

Breaking Through the Darkness

A story and resource about fighting a mysterious illness and adapting to blindness.

By Andrea Mitchell

My name is Andrea, and I was officially diagnosed with MOG-Ab disease in 2013. At that time, there was not much known about the disease. The first two years after the diagnosis were especially hard as I lost most of my sight in both eyes. I am writing my story to help others and provide a resource for the newly blind.

Stepping back in time, I remember walking out of my neuro-ophthalmologist's office just feeling lost. I had dreaded going into his office knowing that I was not going to have a good report. I had gone through a lot of relapses at this point and remember not being able to read anything on the eye chart. Everything was black in my left eye and very blurry in my right eye. I could not see all the colors in the book he used either. I must have scared my doctor and nurse because I was crying so hard. They didn't know how to respond, and I felt like no one understood what I was going through. I remember going through the different stages of loss. I stayed in the anger stage for two years. I had lost most of my sight and my life as I knew it. It started out with my inability to drive, not having my health as I used to know it, loss of a great career and inability to engage with lots of friends. It felt like I had fallen down a rabbit hole into some mysterious world. I could not make out faces anymore. I was having trouble doing basic things that I had been doing all my life. I felt my independence slipping away. I have always been a problem solver, so I decided I needed to take charge and seek help. I went to see a therapist because I needed help to cope and redefine my life. It turned out that she would be instrumental in helping me find some of the resources I needed to get started on finding my independence.

Coping with Loss

When I received my diagnosis, there was hardly any information on MOG-Ab disease, and there were no Facebook groups or other support groups available. I told my therapist that even though I was given my medical report, there was no advice on how to adapt to being blind. She was instrumental in providing some resources and information to help guide my way through this new lifestyle. I am not ashamed to say how valuable those therapy sessions were at that time of my diagnosis and beyond. I was battling this disease to keep what little sight that I had left, and I had to keep my sanity and renew my life, albeit perhaps a little different than the old norm.

My first step was to call the [Lions Blind Center](#), which is a nonprofit organization whose mission is to provide education, training, and certification for members of the blind and visually impaired community in Oakland, CA. The Center offers services such as computer training, job placement, and a vision clinic. They told me they could provide me with mobility lessons. I jumped at the opportunity. A person came to my house and brought a cane that looked like a regular cane but was white with a red tip. We walked around a little and he asked if that was enough. He said he did not want to start out with the regular long blind cane because that would take additional training. I remember thinking what a relief, but,

unfortunately, it was not enough for me. I needed much more assistance than what could be received in an hour or so of introductory training. I called him back and he returned with the long blind cane. He showed me how to use it. I practiced using it around the neighborhood. While I was working on my new skills, I must admit I still was not comfortable being blind and knowing everyone I came across would know I was blind. I still persevered because I felt I needed more training with my mobility and daily living skills. Not being able to use my computer anymore was also a huge detriment.

Taking Charge

My next step was to call the Department of Rehabilitation to see what they had to offer. I met with a counselor, and he gave me a referral for someone to come out and further evaluate my needs. He showed up with another person that was in the blind services department. It was the first time that I heard of a school that could give me my independence back.

Vocational rehabilitation services differ by state (<https://www.askearn.org/state-vocational-rehabilitation-agencies/>). Some states require that you are actively looking for work or education. Below are links for resources in California, but there may be similar resources available in your state.

- <https://www.dor.ca.gov/>
- <http://lighthouse-sf.org/>

The school that was suggested to me is called [The Orientation Center for the Blind](#) (OCB). I took a tour and was amazed at all the school had to offer in the way of training. The training included mobility, computer, adaptive technology, braille, and daily living skills (such as cooking, cleaning, and entertainment as well as health and beauty). The mobility training included a tour of the guide dog school and some Juno training. Juno training involves an instructor playing the role of a guide dog, where the student is guided by the instructor while giving the basic commands of "Forward," "Left" and "Right". It is designed to train the student to use a guide dog. The only thing that caught me off guard was that it was a residential program. I was told that the program could last anywhere from 6 months to a year, which depended on the individual needs and learning process.

