



The Sight-Loss Support Group of Central Pennsylvania, Inc.

Turning Darkness into Light Since 1982

P.O. Box 782, Lemont, PA 16851

814-238-0132 www.slsq.org office@slsq.org

THE OUTLOOK Newsletter

December 2020

Our programs are temporarily suspended due to the Coronavirus. Please check our website (www.slsq.org) for updates and further information. You can also follow "Sight-Loss Support of Central PA, Inc" on Facebook.

**IF EVER THERE WAS A YEAR THAT NEEDED CHRISTMAS,
THIS IS IT**

Winter is a dark time. The two winter festivals of light, Christmas and Hanukkah, dispel the darkness at the time of year when we seek out the light. A fire's embers, the glow of candlelight, and the magic of a glimmering Christmas tree, affirm that the light will return and the world will be renewed.

In the face of a surging pandemic, we need the warmth and solace of religious celebrations and family gatherings more than ever. Hopefully, this is the beginning of our light at end of the tunnel. The spirit of Christmas reminds us that peace and love will prevail. Hanukkah will always be a testament to the resilience of the human spirit.

Living through this pandemic brings us headlong into meeting a most challenging moment. We are doing what is required of us and trying to keep ourselves and our loved ones safe. And, we are receiving an unasked-for lesson in how to live. Enduring hardship and significant loss have a way of distilling what is most important and of revealing the essence of who we are and who we want to be.

Those of us who have struggled with losing vision will understand. It's a crucible of sorts and getting to the other side requires strength, resilience and courage. One key to learning to live with sight loss is coming to understand that you can still do all the things you did before (except drive). You just learn to do things in a different way. Life goes on and can be pretty darn good.

Learning to live through a pandemic is not so very different. Strength, resilience, and courage will get us to the other side of the dark winter we are living through. Necessity being the mother of invention, we are finding creative ways to do the things that keep the joy in our lives. Many of these creative solutions will remain, becoming part of the fabric of our lives. We're still living our lives; it's just different.

For now, we must do the needful, celebrate in a different way, and know that next year the holiday season will be especially sweet. Having our lives upended brings an unexpected gift. None of us could ever have imagined how wonderful "normal" really is. And that is one of the simplest, yet most elusive, secrets of life.

During this season devoted to "turning darkness to light", the Board of Directors of the Sight-Loss Support Group wishes all of you a joyous holiday and a New Year filled

with hope, many blessings, and the gradual return of our pre-pandemic lives.

IMPACT OF COVID-19 PANDEMIC ON SERVICES TO THE BLIND IN CENTRAL PENNSYLVANIA

The Sight-Loss Support Group has suspended all in-person events, including the monthly support group meeting at Mt Nittany Residences and all View Via Voice audio-description events. We had hopes of hosting our annual holiday feast but that too has been postponed. There is light at the end of the tunnel and we will keep you posted as to when we resume our programs, hopefully in late spring or early summer.

The Bureau of Blindness and Visual Service (BBVS) is providing services to clients but they are not doing home visits as they normally do. This situation makes assessing the needs of clients and meeting their needs more challenging, but the social workers and vision rehabilitation therapists are finding creative solutions to providing services.

North Central Sight Services, after suspending services for a time, is currently assisting clients with essential tasks in their homes and providing escort services for medical appointments and grocery shopping.

ACCESSIBLE PHARMACY LAUNCHES IN PA

So how do blind and partially sighted individuals manage their medications? It's yet another hurdle to overcome on the road to independence. Thanks to two enterprising

entrepreneurs with deep experience in health care marketing and consumer accessibility, this challenge just got a whole lot easier. In 2020, Alex Cohen and Andy Burstein launched Accessible Pharmacy in Pennsylvania, a comprehensive and home delivery pharmacy specializing in the needs of the blind and low vision community. The pharmacists at Accessible Pharmacy are trained to understand the unique challenges visually impaired people (VIPs) face when managing their medications. It is the only medication management provider of its kind in the country and was born from VIPs lack of accessibility in the pharmaceutical industry

Alex Cohen and Andy Burstein have a mission – to make the management of medication seamless and accessible, thus enabling VIPs to take control of their medications safely and independently. These two partners, one blind and the other sighted, know the challenges of living in a sighted world as only a blind person can. They know the importance of offering a welcoming, stress-free, and supportive experience to their patients.

Accessible Pharmacy is comprised of a team of blind, partially sighted, and sighted professionals who understand an individual's unique needs. This team provides medication management one patient at a time. A Customer Care Coordinator assesses each patient's unique needs and develops specifically tailored solutions. Some of these solutions include a wide variety of packaging and pill sorting options, high-tech label reading, Braille and large print labels, automatic refilling and reordering of prescriptions, medication consultations, and reminder systems. All these services come at no extra cost to the patient. Free home delivery is available anywhere in

Pennsylvania. Accessible Pharmacy sets everything up for you, coordinating all the details with your physicians, current pharmacy, and insurance carrier to have everything switched over for you. The company accepts all insurance plans and insurance carriers.

