The World of Macular Degeneration
Hi kids! Come explore the world of macular degeneration! This special magazine has been produced just for you created by the BrightFocus Foundation. It is full of information, activities, fun facts, brain teasers, and more!

Do you know someone who has macular degeneration? Macular degeneration is a disease of the eye that makes it hard for a person to see clearly and in focus. In this magazine, you will learn about:

• The human eye and how it works
• What is macular degeneration?
• How doctors diagnose and help someone with macular degeneration
• How people who have macular degeneration see the world
• How you can be helpful to a person who has macular degeneration
• How you can keep your own eyes healthy
• Special devices that help people see
• Frequently asked questions
• How you can spread the word
To learn how an eye works, let’s look closely at the eye itself. Eyes have both outside and inside parts. In a healthy eye, all of the parts must work correctly for a person to see.

Here is a picture of the outside and inside parts of an eye. Descriptions of what all the parts do are provided below and on Page 4. Take time to learn about each part so you can become an eye expert!

### The Outside View of the Eye

When you look at someone’s eye from the outside, the most obvious parts you can see are:

- **The cornea** (“corny uh”) is a clear “window” over the colored part of your eye that protects the eye, and also helps direct light into the interior of your eye.
- **The iris** (“eye riss”) is the pretty colored ring that adjusts how much light comes through by opening and shutting the pupil. Someone with a blue iris has blue eyes. Someone with a brown iris has brown eyes.
- **The pupil** (“pew pull”) is the black hole in the center of the eye. It controls the amount of light that enters your eye. Too much light can be painful, so the pupil gets very small when you are in bright light. When you are in the dark, your pupil enlarges to allow more light in.

### The Inside View of the Eye

The eye also has many parts that are hidden inside of your head. Each part plays an important role in making it possible for you to see clearly.

- **The vitreous** (“vi tree us”) is a clear jelly that helps keep the eye’s shape, but still lets the light through.
- **The optic nerve** is the “cord” that takes the signals from the retina and macula and sends them back to the brain, so that you recognize what you are seeing.
- **The choroid** (“core oyd”) is a wall of blood vessels behind the retina that brings nutrients and oxygen and takes away waste products.
- **The lens** finishes off the focusing started by the cornea and projects the light onto the retina.
- **The retina** (“reh tin uh”) is the paper-thin cover of the inner surface of the eye that collects all the light that enters the eye.
- One of the most important parts of the eye is the **macula**. The macula (“mack you la”) is the central part of the retina, way at the back, that kind of looks like a tiny “bull’s eye.” It helps you to see clearly and in focus.

All right, eye expert, now look very closely at the macula. Make a note of it because it is very important. When it doesn’t work correctly, things start looking pretty weird. This can happen when someone has an eye disease like macular degeneration. Now go to Pages 5 and 6 to check your knowledge, learn some more cool things about eyes, and try an experiment.
The Human Eye

Knowledge Check

Which part of the eye controls the size of the pupil?
A. Iris
B. Cornea
C. Pupil
D. Sclera

The correct answer is A (Iris).

Knowledge Check

Which part of the eye kind of looks like a tiny “bulls-eye” and helps you to see clearly and in focus?
A. Optic nerve
B. Macula
C. Vitreous
D. Choroid

The correct answer is B (Macula).

Did You Know?
The ostrich has the biggest eye of all the animals that live on land? It’s about two inches across versus a human eye that’s about one inch across.

Did You Know?
The giant squid has the largest eyeball on the earth? So far, the biggest one measured 11 inches across, as compared to about 1 inch for a human eye. That giant eye helps it see in the dark depths of the ocean.

Try an Experiment

Look at your eyes in a mirror and watch what your pupils do when the room light is on and when it is off. Can you see them get bigger when the room is dark, and smaller when the room is bright? What happens if you shine a flashlight into only one eye? Do both pupils change or just one?
Macular Degeneration

What is Macular Degeneration?

Remember the macula? You learned about it in the previous section of this magazine. Let’s review: The macula is the central part of the retina, way at the back, that kind of looks like a tiny “bull’s eye.” It helps you to see clearly and in focus.

Some people have spots on their macula. These spots can be tiny yellow-white blobs or like tiny red blisters. They can even turn into a scar in the worst cases. People with a lot of spots on their macula do not have healthy eyes and they have a really hard time seeing clearly and in focus. They often have an eye disease called “macular degeneration.”