I decided to go, and it was the best decision I ever made. I moved in and went home on weekends so that I could spend some time with my husband and family. I was able to learn how to use public transportation in order to do this. We didn't have Uber or Lyft in our area at the time and, being in Albany, CA, it was a good distance from my house in Oakley. It took me about a year and a half to complete and graduate from the program because I had continued relapses. I was definitely at the right place, though. I lost a lot of sight but was told by my mobility instructor that I had enough vision to be dangerous.

It was really tough in the beginning for me as I struggled to fit in. There were a mixture of ages and backgrounds there. Keep in mind that I had not been in a school atmosphere in a long time. I was very fortunate to find some good friends there that I still stay in contact with

to this day. They blindfold you while you are in class so that you don't use any vision for assistance. It is designed to prepare you for the future if you have a progressive condition.

The internet is a great place to look for articles and other organizations across the nation and abroad. For example, this article provides a great starting point for those looking for advice on where to start: <https://www.allaboutvision.com/lowvision/resources.htm>.

Mobility

I learned a lot from my mobility class at OCB. I never knew that there were different kinds of blind canes and tips. My mobility instructor started me out on a rigid cane which doesn't fold up. They start you out on it because you can feel a lot more with it than a folding cane. You can also become mobile faster with the rigid cane because being able to use the folding cane takes additional training. There are also different cane tips which can be interchanged. I prefer the rolling tip but also liked the mushroom tip. It is easier to use the mushroom tip on areas that have dirt roads. You can learn more about the different cane tips [here](#). The cane is like an extension of your hand. You gather information from it as it glides along the sidewalk from left to right. It took a little time to get in the groove of using it, but I did.

As part of the learning, we were blindfolded. I absolutely dreaded using the blindfold, but I am glad that I did. It wasn't easy walking down Adams Street outside of the school, as it had a lot of cracks in the sidewalk. I also had to learn my cardinal directions. In case you get lost it is important that you know what direction you are heading such as North, South, East and West. I learned how to take public transportation and learned the BART system (San Francisco commuter train) as it was my key to getting home on the weekends. I remembered all the stops along the way. I had to count the stops as you can't always hear the conductor announcing the stops and, of course, you can also ask someone on the train to let you know when your stop is coming up. There are some helpful people usually on board and there are some BART apps that are useful in viewing schedules. When you take a bus, it is important to ask and confirm what bus you are boarding. Also, ask the driver to inform you when you are at your stop. There are discounts available as well for public transportation. As an example, in my area, I have a Clipper Card and a Dial-a-Ride service that I also use, but it is a shared ride service so it can take a while to get to your destination considering the number of travelers. I get a good fare using Lyft from my paratransit services. I am so grateful for my mobility training as it helped me get my guide dog, Newcastle. I would practice the commands and do pretend routes using the Juno training method so that I would be able to find the perfect canine match for the way that I moved as well as getting my mobility skills up to par so that I would qualify for using a guide dog. Here is a website that sells canes and cane tips: <https://ambutech.com/>

Guide Dogs

I received my beautiful guide dog named Newcastle a few months after attending the blind school. I attended [The Guide Dogs for the Blind](#) school located in San Rafael, CA. It is a residential school, so I had to reside there for the training for 2 weeks. We worked a lot of

routes, and I remember it raining most of the time. Newcastle has given me my independence back. I feel confident that he always has my back. He alerts me to upcoming curbs, cars, overhanging tree branches and so much more. He has also been my protector at times. There was a dog that tried charging us one time, and he put his body in front of me to shield me. I can hold up my head high when I walk because he has given me my confidence and independence back. I know that he will protect me and that I will not wander into oncoming traffic as I have done before receiving him. If you are thinking about getting a guide dog, make sure that you have the time, space, and dedication to put into it. It takes ongoing training to keep them in practice. They are not like a cane where you can just hang them up. There is also the joy of having a partner and companion. I am forever grateful in having him as my partner. This website has more information about Guide Dogs: <https://www.guidedogs.com/>.