What makes Accessible Pharmacy unique is their ability to reduce the barriers to medication management, increase a patient's independence, and achieve the best medical outcomes as safely as possible. There is a focus on educating each blind patient and their family members, healthcare providers, and caregivers.

The two co-founders, Alex Cohen and Andy Burstein, both from Center City in Philadelphia, met at their children's Little League games three years ago. Alex, who is blind from retinitis pigmentosa, earned his PhD in Marketing with a focus on consumer accessibility for the blind. Andy had experience working at two health care marketing firms. He sought out Alex's advice on how best to serve one of his clients with a disability. Lo and behold, three years later, these two Little League dads are rolling out their new company in Pennsylvania. Their momentum is growing with plans for webinars on topics such as diabetes, Medicare open enrollment, and home Covid-19 testing in partnership with Be My Eyes. They are taking their unique concept nationwide and are already licensed in over 30 states. You can call for a free consultation.

Website: www.accessiblepharmacy.com

Phone number: 215-799-9900

**The Accessible Pharmacy OCR App:
<https://apps.apple.com/us/app/accessible-pharmacy/id1506059852>**

AUDIO DESCRIPTION IN THE AGE OF THE CORONAVIRUS

With our local theaters having gone dark due to Covid-19 restrictions, the Sight-Loss Support Group's View Via Voice audio-description service has been temporarily suspended. We will keep you posted about re-opening plans. We are learning to withhold predictions regarding time frames for a return to normalcy, so just wait to be surprised.

Although we are deprived of live theater for the time being, audio description can still be part of your life. At last, all first-run movies have audio description embedded during the production process. Descriptive video for cable television, DVDs, and streaming video services is also becoming widely available. Two good sources of information on audio description programming can be found at the websites of:

- American Council for the Blind (ACB) Audio Description Project**
- National Library Service (NLS) for the Blind and Print Disabled, Library of Congress**

Vocal Eye, an audio description organization in the United Kingdom, is creating some innovative programming during our Covid year. VocalEye's Almost Live Zoom Events make recorded live arts events available with audio description as part of their virtual outreach initiative during the Covid-19 pandemic. This is yet another creative way of staying connected when we have to be apart. These events provide access for people who are blind and partially sighted, but everyone is welcome.

Try googling VocalEye's Zoom Events for a current listing of their offerings. Registration is required for first-time

guests. Register for your VocalEye's Zoom invitation by contacting events@vocaleye.ca or call 604-364-5949. This one-time registration will give you access to all upcoming Virtual VocalEye events. Registrants will receive a Zoom link and reminder on the day of the event.

VocalEye, established in 1998, works with arts organizations across the United Kingdom to identify and remove barriers to access and inclusion for blind and partially sighted people. Its prime focus is providing live audio description of theatrical plays. The organization also works with museums, galleries, and heritage venues to deliver audio description for exhibitions. Another focus is conducting research and training devoted to increasing access to the arts for disabled people.

LEVODOPA MAY IMPROVE VISION IN PATIENTS WITH WET AMD

Investigators have determined that treating patients with the early wet form of age-related macular degeneration (AMD) with levodopa stabilized and improved their vision. Levodopa is a safe and readily available drug commonly used to treat Parkinson's disease. The drug reduced the number of treatments needed to maintain vision, and holds the potential for reducing the burden of treating the disease, financially and otherwise. The research findings appear in the American Journal of Medicine by Elsevier.

The investigators developed two studies to test whether levodopa improves visual acuity and the anatomical changes caused by AMD. This trial demonstrated that



**Sight-Loss Support Group
of Central PA, Inc.
P.O. Box 782
Lemont, PA 16851**

levodopa is a safe and well-tolerated, and delayed anti-VEGF injection therapy while improving visual outcomes. In the first month, retinal fluid decreased by 29 percent. After six months the decrease in retinal fluid was sustained, and mean visual acuity improved, enabling patients to read an additional line on the eye chart.

The investigators noted that levodopa is most likely not a stand-alone treatment in patients with newly diagnosed AMD, as eleven of the patients did require anti-VEGF injections. However, they required fewer than the standard monthly treatments. In the second trial, monthly injections decreased by 52 percent.

In spite of the small sample size and limited patient diversity, the findings suggest efficacy and support the targeting of the GPR13 receptor that supports retinal health and survival. More studies are needed but prospects for treating AMD with levodopa appear to be encouraging.

THE OUTLOOK, December 2020