

The Question Everything Issue

# Is Monogamy Over?

...and 21 Other Questions About the Way We Live Now

Do Robots Need Rights?

PAGE 62

Would You Trade Brains for Beauty ...

... or Beauty for Brains?

PAGE 67

Should We All Wear Body Cams?

PAGE 72

Is Etiquette Dead?

PAGE 71

Can Offensive Art Be Great?

PAGE 74

Are Computers Too Smart?

PAGE 80

Topless in Public?

PAGE 70

How Do You Know When You've Made It?

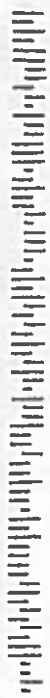
PAGE 69

with answers by

- Charles Koch
- Sarah Silverman
- Stephen King
- Ray Kurzweil
- Ellen DeGeneres
- M. Night Shyamalan
- Condace Bushnell
- Mark Duplass
- George Takei
- Tyra Banks
- Jason Derulo
- Ellen Pao
- Buzz Aldrin
- Tracee Ellis Ross
- Milton Glaser
- and, of course, Miss Piggy

What Will We Regret?

PAGE 73



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# Step Into The Light

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In a race to cure blindness, three advances come closer to reality

**By Alexandra Sifferlin and Alice Park**

SCIENTISTS HAVE LONG KNOWN THAT WHILE OUR EYES DO MOST OF the heavy lifting of sight—taking in particles of light, bending and refracting them, turning them into electrical impulses—we actually “see” with our brains. Between the eye and the mind, however, a lot can go wrong, and until recently, if someone’s vision started to go or was never there to begin with, there wasn’t much doctors could do about it. Now, thanks to an explosion of new research, scientists have an ever more sophisticated understanding of vision problems. This has led to a number of major advances in the treatment of blindness, using implants, gene therapy and stem cells. Even some in the field are stunned at the progress. “If you asked me five or 10 years ago if you could replace lost photoreceptors in eyes, I would have said it was biologically impossible,” says Dr. Robert Lanza, a stem-cell researcher who is doing just that. Read about three people receiving cutting-edge experimental treatments that even a decade ago would have been unthinkable.



## THE BIONIC EYE

**THE PATIENT:** Ohio's Steve McMillin, 59, lost his eyesight to retinitis pigmentosa (RP), a rare inherited vision disorder that affects around 100,000 people in the U.S. RP destroys photoreceptors, the cells in the retina that detect light and transmit signals to the brain, where they're processed as images.

**THE TREATMENT:** The Argus II—a kind of retinal prosthesis system, or “bionic eye”—was approved by the FDA in February 2013. Several other experimental retinal replacements are being tested, but the Argus II is the only one approved for use. Covered by Medicare in some states and by some private insurers, it's essentially a substitute eye. (Without insurance, it costs \$145,000.)

**HOW IT WORKS:** Complicated surgery is required to insert the Argus II retinal implant into a patient's eye. Then the patient is given a pair of high-tech sunglasses with a small video camera mounted on them. The glasses capture an image and send a signal to a video-processing unit attached to the glasses. The unit takes that image and transmits another signal to the retinal implant. The implant then sends out electric pulses that bypass the patient's damaged photoreceptors and reach healthy cells inside the retina. These cells, once stimulated, are able to send a signal to the brain alerting it that there is an image—which it then “sees.” With weekly training sessions, vision should continue to improve over time. “The human brain has a lot of plasticity,” says Dr. Alex Yuan, a surgeon at the Cleveland Clinic who did McMillin's surgery. “It can learn and adapt to changing environments.”

**WHAT IT'S LIKE FOR MCMILLIN:** “For over 30 years I worked on the floor of a Ford Motor factory in Brook Park, Ohio, as a millwright, doing tough physical labor to keep maintenance in check at the factory. I loved it. During a routine physical exam in 1989, when I was 32



McMillin, 59, spends time with his grandchildren at his home in Ohio

years old, my doctor noticed something strange about my vision. I could see some things but not others. Eventually I was diagnosed with retinitis pigmentosa. At the time it didn't mean too much. From what I understand, the ophthalmologist didn't know much about it. I might go blind, but I might not.

“For a while, I thought I got lucky. My doctor told me my RP appeared stable, and I was still able to drive. Then suddenly at age 46 my vision started to go quickly. At first it was hard to see objects coming toward me. If a guy at the factory threw me a tool, I would see it leave his

‘I can't really make out exact shapes yet, but I'm making progress. The other day ... I saw my wife's face.’

hand, and then it would just disappear. After that I noticed my vision severely closing in on the sides and getting hazy in front of me. By age 50 it was totally gone. I couldn't even see light.

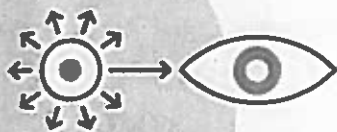
“Guys were asking me, ‘Why don't you retire? How can you deal with that?’ I said, ‘Look, you want me to go in a corner and cry?’ I am going to do whatever I can to stay active. Eventually Ford downsized, and I decided to retire. I was in a deep depression for six months. I've always been the provider. I worked six, sometimes seven days a week for about 15 years. All of a sudden I couldn't, and that hurt.

“I'd heard about the Argus II, and when it was approved in 2013, I spoke with my doctor and found out I was a good candidate. The Cleveland Clinic decided to take on the procedure and chose me to be their first patient. On June 19, 2015, I underwent four hours of surgery to be implanted with the device.