Computer

I cannot see anything on a computer or monitor. I learned how to use my [Jaws screen reader](#) on a regular PC. I sometimes have some issues using it because you have to remember a lot of keyboard commands. It can be challenging when you are on certain medications or have brain fog from your condition. I love the fact that I could do everything but use a mouse using Microsoft Office Suite. I practice every day to not lose my skill. I have grown used to the robotic voice that reads to me. There is an option to change it though. There are also programs such as [Zoom Text](#) that assists people with magnification, and it can read text. Dragon is another screen reader that people use. Your choice depends upon the level of sight that you have. Due to my blindness, I cannot read anymore without technology. The key is finding the right program that works for you. The Department of Rehabilitation was so helpful in providing me with my computer and screen reading software, but it can be very expensive. The best part is being able to do everything on the internet and staying connected.

Adaptive technology

There are a lot of adaptive technology and apps out there today for your smartphone. My personal preference for a smartphone is the iPhone, but for those who prefer Android, many options are available as well. Below is a list that I have found to be helpful.

Informed Delivery to let me know what is coming in the mail.

- <https://informeddelivery.usps.com/box/pages/intro/start.action>

KNFB Reader helps you get easy access to print and files. Their app will use a photo you provide to read text to you or turn it into Braille.

- <https://knfbreader.com>

TapTapSee allows you to take a picture and a person in their network identifies it and relays that back to you.

- <https://taptapseeapp.com>

Be My Eyes is similar where, again, a person in their network assists you with whatever help you may need.

- <https://www.bemyeyes.com>

Seeing AI is a free app that does it all. It is designed to narrate the world around you. It recognizes paper money and immediately speaks the denomination. It can also read text on documents and prescription bottles, read barcodes to identify products and it serves as a color reader as well. This can be quite helpful in reading menus and identifying products in your pantry.

- <https://www.microsoft.com/en-us/ai/seeing-ai>

LookTel Money Reader recognizes money and tells you the denomination.

- <http://www.looktel.com/moneyreader>

LookTel Recognizer is a better version of the money reader that allows you to recognize money as well as all kinds of objects in real-time with no need to capture a picture.

- <http://www.looktel.com/recognizer>

NantMobile Money Reader is another free money reader.

- <https://nantmobile-money-reader-ios.soft112.com>

Blind Square and **Google Maps** are some of my favorites apps for getting around and navigating.

- <https://www.blindsquare.com>
- <https://www.google.com/maps>

Victor Reader is a very valuable tool as it allows you to record notes, store files and play internet radio. The "Trek" version has a built-in GPS.

- <https://store.humanware.com/hus/victor-reader-trek-talking-book-player-gps.html>

Colorino Color Identifier-Light Detector, which is available in English and Spanish, discerns and clearly announces up to 150 shades of color. Not just red, for example, but pale red, light red, dark red, as well as intense red. It also detects the presence of light and indicates intensity and proximity by audio signal. This is a fairly expensive device, but there are other color reader apps available for free.

- <https://www.maxiaids.com/colorino>

Calculators are available on most smartphones as well, and the accessibility options like Voice Over for the iPhone help make calculator apps easy to use.

Braille

Braille is something I learned at OCB, but you can take some online classes at [Hadley](#), a non-profit 501(c)3 organization with a mission to create personalized learning opportunities that empower people to thrive – at home, at work and in their communities. I use jumbo Braille as I have a hard time feeling the dots. Jumbo Braille is used primarily for labeling items. I find it helpful but find myself using more adaptive technology. There is not much available in Jumbo Braille. I am glad that I learned how to use Braille and read it. The alphabet from A through Z is considered Grade 1. Grade 2 has contractions and advanced punctuation. There are Braille tags that can be pinned into your clothes for color identification. I will also use my Colorino Color-Identifier as well. When I need to purchase clothing at a store, I will ask for assistance. There are other color identifier apps as well. I will let them know what I am shopping for and they will give me some options. My husband also helps me out a lot.

