INFORMATION ABOUT ALBINISM What Do You See?

An Adult with Albinism Describes What He Sees by Matt Bailey

Normally-sighted people often ask those of us with albinism, "What do you see?" Parents of children with albinism are especially interested in the answer. Here you'll find a brief explanation of how a person with albinism "sees."

Banishing the Blurry Misconception There is often a misconception that our vision is blurry. Many people are baffled to learn that it's not.

When normally-sighted people experience vision problems, it is because the lens in front of the eye doesn't focus the image clearly onto the back of the eye causing blurriness. Near-sightedness, far-sightedness and astigmatism are "out of focus" problems. Glasses and contacts correct these problems by reshaping the light entering the eye so that images are focused correctly onto the back of the eye. This is similar to the way you would turn the focus knob to correct a blurry image when using binoculars.

Although blurriness isn't associated with the major vision issue related to albinism, we may be affected by the same "out of focus" problems as normally-sighted people. If near-sightedness, far-sightedness and astigmatism aren't addressed, our vision could become blurry. That's why it can be important for young children and even babies with albinism to wear glasses. In many children, the use of their vision and their eyes develop more fully when images entering the eye are focused correctly.



Photo courtesy of Positive Exposure, Rick Guidotti

Clear, but not Hi-Def

Understanding the concept of resolution will help clarify the problems in the back of the eye that albinism causes but glasses cannot fix. All pictures are made up of dots, with each dot capturing a different color and brightness level. The pictures in magazines and newspapers, the pictures on TV and on social media, as well as the pictures taken by digital and film cameras are composed of a bunch of dots. You see more details in a picture that has more dots.



The picture on the back of the human eye is also made up of dots, millions and millions of them in fact. They're the "cones" and "rods" on the retina in the back of the eye. The primary reason people with albinism can't see as well as normally-sighted people is because we have fewer cones in the fovea which is within the macula. In other words, we have fewer "dots" to make up the picture we see. The cones in particular are the "dots" that people use to see details, such as printed letters and numbers or the details of people's faces.

Nystagmus (the back and forth movement of the eyes) as well as the lack of pigment in the iris and the retina are also contributing factors to our reduced vision, although to a lesser degree.

The easiest way to understand how the lack of cones affects the vision of people with albinism is to turn on your television. If you have upgraded to a High Definition Television (HDTV), you have experienced an upgrade in the "visual acuity" of your television. That's because a high-definition



Older TV (left) vs. High-Definition TV (right)





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television signal contains five times the visual information. The picture on an old-fashioned TV is made up of five times fewer dots therefore each dot covers a larger portion of the total picture so you can't see as many fine details. When TV manufacturers tout a television's resolution with terms such as "1080p," they're telling you how many "dots" the picture on their TV screen has.

To experience the difference in low visual acuity and normal visual acuity, watch a program in High Definition (HD) on your HDTV. Then, go to an old TV and watch the same program on the standard definition TV. (Alternatively, many cable and satellite TV companies offer both a HD and a Standard Definition (SD) version of the same channel. Simply switch between the HD and SD channel.) Notice how the standard definition image on the old TV isn't blurry. It simply lacks the fine detail of the image on the HDTV. You can still recognize faces, but you'll see more details in HD than on the old TV. You can still follow the action of sports on the old TV, but you won't see the individual blades of grass on the field the way you can on a HDTV.

Another trick to see how reduced resolution does not make a picture blurry is to watch a video online with a service such as YouTube that allows you to select the quality of the video image. First, watch the video with the highest resolution or quality setting, such as 1080p. Then, switch to a lower resolution or quality setting designed for slower Internet connections, such as 480p. The difference between how those of us with albinism see and normally-sighted people see is a lot like the difference between the low resolution video versus the high resolution video: Neither is blurry, however, we can't quite make out some of the finer details that normally-sighted people see.

Just like that low resolution video or the program on your old-fashioned TV, we often don't need to see the details we're missing to fully understand and participate in the world we see.

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NOAH envisions a world where people with albinism are empowered to be fully functioning members of society, where barriers and the stigma of difference no longer exist, and where people with albinism have a quality of life that is rewarding, dignified and fulfilling. The organization sponsors national and regional conferences and a biennial family summer camp. In addition, local chapters meet in many areas of the U.S. and Canada. NOAH can provide a list of chapters and contact persons.

Visit **www.albinism.org** for more information about albinism including bulletins, events, ways to connect with the albinism community and to subscribe to NOAH's large-print quarterly magazine, *Albinism InSight*.

National Organization for Albinism and Hypopigmentation

PO Box 959, East Hampstead, NH 03826-0959 USA Phone: 800-473-2310 • 603-887-2310 Toll-free fax: 800-648-2310 www.albinism.org • Email: info@albinism.org