What a mouthful! The number of spots and where they form on the macula can cause different types of macular degeneration. Pay close attention so you don’t miss anything.

“Dry” vs. “Wet” Macular Degeneration

There are two forms of macular degeneration: dry and wet. It is even possible for a person to suffer from both forms! Macular degeneration can affect one or both eyes, and can progress slowly or very rapidly. Dry macular degeneration may cause loss of vision without ever turning into the wet form of the disease. However, sometimes early-stage dry macular degeneration can change into the wet form of the disease.

“Dry” macular degeneration is the most common form of the disease. It is diagnosed in 85-90 percent of cases. In this form, the retina cells that capture light slowly break down in the macula. Yellow waste materials, called drusen (“drew zen”), form and accumulate under the retina next to the Bruch’s (“brooks”) membrane. The Bruch’s membrane supports the retina.

Drusen are very common in the eyes of older people. However, an increase in the size and number of drusen is often the first sign of macular degeneration. Over time, drusen are associated with destruction of the macula and the death of lots of types of cells, including the photoreceptor cells and other cells that help nourish the retina. This results in a blurring or spotty loss of clear, straight-ahead vision.

Wet macular degeneration occurs when abnormal blood vessels grow behind the macula and lots of cells, including photoreceptor cells start to die. The Bruch’s membrane begins to break down, usually near the drusen deposits, and new blood vessels grow. Eye experts use a very big word to describe this problem. That word is “neovascularization” (“knee oh vask you lar is ay shun”). These vessels are very fragile and can leak fluid and blood, resulting in scarring of the macula and the potential for rapid, severe damage. Straight-ahead vision can become distorted or lost entirely in a short period of time, sometimes within days or weeks.

Wet macular degeneration accounts for approximately 10 percent of the cases. However, it results in 90 percent of the cases of severe vision loss, or “legal blindness.”

Diagnosing Macular Degeneration

An eye doctor can see macular degeneration spots using special equipment. The doctor can diagnose whether someone has dry or wet macular degeneration and give advice on whether there are prevention or treatments that can be done.

Once a person is diagnosed with macular degeneration, the quality of his or her vision can be monitored every day by having them look at a card with parallel lines and boxes. This card looks like graph paper and is called an Amsler Grid.

This is what the card might look like if you have macular degeneration.

Why “Dry”?

Why do they call it wet and dry forms of macular degeneration? If you have read the section on wet macular degeneration, you remember that the weak blood vessels that grow in wet cases of macular degeneration sometimes break and leak blood. That’s kind of gross, but it’s also “wet.”
Unfortunately, there is currently no cure for dry or wet macular degeneration. And the damage done by macular degeneration cannot be repaired. However, some people who have the “dry” form of the disease can help prevent the disease from getting worse and converting to the “wet” form by taking special daily multivitamins based on the Age-Related Eye Disease Study (AREDS).

There are some treatments for wet macular degeneration, but they all involve some form of injections from a needle! The more current treatments are injections right into the eye. Their purpose is to deliver drugs to the back of the eye that stop the blood from leaking into the retina. Many people have some improvement in vision. However, this isn’t a cure, so when the drug “wears off,” another injection is needed.

### Knowledge Check

1. What appears on the macula if someone has macular degeneration?
   - A. Holes
   - B. Yellow-white blobs
   - C. Tiny red blisters
   - D. B and C

2. What are the two forms of macular degeneration?
   - A. Blue and yellow
   - B. Dry and red
   - C. Blistered and non-blistered
   - D. Dry and wet

3. True or False: The dry form of macular degeneration is diagnosed in 85-90% of cases.
   - A. True
   - B. False

4. An increase in the size and number of _______ is often the first sign of macular degeneration.
   - A. Tears
   - B. Drusen
   - C. Blood shot eyes
   - D. Eyelashes

5. In the ‘wet’ form of macular degeneration, which of the following problems occur?
   - A. Enlarged tear ducts
   - B. Puffy eyes
   - C. Neovascularization
   - D. Polarization

6. What can a person with macular degeneration use to monitor the quality of his or her vision?
   - A. Amsler grid
   - B. Telescope
   - C. Binoculars
   - D. Image map

7. True or False: There is currently no cure for macular degeneration.
   - A. True
   - B. False

8. People with the dry form of macular degeneration can do what to help prevent the disease from getting worse?
   - A. Use an eye wash
   - B. Take a regime of vitamins based on the AREDS study
   - C. Get an injection in their eyes
   - D. Wear eyeglasses

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1. The correct answer is D (Yellow-white blobs and tiny red blisters)
2. The correct answer is D (Dry and Wet)
3. The correct answer is A (True)
4. The correct answer is B (Drusen)
5. The correct answer is C (Neovascularization)
6. The correct answer is A (Amsler grid)
7. The correct answer is A (True)
8. The correct answer is B (Take a regime of vitamins based on the AREDS study)
What is it like to see the world if you have macular degeneration? Macular degeneration primarily makes people lose their ability to see what’s right in front of them. In other words, they lose their straight-ahead vision.

