



# InSight

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Association for Vision Rehabilitation and Employment, Inc.

## ALL ABOUT RETINITIS PIGMENTOSA

### What is retinitis pigmentosa?

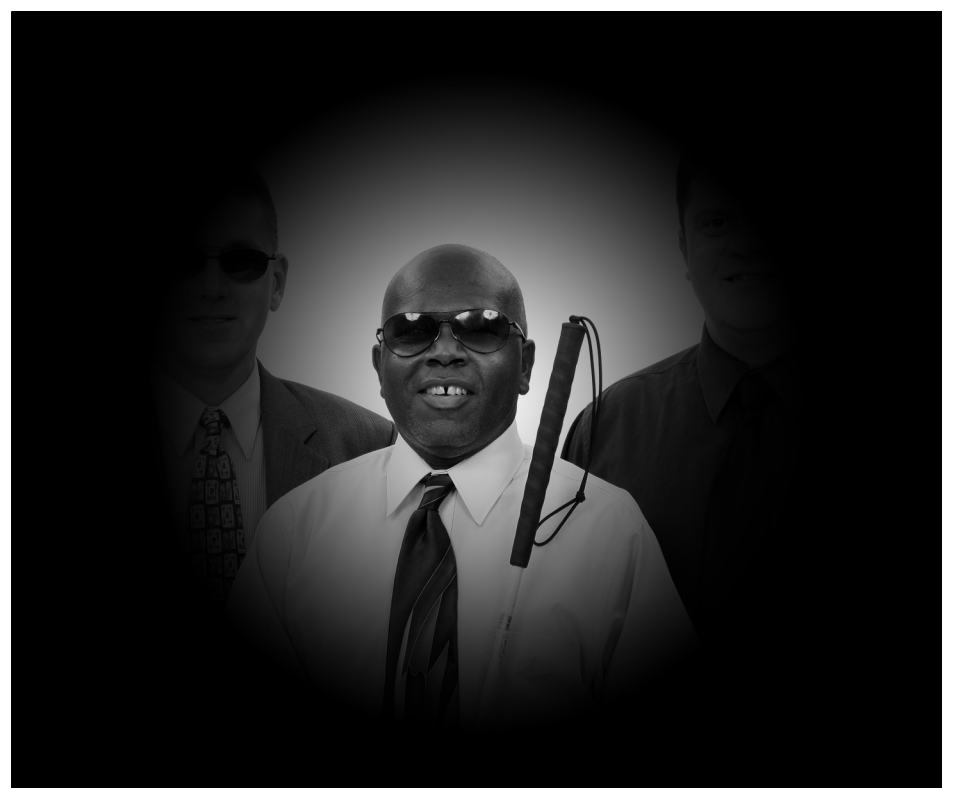
Retinitis pigmentosa (RP) is not one eye disease, but a group of diseases with common attributes that affect the retina of the eye. RP is considered to be a rare eye disease, with only about 100,000 people in the U.S. being affected – about 1 in every 4,000.

The term “retinitis” is a misnomer, as it implies that an inflammation of the retina is present. This is generally not the case. RP causes the retina, which is the thin layer of tissue in the back of the eye, to deteriorate. In particular, it damages the photoreceptor cells in the retina that capture and process light, which helps us to see. These cells are known as “rods and cones.” The rods are associated with peripheral (side) vision and night vision, and the cones are associated with the central vision and color vision.

### What causes RP?

RP diseases are genetic and can be passed down from one or both parents. The eye condition is associated with at least 32 different genes. At times, the genetic trait is dominant and likely to be passed along to a child when a parent has RP. At other times, the trait is recessive and may be present for many generations before it appears in a family member. This means that even if neither parent has the disease, a child can still have it if one parent is the carrier of a gene associated with RP. In fact, about 1 out of 100 people in the U.S. can be considered carriers of genetic tendencies for RP.

RP is sometimes associated with other systemic illnesses or conditions. Usher syndrome is the most common cause of deaf-blindness in the U.S. It is characterized by a moderate to profound hearing impairment, which is present at birth or shortly after, and progressive vision loss due to RP. Usher is passed to the children of parents who both carry a recessive Usher syndrome gene. For that reason, it is quite rare, with only about 15,000 people in the U.S. having it. (Continued on next page.)



