA?



### DMEK Course provided to cornea surgeons October 23-24

Dr. Francis Price, Dr. Matthew Feng and Dr. Marianne Price will host the second Advanced Cornea Course for DMEK of the year in late October.

This intensive course is designed for experienced corneal surgeons who hope to provide the latest in surgical advances to their patients or have a greater understanding of DMEK as they help co-manage patients.

The course includes presentations, 3+ hours of wetlab (pictured left), live surgery, post-op patient observations, complicated case reviews, discussions and more.

More than 600 doctors have been trained to date through Advanced Cornea Courses.

## Have Questions? Need Support? Join our Facebook Community

The Cornea Research Foundation sponsors a Facebook group called "Fuchs' dystrophy & DMEK" and has 700+ members to help share news and offer support. Ask a question and get honest feedback from fellow patients. Family members are also welcome. Visit to join: [www.facebook.com/groups/FuchsDMEK](http://www.facebook.com/groups/FuchsDMEK)

## CRFA Study Leads to FDA Approval

The U.S. Food and Drug Administration recently approved CEQUA, a new eyedrop for dry eye indicated to increase tear production. The Cornea Research Foundation participated in studies which led to the approval of this new treatment option.

## CRFA Presents Lakeside Lectures

Drs. Francis and Marianne Price provided two talks to the Lakeside, OH Chataqua Lecture Series on medical advances entitled "Replacement Parts of the Eye" and "New Ways to Improve Your Vision" in July to share the latest developments in vision research.

## Gaining Through Giving: Note from the Treasurer

Most people give to charity because they believe in the high impact work they do. We appreciate those who support cornea research every year! But, who doesn't like the idea of reducing taxes while maximizing your gifts to the causes you believe in? Every issue we share a tip regarding smart ways to support your favorite causes.

### Donor-Advised Funds



Donors make a tax-deductible donation,



... grow the donation tax free



... and support charities.

There are many charitable giving vehicles. When most people think of giving to charity they think of writing a check. However, there may be better ways to donate such as a gift of stock directly to avoid the capital gains tax, or a special tool such as a donor-advised fund. A donor-advised fund (DAF) is like a charitable investment account, for the sole purpose of supporting causes you care about. When you contribute cash, securities or other assets to a DAF, you are generally eligible to take an immediate tax deduction. Those funds are then invested for tax-free growth and you then recommend grants to virtually any IRS-qualified public charity.

### How do you establish a donor-advised fund?

Fidelity, Morgan Stanley and Charles Schwab are just a few wealth management firms that offer giving accounts. You can begin a donor-advised fund in just a few minutes online with an initial contribution as little as \$5,000 and a surprisingly low administrative fee. DAF's are more beneficial than ever due to recent tax changes.

For example, if you have stock or securities that have increased in value, it can be beneficial to donate them to claim a charitable deduction on your income taxes and eliminate capital gains tax. If you donate appreciated securities to a DAF, you can grant out the value over time to various non-profits of your choice. The value of any funds you haven't yet distributed may continue to grow in value depending on how you invest your DAF. Having a DAF makes it easy to maximize your charitable deduction in certain years and take advantage of the increased standard deduction in alternate years.

### **Speak with your financial advisor about the best way to maximize your charitable impact and tax benefits.**

If you would like to learn more about donor-advised funds, visit a website such as [fidelitycharitable.org](http://fidelitycharitable.org). Gifts of stock may be made directly to the Cornea Research Foundation of America. Contact our office at 317-814-2993 or [info@cornea.org](mailto:info@cornea.org) if you would receive more information about this giving option.

## Dry Eye Study Enrolling

Are your eyes dry, irritated, burning?

Do you sometimes find it hard to focus your eyes when you have been reading or using the computer for a long time?

Are you:

- 18 or older
- In good health
- Willing to refrain from using eye drops and contact lenses during the 4-week dosing period

If so, you may be eligible to participate in a research study to evaluate the safety and effectiveness of an investigational eye drop for the signs and symptoms described above. Call 317-814-2996 or email [study@cornea.org](mailto:study@cornea.org).