Try looking at a door or blinds on a window. Try imagining what it would look like if the straight lines started looking wavy, or blurred.

Think about all of the things you do during the day that require you to see something clearly that is straight ahead!

A person with macular degeneration might not be able to read a restaurant menu very well without help, even though they probably can still see the things on the side of their dinner plate, like the utensils and napkins.

Take a look at the picture of boys and girls shown below. This picture shows the boys and girls through the eyes of someone with normal vision. Notice that the picture is clear and in focus. Then go to Page 12 to view this same picture of boys and girls through the eyes of someone who has macular degeneration. People with macular degeneration might have fuzzy and wavy vision, and see spots in the middle.

A View Through Healthy Eyes

Did You Know?

People with macular degeneration rarely go blind. They usually have some vision. Sometimes you will see macular degeneration described as causing “legal blindness.” Legal blindness means that the person may not have lost all sight but might qualify for certain medical programs provided for blind people.

A View Through Eyes with Macular Degeneration

True or False: People with macular degeneration tend to lose their straight-ahead vision.

A. True
B. False

The correct answer is A (True)

Intermediate Dry Macular Degeneration

A View Through Eyes with Macular Degeneration

Knowledge Check

True or False: People with macular degeneration tend to lose their straight-ahead vision.

A. True
B. False

The correct answer is A (True)

Try This!

Try making a pair of magic goggles. Once you’ve made your own goggles try eating a meal or walking around with the goggles on. Be very careful and be sure to have an adult help you while you try this activity.

DOWNLOAD THE INSTRUCTIONS FOR MAKING MAGIC GOGGLES
Make it Safe

There are many ways that an eye expert like you can help someone with macular degeneration. Remember when you had to think about all the things that require having good straight-ahead vision? Now think about the kinds of things that people with macular degeneration might have problems with. How can you help make their life easier? How can you help keep them safe? Write your ideas down on a piece of paper, then compare your ideas to the ideas below.

- Pick up your games, toys, clothes, shoes, and other personal belongings so that a loved one with macular degeneration doesn’t trip over them. Falls are very dangerous, especially as we get older. Just by picking up around the house you can help other people stay safe and healthy!
- Make sure you put things back where you find them. If you move personal items belonging to a loved one with macular degeneration, then he or she may not be able to find them. That can be really frustrating!
- People with macular degeneration usually like to leave things in the same place, so they remember where to find them. Make sure you don’t move furniture from where it belongs. A chair or table out of place can cause a person with macular degeneration to fall.

Spend Time and Share

Spending time with a loved one with macular degeneration can mean the world to them. Take a look at all of these things you could do together.

Be Sure To Communicate Clearly

When you spend time with a person who has macular degeneration, make sure you are careful with how you talk and communicate.

People with macular degeneration have difficulty seeing. However, they may also have some difficulty understanding what other people are saying. This is because the eyes and ears kind of work together to help us hear and understand what is being said. Many of us actually do a little bit of lip-reading without even knowing it. Our brains help stitch together little clues that our eyes give us, to help make sense of what we hear. However, a person with macular degeneration may not be able to clearly see your lips or your gestures in their straight-ahead vision. So that may make it difficult for someone with macular degeneration to clearly understand you, because their vision problems cause them to miss out on your body language. This can make them feel left out of conversations.
How Can You Help?

Keep Your Own Eyes Healthy

Risk of macular degeneration can be passed between generations. You can also be helpful to yourself and your family by keeping your own eyes healthy!

- **Protect Your Eyes From the Sun:**
  When it’s sunny outside, don’t forget to wear a hat and sunglasses to protect your eyes from the sun. Did you know that getting too much sun for many years can increase the risk of developing eye troubles, like macular degeneration?

- **Eat Your Fruits and Vegetables!**
  The colored pigments found in yellow, orange or green vegetables and fruit may help to lower the risk of developing macular degeneration.