*The photo on the left of A.V.R.E. employees (left to right) Ken Fernald, Ralph Gedeon, and Steve Comency shows what a person with normal vision would see. The photo on the right shows the same view the way a person with retinitis pigmentosa might see it.*

**Our Mission: “To assist people who have a vision disability enhance life quality through attaining or maintaining personal and economic independence, and help remove obstacles imposed by vision disabilities.”**

## **What are the symptoms of RP?**

The first sign of RP is often poor night vision. When RP first starts to appear, the light-sensing cells (the rods) that are responsible for vision in dim light gradually deteriorate, and seeing at night becomes difficult. This can occur years or even decades before the next phase. As the rods continue to stop functioning, the field of vision begins to narrow until complete loss of peripheral (side) vision occurs. This is commonly called "tunnel vision." Although RP is generally diagnosed in young adulthood, the symptoms can begin occurring as early as childhood to as late as the 40s. The majority of people with RP are legally blind by the age of 40, with a central visual field of less than 20 degrees in diameter. Many patients with RP retain a small degree of central vision throughout their lives; however, there is a strong possibility of eventual total blindness.

Other forms of RP, sometimes called cone-rod dystrophy, first affect the cone cells, which affects the central vision. These patients experience a loss of central vision that cannot be corrected with glasses or contact lenses. With the loss of cone cells comes loss of color perception. As the deterioration progresses, the rod cells begin to deteriorate, as well.

## **How is RP diagnosed?**

Having a family history of RP diseases is certainly a strong clue to a correct diagnosis. However, it is primarily diagnosed during an eye examination by an ophthalmologist. He/she will look at the back layers of the eye with an ophthalmoscope and will do a visual field test to find defects in the peripheral vision. A referral to a university ophthalmology department for electrophysiological testing may be necessary for a complete diagnosis.

## **Are there other complications of RP?**

Cataracts occur at a higher incidence in RP patients. Cataract removal can be performed; however, this does not improve the lost retinal function due to the RP.

## **How is RP treated?**

As of now, there is no cure for RP. The prognosis is poor, but there are researchers working hard on this disease. Studies have shown that a specific dose of Vitamin A can slow the course of the disease among adults with typical forms. Another study has shown that an omega-3-rich diet can further slow disease progression. Researchers estimate that the combination of Vitamin A plus omega-3 fish oils could provide almost 20 additional years of useful vision for adults who start the regimen in their 30s.

Significant progress is being made, and researchers feel that the near future will bring treatment that may stabilize the disease, prevent it, or both. With recent developments in gene therapy and implanted devices that stimulate the retina, at least some sight could possibly be restored for certain people with RP. If as few as 5% of cones can be kept alive, a person with RP can continue to function independently. A promising treatment aimed at preserving cones with a certain type of protein is in a phase 1 clinical trial. Researchers are also experimenting with retinal transplants, artificial retinal implants, and stem cell therapy.

After a definite diagnosis, the patient can be counseled on what therapies are available to maximize remaining vision. Low vision therapy, like that provided by A.V.R.E., is very helpful in coping with the disease and its resulting loss of vision. The use of low vision devices that magnify and illuminate, such as those sold in A.V.R.E.'s ViewPoint store, can greatly help people with RP to continue to live independently.

As with all eye diseases, early diagnosis is crucial to slowing the progression of RP. It is important for people who are experiencing symptoms to see an eye doctor who is knowledgeable in retinal degenerative diseases. The earlier the diagnosis, the better the chance of preserving some vision!

Sources:

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## IN HIS OWN WORDS

### How A.V.R.E. Has Helped Me

By James Hitchcock

My name is James Hitchcock, and I am employed at A.V.R.E. in the Business (manufacturing) Division. I have had vision problems since my youth, and needed my first pair of glasses when I was five. However, it did not stop me from participating in an active childhood. I was especially interested in working on cars. My dad was an auto mechanic and taught me how to repair cars. As an adult, I built my own race car for drag racing. I also enjoyed boating, camping, and snowmobiling.

In 1995, my eyesight was noticeably changing. I couldn't see well enough to drive at night anymore. I had been working out of town on construction and had to wait until the sun came up to drive to my job. In 1997, I saw a specialist because I knew it was time to find out why my sight was getting worse. It was then that I was diagnosed with retinitis pigmentosa, known as RP.