“Currently I only see wavy lines or edges. I can't really make out exact shapes yet, but I'm making progress.

“After the surgery my daughter-in-law moved a blob in front of me that was jumping up and down, and I knew it was my grandson. The other day I asked my wife Karen to point me toward the moon to see if I could see it. I couldn't see the moon, but I turned around, and suddenly I saw her face.”





## STEM-CELL INJECTIONS

**THE PATIENT:** Michael Ganley, 27, is a New Yorker who is losing his vision to Stargardt's macular degeneration, which affects 1 in 8,000 young people. Stargardt's is the juvenile form of macular degeneration, the leading cause of vision loss in older people, a condition in which the cells feeding the retina deteriorate, causing the retina to eventually die. Without the retina, the eye can't process light and send signals to the brain.

**THE TREATMENT:** Stem-cell treatments replenish the supply of retinal pigment epithelial (RPE) cells that bring nutrients to the retina. Because stem cells are so-called grandfather cells, which can develop into any cell type in the human body, they can be coaxed to become RPE cells—improving vision in people with genetic or age-related macular degeneration.

**HOW IT WORKS:** Scientists take stem cells from excess IVF embryos and treat them with compounds that encourage them to grow, in a lab dish, into RPE cells. Up to 150,000 of these cells are then injected into the eye, where they grow. "Stem cells work like reseeding a lawn," says Dr. Carl Regillo, director of the retina service at Philadelphia's Wills Eye Hospital, who is conducting one of the trials using stem cells to treat blindness. "If you have a big patch of dead grass, you can spread grass seed and hope for uniform growth and replenish what is lost."

**WHAT IT'S LIKE FOR GANLEY:** "Vision loss started for me in college. I was 21. I noticed I had to sit closer to the front of the classroom because I couldn't see the chalkboard or the screen. I went to a doctor, and he prescribed glasses, but they didn't really help. If you think of a movie projector that's shining an image on a screen, it was like someone had poked a bunch of holes in my screen.

"When I was diagnosed, the doctor said my central vision would be the main

thing to go and that it would get worse. Reading a newspaper is hard, and one of the hardest things for me is facial recognition. If I'm walking down the hallway at work or down the street and someone calls my name, I have to get much closer until I realize who it is.

"When I read about the stem-cell trial online, I sent in emails for a couple of months straight until someone responded to me. I was excited. The trial gave me a little bit of hope that maybe something can fix my vision.

"I had the surgery in December 2013. I was definitely a little scared and nervous going into it—it's a little weird having your eye operated on—but it wasn't that bad in the end. They removed the gel inside the retina and replaced it with the stem cells that they hope will reverse my vision loss. It was hard to tell if it made a big difference, but a few weeks after the procedure, I could read two additional lines on the eye chart.

"I'm getting married in a few weeks. My fiancée and I have been together since high school, so we've been through a lot. She's very supportive of the whole thing.

"But to give you an honest answer of what I'd like to see better? I wish I could see the golf ball better! I'm still playing golf, but it's getting more difficult."



## GENE THERAPY

**THE PATIENT:** Dale Turner, 29, a lawyer in Ontario, was diagnosed at age 5 with Leber congenital amaurosis (LCA), an early-childhood blindness disorder that affects around 3,000 Americans. Some people with LCA, including Turner, have a genetic mutation that interferes with photoreceptors in the eye. Turner underwent one of the first gene-therapy trials for his type of vision loss eight years ago.

**THE TREATMENT:** Gene therapy for blindness is an experimental treatment in which nonmutated genes that produce a protein necessary for photoreceptors to work are injected into the eye.

**HOW IT WORKS:** Doctors inject into the eye a harmless virus that carries healthy genes into the retina and improves vision over time. Those who undergo the experimental therapy sometimes get it in one eye; their other eye serves as the control. A 2013 study showed that in some people, the improvement isn't permanent and photoreceptors continue to deteriorate. "We found a slow and progressive contraction of the area of vision that was treated," says Dr. Samuel G. Jacobson of the University of Pennsylvania, who led the trial. "Even though the improvement of vision is not forever, I think we must reckon with the truth to advance progress. Is it all done? No. Is it a major start? Yes." Scientists continue to study the treatment in hopes of improving outcomes.

**WHAT IT'S LIKE FOR TURNER:** "When I was 5 years old, I was diagnosed with what was, at the time, an incurable eye disease. Having LCA is like having a very thin layer of gauze that you are trying to see through when you're looking at things. Since I was 8 years old, I have been seeing Dr. Jacobson. He does cutting-edge research and clinical trials, and when I was a kid I recall Dr. Jacobson telling me about a gene-therapy research project they were working on with dogs. In 2007 they launched the first human clinical trial in 15 patients, including me.

"After the procedure, my eye was covered for two to three days, and when it was healed, I remember walking outside on a sunny day and uncovering the patch. I will never forget the color of the sky or the green of the trees. It's something I had never seen before. Before my eyesight went, I could distinguish between colors to a certain extent, but with gene therapy it was like someone had taken that piece of gauze and ripped a little hole in it. I didn't know what I had been missing.

"I used to not be able to see anything at night, but now I have increased night vision, and I can walk my dog in the evening. I have my own law practice in Oshawa, Ont., and being blind doesn't prevent me from living a normal life.

"It isn't easy. We live in a society that assumes everybody can hear and everybody can see. So the prospect of being able to see and overcoming something that's supposed to be incurable is remarkable." □