Cooking

I have always enjoyed cooking as I am a foodie. There are items that help you with the cooking process. The [i.d. mate](#) is a barcode reader that will tell you what canned items are as well as most items that have a barcode. There is also an item called the [PenFriend](#) that helps you label your items. You can find gadgets such as measuring cups, spoons, cutting boards with contrast and so much more. I like using a cut-resistant glove for chopping. I use my iPhone as a timer. There is also a gadget called the “[Say When](#)” that whistles if you are pouring liquid in a cup so that you don’t over fill it. I like using the [Keurig](#) coffee maker as it so much easier in getting my favorite coffees and teas. I have marked my microwave, stove and oven as well and my washer and dryer with bump dots to mark the power and certain settings. The refrigerator’s water setting is the hardest of all. I have tried labeling items, but the labels fall off. The “system” I have now is that I have my own shelf. If I am making new recipes, I record the recipe on my [Victor Reader Stream](#) or use my iPhone with voiceover turned on. When I go shopping for food and I am alone, I ask the store to have someone assist me. It is most helpful to have a shopping list prepared.

Cleaning

Cleaning is not one of my favorite things to do, as I have a bad back and neck. The technique that I learned at school was called the grid pattern technique. You start in one corner and go from left to right until you complete the row. It takes some time and practice but can be done. I find that the [Swiffer mop](#) works best for me. The [Webster Duster](#) also comes in handy for taking down spider webs. The best way to check for your cleaning results is to feel the area with your hand or have someone check for you. I like using anything that makes the process easier. The [Clorox toilet wand](#) with disposable cleaning heads is very good. There is no mess like when using a regular toilet brush. I use [Clorox disinfecting wipes](#) to clean my counter tops.

Entertainment

I am a movie lover and enjoy movies with audio description. You hear all of the movie but also get filled in as to what's going on in the movies when there are pauses. Some movies that you can purchase have this feature available, as well as movie theatres. I have noticed that some local broadcast channels now offer it. On my cable box, I have my "Audio Description" turned on. This allows a program to play the audio description automatically if it's available. I use streaming services, and most theatres have a box or headphones that you can use for the movie. It is very easy to take advantage of these features. For example, after signing into Netflix, you can use the search feature to search for "Audio Description" movies. It will bring up a list. I have learned that a lot of their original programming will have audio description available. You can also select a movie and check the settings in the Audio and Subtitles area. Select the English Audio Description 5.1 in the Audio settings. Back out of settings and press play.

I also enjoy using my DVR and the guide using voiceover that is offered through Comcast. It has given me my independence in surfing for TV channels and some content has audio descriptions available. I can enjoy all of my shows just like a sighted person.

I use BARD offered by the government in providing free Braille and audio books to the blind and physically disabled. [BARD](#) is the Braille and Audio and Reading Download from the National Library Service for the Blind and Physically Handicapped (NLS). It is a web-based service that provides access to thousands of special-format books, magazines, and music scores. Amazon has some audiobooks available for free with a prime membership. Audible is also another way to get audiobooks but you must pay for them.

Health and Beauty

Exercise is very important to your health. I make sure that I walk with my guide dog Newcastle on the days that I am not in the gym. I try to do two miles if I can around my neighborhood. I joined a gym and enjoy that as well. My husband helped me get acquainted with the equipment. When I use the treadmill, I must hold on to the handrails or else I will lose my balance. I have memorized where the quick start buttons are and can tell as I walk what speed it is set to. I use the timer on my phone to let me know when my time is up. I know where the stop button is in case I need to stop. You can also clip an emergency stop to yourself if available on the machine. I like to use the weights that have seats and adjust the weight. I use the pin and find the hole and adjust it by using my fingers. It's great if you have a person to work out with you so that they can set up the equipment for you. It takes practice like anything else.

I learned how to apply my makeup at the OCB school. I use my fingertips to apply my eye shadow. You must count the number of strokes that you apply on each eye, that way it is even. It is also helpful to use makeup sponges to blend the makeup. Eye liner can be a little tricky. I find the corner of my eye and lightly trace the line of my eye. I have found mascara to also be challenging. I find that a small wand is easier than using a big one. It gives you more control. When using blush, use the same number of strokes on each side.

I have a wash and wear haircut so that I don't have to fuss with my hair too much. I still remember how to use a hair straightener, if needed.

I hope that these resources will also help you on your journey as either a newly blind person or someone who has been blind and was not aware of these resources. Please feel free to reach out to me for any questions. Good luck on your journey and break through the darkness, as life can be very fulfilling.