Even after that, I started my own business as a pressure washing contractor and a car dealer. In 2001, I went to renew my driver's license, and that was when my world changed. I couldn't pass the Department of Motor Vehicles vision test, and my eye doctor agreed that I was no longer able to see well enough to drive.

I continued to keep the pressure washing business with help. In 2006, I was struggling to make a living because I couldn't see well enough to pressure wash. My girlfriend called the NYS Commission for the Blind and spoke with James Dolph, who was very helpful. Jim introduced me to A.V.R.E.

A vision rehabilitation therapist from A.V.R.E. came to meet with me and evaluate what sight I had left and what skills I had. I was offered a job at A.V.R.E. in manufacturing, and started working full time in 2007. I became a machine operator, making copy paper. I was grateful to have a job where I felt productive and useful. Our copy paper business has taken off, and we are now producing about 2,000 boxes per week. I have been photographed for articles about the convenience pack copy paper and even have my picture on one side of A.V.R.E.'s delivery truck!

A.V.R.E. also provided me with devices to improve my ability to function in my home: talking thermometers, a talking alarm clock, measuring devices, and even a talking tape measure. Recently, I was blessed with a CCTV (Closed Circuit Television) that allows me to read my own mail and publications once again.

I was happy and relieved that I could continue to support myself, as well as function more independently. I still enjoy life because I feel productive again. I am not able to do some of the hobbies I used to, but in my spare time, I still enjoy boating on the lake. Life has definitely improved for me since being involved with A.V.R.E. It is an honor to be a representative of this organization that has made such a difference in my life.



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## THANKS TO OUR DONORS!

We would like to extend our most sincere "Thank You!" to all of our loyal donors who have responded to our 2010 Annual Appeal. Your kindness and generosity is so greatly appreciated by all of us at A.V.R.E.

If you have not yet responded, or would like to give an additional gift, it's not too late! You may use the courtesy reply envelope that is enclosed in this newsletter. Or you may go to our website, [www.avreus.org](http://www.avreus.org), and make an online donation. Just follow the link on our home page. It's quick and easy, and you don't have to pay any postage!

We look forward to keeping you up-to-date on all of our exciting news, as we prepare for our 2011 Annual Appeal in October. Please keep us in your thoughts as you plan your 2011 charitable donations. And thank you, again!

## APPLE IPHONE – AN ACCESSIBLE SOLUTION

For many years, we have been hoping, watching, and waiting for someone to come up with a viable solution to the challenge of making cell phones completely accessible to people who have a vision impairment. Finally, Apple has done it.



The revolutionary iPhone 3GS, that was introduced several years ago, and the new iPhone 4 both feature VoiceOver, the world's first "gesture-based" screen reader. VoiceOver allows the user to control the iPhone by touching the screen using simple gestures, such as taps, double-taps, flicks and drags – all with the fingers – to access its functions and applications. There is no need to memorize scores of keyboard commands, or to endlessly press tiny arrow keys to page through and find what you are looking for.

Because VoiceOver works with a touch screen, the user interacts directly with objects on the screen. For example, when the upper-left corner of the screen is touched, VoiceOver will read what is in that area of the screen. By lightly dragging your finger around the screen, VoiceOver will tell you what is there. You'll hear descriptions of every item on the screen, including status information such as battery level, Wi-Fi and cellular network signal levels, and the time of day. It also tells you when the display changes to landscape or portrait orientation and when the screen is locked or unlocked. When you find the application you want, simply double tap with your finger and the app will open. If you wish to type a text or email, VoiceOver speaks each character on the keyboard as you touch it. You can also have it speak each completed word that is typed. Flicking up and down the typed text moves the cursor around within the text so you can edit as needed.

VoiceOver works with all of the built-in apps that come with the phone, such as Mail, iPod, iTunes, Safari (a web browser), Maps, and of course, making phone calls. Apple is working with software developers so they can make even more applications VoiceOver compatible.

iPhone has other great features that can be used. Buttons that are needed to control certain phone features – sleep/wake, ring/silent, volume control, etc. – are tactile and easily discernible. Braille readers can use a refreshable Braille display that uses Bluetooth technology to read VoiceOver output in

Braille. Voice control can be used to make a phone call and play music. iPhone features "Zoom" which, when activated by tapping with 3 fingers, lets you magnify the entire screen of any app you're using. Font sizes for email messages can be increased to 3 larger sizes. For those who need higher contrast, iPhone has an option to change the display to white-on-black. The usual phone features are still there: headset capability, hands-free speaker phone, and audible and vibrating alerts.

iPhone sells for about \$200 - \$300, depending on the model and type. Users have the option of choosing either Verizon or AT&T for the service provider, and a new 2-year contract is required. There are several service plans to choose from to suit your needs.