- **Don’t Smoke.**
  Smoking not only increases your risk of developing diseases like cancer and asthma, but it also greatly increases your risk of developing macular degeneration.

What Will You Do?

How will you spend time with a loved one who has macular degeneration?

How can you help make things safe for a loved one who has macular degeneration?

True or False: The colored pigments found in yellow, orange or green vegetables and fruit may help to lower the risk of developing macular degeneration.

A. True
B. False
In the future, we may be able to develop artificial eyes that function just like a real eye to send signals to your brain. Scientists are getting close, but that’s still only in the movies for now. In the meantime, did you know that there are a lot of devices to help people see? A special eye care provider called a “low vision” specialist can demonstrate these devices, and help you find them for your loved ones with macular degeneration. For information on more resources, you can visit the BrightFocus site for "Low Vision Resources."

**Cool Gadgets That Help People See**

- **kReader Mobile and the knfbReader Mobile** — This cell phone sized device can take photos of signs or menus. If there are words in the picture, a computer voice reads it out loud.

  Photo courtesy of K-NFB Reading Technology, Inc.

- **Pouring Assistance** — Can you imagine what pouring coffee or juice would be like if you had trouble seeing? How would you know when your cup was full? Devices exist to help pour the liquid without spilling it over the sides of the glass or mug.

  Photo courtesy of Independent Living Aids

- **Screen Readers** — Are you enjoying this website? How would you see it without your straight ahead vision? Luckily, there are computer programs used to magnify the screen and read out loud. Some examples include: Jaws, Window-Eyes, and even little web browser “plug-ins” like Low-Browse.

  Photo courtesy of Freedom Scientific

- **Shopping Product Scanner** — Because the macula helps us to see clearly and in focus, as well as seeing colors, when you go shopping, it can be difficult to read the sizes and see the colors. Special scanners that read descriptions out-loud can help with that.

  Photo courtesy of Freedom Scientific

**Dear Dr. Mac**

You’re almost an eye expert! Now get some advice from a real doctor! Here are some questions asked by other kids.

**Can Younger People Get Macular Degeneration?**

Unfortunately, yes. There are several forms of juvenile macular degeneration (JMD). All are inherited, so if your family members don’t have them, it’s much less likely that you would develop these diseases.

- **Stargardt’s disease** is the most common form of JMD; it can also be called macular dystrophy, and normally develops in the childhood or teen years.
- **Best disease** or “vitelliform macular degeneration” is the second most common form of JMD; symptoms usually occur between birth and age 7.
- **Adults in their thirties or forties can sometimes develop genetic forms of macular disease such as Sorsby’s fundus dystrophy, Behr’s dystrophy and Doyne’s honey-comb retinal dystrophy.** These are rare and usually people who develop the disease have other people in their families or ancestry with the same disease.
- **Myopic macular degeneration** can occur in people who are severely nearsighted. This happens when they have eyes that are abnormally long. When the eyeball is shaped like this, it can cause tears to develop in the macula, and bleeding beneath the retina.

**Can “regular” macular degeneration be inherited, from grandparents to parents and down to their children?**

While there is definitely a strong genetic, or hereditary, component to this disease, macular degeneration is believed to be caused by a combination of multiple factors including genes, but also environmental factors such as sunlight exposure, diet and smoking. Just because one family member has the disease does not mean that their child or grandchild will get the disease, too. But if one person has the disease, the other family members may have to adapt their lives to help out the person with the disease. Do you remember ways that you can help?

**Did You Know?**

Almost 11 million people in the United States alone have macular degeneration.
Very few people know what macular degeneration is!

Now that you are an eye expert, you can share what you have learned and help other people know what it means to live with macular degeneration.

Are there other ways that you can help spread the word about macular degeneration? What can you teach your friends, neighbors, and other people in your life? How will you teach them?

- Invite a Loved One Who has Macular Degeneration to Your Class to Give a Talk
- Give a Presentation at School
- Tell Your Friends About Macular Degeneration and What They Can Do To Help
“FOR Parents”

The “World of Macular Degeneration” magazine was created by BrightFocus Foundation® to help promote understanding and dialogue among children about a disease that primarily affect older adults. This material is designed for 5th and 6th graders and general audiences. The key learning objectives of this magazine are to help children: identify anatomy affected by the disease, describe variations of the disease and treatment options, and list action items that children might use to help facilitate empathy for and dialogue with elderly people directly affected by the disease.