# Dr. Price's Top 5 Tips for Maintaining Transplant Health & Maximizing Vision



It's important to be mindful of proper eye care and safety every day, but especially after a cornea transplant.



Having a cornea transplant is an emotionally-charged, physical and financial investment in your sight. The surgery can dramatically improve your quality of life, particularly if vision loss has caused you to stop doing the things you once enjoyed. Congratulations on making it past the biggest hurdle—the surgery itself. What can you do to ensure its success in the long-term?

## 1. Never rub or push on your eye

This applies to all people, whether or not you have had a transplant, but is especially important following eye surgery. The eye is delicate and rubbing or pushing can cause damage as your eye heals.

If you have recently had surgery, be sure to take additional precautions such as:

- No bending with your head below your waist for one week
- Do not wear eye makeup or get water in your eye for two weeks
- Do not swim in any body of water including a natural body of water, pool or hot tub for two months (or as long as you have sutures in the cornea)
- Wear a shield over your eye at bed time for one month for DMEK and DSEK, 2 months for full-thickness (PK) and anterior lamellar (DALK) grafts
- Protect the eye with some sort of covering for a minimum two months after surgery (wear old glasses, a shield, sun glasses or safety glasses)

## 2. Know the signs of transplant rejection "R.S.V.P"

If you experience these symptoms, call your doctor immediately:

- **Redness**
- **Sensitivity to light**
- **Vision** (decreases in vision, especially if foggy or cloudy)
- **Pain** (discomfort, irritation or foreign body sensation)

## 3. Protect your eyes with proper glasses

This includes sunglasses on sunny days and safety glasses to prevent injury—even with simple household chores like gardening or cleaning with chemicals.

As someone who has had their sight threatened, you understand the importance of protecting your eye health soon after surgery, but long-term, as well.



## Did you know?

In addition to pioneering DSEK and DMEK transplant techniques, the Cornea Research Foundation has helped get approval for multiple new medications for allergies and dry eye. Dry eye is one of the leading complaints made after any type of eye surgery.



## 4. Follow your doctor's instructions to the letter

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This includes staying on eye drops as prescribed and keeping your scheduled follow-up exams. Each doctor's office may have different protocols, so it's important to follow instructions given from your surgeon.

### The Importance of Steroids for Transplants:

Since steroid eye drops are prescribed for long-term use after a transplant, we have found that one of the biggest risks to long-term graft survival is compliance of medications used post-operatively. Steroids are used to keep your immune system from identifying the donor tissue as foreign and rejecting it. Steroids are unlike many medications. If you have a headache, you take an ibuprofen and the pain subsides. Patients don't experience positive reinforcement or an immediate benefit to steroid use that they can feel. It's been reported that those who stop taking steroids do so, not out of intention, but rather they simply forget over time. They neglect refilling their prescription and a week passes. They don't notice any change in vision. The next thing you know, a month passes and still no change. Soon enough, a few more months slip by and they appear to be doing fine, so they choose to not refill their prescription again.

The problem with this natural discontinuation of steroid drops is that, as we found in one study, most patients do not experience symptoms with early graft failure. Many times significant cell loss will occur before a patient notices a change in vision. At that point we may be able to save the graft with intervention, but it may shorten the overall lifespan of the transplant. Bottom line—it is very important to take your medications as directed and that you do not miss or run out of your drops!

## 5. Flu & Shingles Vaccine Reminder

Each year, patients call asking about the safety of these vaccines as they pertain to their transplant. We believe both vaccines are important to help prevent these diseases and their associated complications. A new shingles vaccine called Shingrix® was recently approved by the FDA and is recommended for adults age 50 and older. Nearly 1 in 3 people will develop shingles in their lifetime if not vaccinated, and 30% of shingles are on the face. Shingles in the eye is a very serious threat to your vision. If you do develop shingles on or near the face, seek immediate treatment from your doctor.