## NEW ACCESSIBILITY LAW

Our technology-dependent world is advancing at a rapid pace. Unfortunately, the technology that would make all of the wonderful things we now have accessible for people with vision disabilities has come along at a much slower pace. However, more changes and advancements are on the horizon. In October 2010, President Obama signed into law a bill that is designed to open the doors to more accessible technology.

The 21st Century Communications and Video Accessibility Act is designed to provide expanded access to "smartphone" (cell phones such as the iPhone) and digital (both TV and internet) video programming. The act outlines several steps to ensure that people with vision and hearing impairments have full access to the video, voice, text, and other capabilities of smartphones, digital television, and internet-based video programming. The law is directed at manufacturers, software developers, telecommunication service providers, and others in the communication industry. It requires them to make their products and services accessible and gives them a timeline in which to accomplish it.

Here are some of the areas on which the new law focuses:

1. Internet browsers built into smartphones will need to support accessibility in the browser's features and functions.
2. TV networks will be required to provide an increasing amount of audio description capability. This will also extend to video programming that is available over the internet.
3. All devices that receive or play back video must be capable of displaying closed-captioning and audio description. This would include devices such as set-top boxes, TiVo, and other DVR devices.
4. All control features that accompany video programming – such as play, pause, volume, etc. – must be accessible.
5. TV on-screen menus and program guides must be made accessible.
6. In addition, closed caption features for people with hearing impairments are covered.

This new law will help to ensure that accessibility keeps pace with technology.

## LEAVING A LEGACY

### Securing our future and preparing for growth – Through Planned Giving

By Robert K. Hanye, President & CEO

For over 80 years, A.V.R.E. has provided vision rehabilitation services and employment opportunities for people who are blind and visually impaired. We have experienced significant growth over the years, from a tiny “workshop” that employed a handful of blind people to a large, state-of-the-art, full-service agency. This has been possible, in large part, because of loyal donors who believed in our mission and supported it with their generous gifts.

Many donors supported general operations throughout the year; others sponsored a scholarship fund or new program initiative. And there are those who committed longer term to helping us secure our future and prepare for growth. Planned giving in the form of legacies and bequests enables donors to make a significant and lasting impact on A.V.R.E., as well as providing opportunities to be remembered through naming options and giving circles.

A fine example of this is A.V.R.E.’s Norman Richterman Low Vision Center. The center was named in honor and memory of Norman Richterman, by his parents, Harold and Anita. Harold (Ric) Richterman was a pioneer in the field of Orientation and Mobility for the blind. He had a fierce dedication to the independence and dignity of people with vision loss. Ric and Anita developed strong ties to the Binghamton community, and their son Norman lived in the area for quite some time. When Norman passed away suddenly and much too early, they sought a way to keep his memory alive.

Because of their connections to the very beginnings of low vision services, Ric and Anita understood how important a low vision clinic is to offering comprehensive services to people with vision loss. They made the decision to create a bequest that would help us create our own clinic. Our Norman Richterman Low Vision Center has now helped hundreds of people with low vision reach goals they thought were beyond their capabilities!

We continue to dream big and set high goals for the future. We want to create an Infants and Children Center where blind kids and their families can gather for training or just for fun. We want to build an Adaptive Living Center – a full-scale apartment setting – where adults with low vision can come to learn independent living skills in a safe environment. We want to create more jobs for people with low vision so they can lead productive and independent lives. In order to do these things, we need long term financial support from our friends.

Legacies and bequests provide a realistic, practical way for donors of all backgrounds to invest in our future. If you would like to consider remembering A.V.R.E. in your will, or in other types of planned giving, please call our Director of Development Jenn Cubic at 607-724-2428. She will be happy to talk with you about your planned giving options.



## NEED A JOB?

It is estimated that about 70% of people who are classified as legally blind are unemployed. Some of these may have other reasons for not working, but many simply cannot find a job that is suited to them and their vision disability. A.V.R.E. is constantly looking for people who are legally blind and want to work, with the goal of helping them get matched up with a good job. Does that description fit you?