All the best,

Andrea Mitchell

Summary of Resources

Below is a summary of the resources used in this article. Some are particular to the greater San Francisco area, US nationwide, or to anyone in general, worldwide. There are a lot of other resources out there depending on location. The MOG Project at the TMA is in the process of gathering and publishing resources from around the world.

- **List of Vocational Rehabilitation Agencies by State:** <https://www.askearn.org/state-vocational-rehabilitation-agencies/> <https://www.dor.ca.gov/>
- **All About Vision - Resources for the Visually Impaired:** <https://www.allaboutvision.com/lowvision/resources.htm>
- **San Francisco are Lighthouse for the Blind and Visually Impaired:** <http://lighthouse-sf.org/>
- **Orientation Center for the Blind:** <https://www.dor.ca.gov/Content/DorIncludes/documents/OrientationCenterfortheBlind/OCB-handbook-07-18.docx>
- **Ambutech:** <https://ambutech.com/>
- **Guide Dogs For the Blind:** <https://www.guidedogs.com/>
- **JAWS Screenreader Software from Freedom Scientific:** <https://www.freedomscientific.com/products/software/jaws/>
- **ZoomText Magnifier/Reader Software:** <https://www.freedomscientific.com/products/software/zoomtext/>
- **Talking Typing Teacher:** <https://www.maxiaids.com/talking-typing-teacher-standard>
- **USPS Informed Delivery:** <https://informedelivery.usps.com/box/pages/intro/start.action>
- **KNFB Reader:** <https://knfbreader.com>
- **TapTapSee:** <https://taptapseeapp.com>
- **Be My Eyes:** <https://www.bemyeyes.com>
- **Seeing AI:** <https://www.microsoft.com/en-us/ai/seeing-ai>

- **LookTel Money Reader:** <http://www.looktel.com/moneyreader>
- **LookTel Recognizer:** <http://www.looktel.com/recognizer>
- **NantMobile Money Reader:** <https://apps.apple.com/us/app/nantmobile-money-reader/id417476558>
- **Blind Square:** <https://www.blindsquare.com>
- **Google Maps:** <https://www.google.com/maps>
- **List of Smartphone Apps for the Visually Impaired:** <https://www.visionofchildren.org/voc-blog/2018/7/13/smartphone-apps-for-the-blind-and-visually-impaired>
- **HumanWare Victor Reader Trek:** <https://store.humanware.com/hus/victor-reader-trek-talking-book-player-gps.html>
- **Colorino Color Identifier-Light Detector:** <https://www.maxiaids.com/colorino>
- **List of Additional Apps:** <https://www.visionofchildren.org/voc-blog/2018/7/13/smartphone-apps-for-the-blind-and-visually-impaired>
- **More Color Identifier Apps:** <https://techigem.com/color-identifier-apps/>
- **Hadley Non-Profit Organization for the Visually Impaired:** <https://www.hadley.edu/>
- **PenFriend:** <https://www.maxiaids.com/penfriend2-voice-labeling-system>
- **i.d. mate Galaxy:** <https://www.envisionamerica.com/products/idmate/>
- **BARD:** <https://www.loc.gov/nls/enrollment-equipment/register-for-bard-get-bard-mobile/>
- **Xfinity:** <https://www.xfinity.com/learn/digital-cable-tv/x1>
- **Netflix:** <https://www.netflix.com/>
- **AMC Theaters Assistive Moviegoing:** <https://www.amctheatres.com/assistive-moviegoing>

UK Resources

This list was compiled by a resource in the UK:

Royal National Institute of Blind People (RNIB): <https://www.rnib.org.uk/>

BBC radio program called In Touch: <https://www.bbc.co.uk/programmes/b006qxww>

Here is an excellent collation of organizations for people with visual impairments:

<https://www.charitychoice.co.uk/charities/visual-impairments>

Guide Dogs: <https://www.guidedogs.org.uk/>

This is an organization that helps you find local support groups: <https://visionary.org.uk/>

National Health Service information: <https://www.nhs.uk/conditions/vision-loss/>

For children: <https://www.rsbc.org.uk/>