### Steroid regimen during vaccines:

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- Resume Pred forte® 4 times per day in the grafted eye for two days before and two weeks following the vaccination (even if switched to lower dose steroids for everyday use)
- After two weeks, resume your normal dosage that you were taking prior to the vaccine

Please note, if you have a history of a viral or other infectious eye disease that prompted your initial transplant, call your doctor's office to verify instructions prior to your vaccine.

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### One Last Thought...

It is important for you to stay current on the research regarding the medications used for your cornea transplant. The pace of medical research is astounding and since the development of DMEK we have already changed eye drop recommendations based on our latest clinical research studies!

# “Do you know what a miracle is?”

## Dr. Lynn Mitchell shares his Cornea Story



For years, Dr. Lynn Mitchell knew a cornea transplant was in his future and he dreaded it with every ounce of his being. After surgery, when people ask him how his vision is, he responds, **“Do you know what a miracle is like? Well, I thought I knew at one time but now I have a whole lot better idea.”**

You see, for years, he had seen the struggle that patients in his family medical practice had after a cornea transplant. “I saw people suffer for a whole year or more to get back even halfway usable vision and I thought to myself that I never wanted to go through that.” said Dr. Mitchell.

“One day I went to the license branch to renew my license and I asked if the machine was broken. The woman responded, no, you just can’t see.” he explained how he knew it was time to seek treatment. He heard about a newer technique and found four people in the country who were offering it. Dr. Price’s name kept appearing, so he ultimately came for a consultation, and later surgery.

“This was right around the time when he started offering DMEK,”

he explained. “Dr. Price had asked me if I wanted to be included in the group that got DMEK and after some debate I decided I should. On the morning of the surgery, I was in the prep room and time was dragging slowly. He came in and said we would probably have to do the thicker DSEK graft because the thinner didn’t harvest well and we were disappointed. Then, he said, ‘wait here for a bit.’ After a few minutes he returned and said we got another graft and it’s a thin one. I consider myself deeply fortunate that it worked out the way it did but what I think is even more amazing is that Dr. Price, through his research and surgical skills, has made this readily available to so many people worldwide.”

“When I returned home, my doctor said that if he didn’t know I had a transplant he didn’t think he would be able to see the graft. Columbia, MO is a university town and I’ve been invited to the university to show the fellows my eyes. They just couldn’t hardly believe it! My vision got better and better and for a while I was seeing 20/20.”

Eight years later, it was time to return for his second DMEK, which was just recently done. “When I was asked to share my experience

I jumped at the opportunity, not to brag about my vision but to express my sincere gratitude for what Dr. Price has done for me personally. As an avid photographer, bird hunter, and tennis player, I’ve been able to enjoy hobbies that I haven’t been able to for many years. The stuff just sat on the shelf for literally years.” You can enjoy Dr. Mitchell’s wildlife photos above.

People talk about going and seeing two or three doctors here or there. When you have someone with his skills within a few hours of your own backyard and can have surgery in a reasonable time with good outcomes, why would you go anywhere else?

**Research today, brighter futures tomorrow**



**Please welcome our latest Visionary Society Member:**

- Annie Castelnovo-McMullen
- Juna Mae Brandenburg

**The Visionary Society** is CRFA’s donor recognition society for those who have made a planned gift in their will. We proudly recognize your non-binding commitment.

Please contact Jessica Dinglely if you have made a gift to benefit CRFA in your estate planning so we can properly recognize your commitment to vision research!

**We love hearing patient stories!**

Send yours to [Jessica@cornea.org](mailto:Jessica@cornea.org)



# How We're Making an Impact with your Support

## Breaking Research News with Marianne O. Price, PhD

We were excited to receive funding from the National Eye Institute to investigate the genetic reasons why up to 30 percent of cornea transplant patients experience steroid-induced glaucoma. This is when the pressure in your eye goes up as a side effect of the eye drops used to prevent your body from rejecting the donor tissue. We currently have no way to predict who may be affected and are working on several studies to combat this leading complication.

We believe the genetic study will help identify which transplant recipients are at risk for this complication before surgery so we can personalize their treatment to reduce that 30% risk. This study may also shed light on the genetic basis of open angle glaucoma, which affects 3 million Americans and is called the "sneak thief of sight".