One of the important areas of our Program Services is our Employment and Career Services. We offer a variety of employment options for people who have a vision impairment. Our options are designed to offer the widest range of training, employment, and career development based on your own skills and wishes.

Colleen Ciarletta, A.V.R.E.’s Employment and Career Specialist, is continuing our long-standing policy of working hard to place visually impaired people into the best possible employment opportunities. Full of enthusiasm and possessing a fun personality, Colleen really knows how to bring out the best in people. She is always excited to get started with counseling, advising, and assisting anyone who comes through our doors looking for a job, and she will make you feel right at home while doing it!



Colleen works with people of all ages who have a variety of experience and skill levels. Colleen says that she has worked with people who have college degrees, and she has worked with people who are manual laborers.

Colleen offers pre-vocational services to transition-age students from 14 to 21 to help them obtain summer work experience, as well as helping them with career research and in preparing for college. She works with adults who may have developed vision loss in their adult years and have been displaced from their jobs because of it. She has developed and teaches Work Readiness classes. She assists with and teaches the skills of job searching (through networking or the internet), making cold calls, creating resumes and cover letters, and handling a job interview. She also provides support and training on adaptive computer equipment, if needed, in our ACCESS-Tech lab.

Once you are ready to go to work, Colleen will assist you in finding the right job. If you wish, you may start out in our own on-site Manufacturing and Business Division, then transition to a job in the community later on.

If you are legally blind and are interested in going back to work, give Colleen a call. She’d love to hear from you!



## THE MATTINGLY MOUSE

It may be little, but it's mighty! It's the Mattingly Mouse CCTV. We've talked many times about CCTVs, or Closed Circuit Televisions. These wonderful devices have literally changed people's lives by making it possible to see tiny print on mail and important documents, sign checks, and even see the faces of grandchildren in a photograph for the very first time.

CCTVs come in all sizes, from large desktop models to about the size of a book. But the Mattingly Mouse is just about the smallest one we've seen yet. Literally the size of a common computer mouse, it fits neatly and comfortably into the palm of the hand. To use the mouse, one simply places the mouse directly onto the reading material and glides it across the printed lines.

So, where does the image show up? On your TV! The mouse is connected via a cable that plugs into the yellow RGB video-in port on your TV. Plug the AC adapter into a wall outlet, turn on the TV, press the "video" button, and you are ready to read.

The Mouse CCTV features 3 viewing modes: full color, high-contrast black on white, and high-contrast white on black. There are 7 levels of magnification: 17.5x to 70x digital zoom on a 20-inch TV monitor. A larger TV will increase the level of magnification even more. The quality and clarity of the image is reported to be very good. The Mouse is very lightweight and

also features the ability to freeze and unfreeze the image being viewed.



While full-sized CCTVs certainly have their place in the world of low vision, they can cost \$2,000 - \$3,000. The Mattingly Mouse CCTV is a very affordable option. The Mouse is available to purchase through our ViewPoint retail store. The cost is \$128.70. A special adaptor that enables connection to a computer monitor is available and is sold separately.

If you are interested in purchasing the Mouse CCTV, call us at 607-724-2428, and ask for Kim.



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Association for Vision Rehabilitation  
and Employment, Inc.  
174 Court St.  
Binghamton, NY 13901-3514



Address Service Requested

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**174 Court St., Binghamton, NY 13901**

**607-724-2428 FAX: 607-771-8045**

**Email: [avreinfo@avreus.org](mailto:avreinfo@avreus.org)**

**[www.avreus.org](http://www.avreus.org)**

Editor: Joyce Bucci

**A.V.R.E.** serves visually impaired individuals of all ages who live in the New York counties of Broome, Chemung, Chenango, Cortland, Delaware, Otsego, Tioga, Tompkins and Schuyler, as well as the Pennsylvania counties of Bradford, Susquehanna and Tioga.

**A.V.R.E.** is an Affirmative Action and Equal Opportunity Employer.

If you would like more information about **A.V.R.E.** or its services, please feel free to contact us.

**Our vision is to be the first in choice and quality with respect to vision rehabilitation and employment services in the Twin Tiers, and to be a model for the broader community in understanding vision disability.**

**"Seeing Things Differently!"**