We're inviting DSEK and DMEK transplant recipients to voluntarily participate, whether or not they experienced a pressure increase while using the anti-rejection eye drops, so that we can make

the comparison. Participants will provide a saliva sample, either via mail or in the Price Vision Group clinic. The sample will be analyzed to look for genetic differences between those who did and did not develop a pressure increase. Samples collected will only be used for this particular analysis.

We used to have to take a blood sample for studies like this. It is truly amazing that just with a little saliva/spit, we can study the genetics of what causes some diseases!

We need 800 past cornea transplant recipients to participate in this study. This is quite the undertaking but we are excited for the potential findings and what it may mean for cornea transplant recipients and people with glaucoma. If you are interested, please complete the form below to see if you meet the criteria and return it in the enclosed envelope or email [study@cornea.org](mailto:study@cornea.org).

Each person's help is crucial to bring us one step closer to the next breakthrough "so that all who look may see."®

### BY THE NUMBERS

#### Our Last Fuchs' Genetic Study

Over **5,000** participants were involved to identify the genetic link for families with Fuch' dystrophy.

We found three new genes associated with Fuchs' and confirmed the importance of a previously identified fourth gene, and more!

Watch the full video update of the study at **Youtube.com/cornearesearch!**

*Cut and return to CRFA with the enclosed envelope or email [study@cornea.org](mailto:study@cornea.org).*

## Fuchs' Genetic Study Interest Form:

### Are/Have You (must meet all criteria):

- Been diagnosed with Fuchs' dystrophy and had a DMEK or DSEK cornea transplant in the last 15 years at Price Vision Group
- Took the Pred forte® 1% corticosteroid for a minimum of one year
- Willing to provide a saliva sample by mail or in the office

Name:\_\_\_\_\_ Preferred Phone:\_\_\_\_\_

Email (to receive sign up/consent):\_\_\_\_\_

Will you be visiting Price Vision Group within the next year? Approx. when:\_\_\_\_\_

**9002 N. Meridian St. #212**

**Indianapolis, IN 46260**

**Cornea.org**



## ASK YOUR DOCTOR

**Dr. Francis W. Price, Jr.**

I had my Fuchs' dystrophy treated with DMEK transplants. However, I also have glaucoma and am currently taking drops to control pressure. My local doctor told me that there are glaucoma surgeries we can do if the drops stop working. Can you explain how those might affect my transplant?

It can sometimes be difficult to control the pressure in the eye when someone has glaucoma as well as a transplant, because the anti-rejection eye drops used to prevent transplant rejection can cause the pressure in the eye to increase. Normally there is a balance between fluid production and fluid outflow, but in glaucoma the plumbing in the eye gets clogged, impeding the normal outflow. High pressure in the eye can kill the optic nerve that transmits visual information to the brain resulting in irreversible blindness.

Eye drops are the first line of treatment for glaucoma. Fortunately, there are several different kinds and they can be combined for greater effect. When the pressure cannot be treated any longer with eye drops alone, glaucoma surgical procedures can be done to "open up the drain". However, these procedures can be hard on the cornea and increase the risk of transplant failure. Therefore our doctors have started using a micropulse laser to selectively treat the area that produces fluid to reduce the amount that is made. Less fluid to drain means less chance of fluid buildup causing increased pressure. We have found that this is successful in reducing pressure in about 4 out of 5 cases. The laser treatment, called MicroPulse Transscleral Cyclophotocoagulation (mTSCPC), can be repeated several times as needed to help control pressure and is less invasive than other surgical techniques and therefore easier on the cornea.

Our international research fellow, Dr. Kavitha, and our team are working on an analysis to report these outcomes. This new treatment appears to both increase the outflow of fluid from the eye and to reduce fluid production which successfully helps keep the pressure low. We are excited to have yet one more tool in our arsenal to help those with complicated conditions and look forward to sharing the information gained from our analysis with other doctors.

**Gifts to CRFA are tax-deductible as allowed by law. Thank you for your interest & support!**