



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

Turning Darkness into Light Since 1982
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THE OUTLOOK Newsletter Fall 2022

2nd THURSDAYS SUPPORT GROUP MEETING Eat, Share, Connect

- **August 11: Assistive Technology Specialist from North Central Sight Services will demonstrate technology for the visually impaired.**
- **September 8: Social Meeting**
- **October 13: Orientation and Mobility specialists from the Bureau of Blindness and Visual Services will demonstrate how we can safely navigate our homes, neighborhoods, and beyond.**

Our 2nd Thursdays lunch group meetings resumed in March, one more step towards reclaiming our normal lives. We meet on the second Thursday of each month (thus the name) at Mount Nittany Residences, rain, snow, or shine. If you are new to vision loss or are an old hand, this is a good place to be. We always share a simple lunch, learn from one another, and enjoy each other's company. We share our stories and experiences, learn about services and resources, and offer support to one another. We're an informal group; sometimes we have a speaker, sometimes not. Occasionally we'll arrange a special event: a play, baseball game, or special tour. We hope to meet you soon.

- **When: The second Thursday of each month, 11:30 am to 1:00 pm.**
- **Where: Mt Nittany Residences, 301 Rolling Ridge Dr, State College, in the community room on the first floor.**

- **Details:** Lunch is provided and is “on the house.” If you need help with transportation, please call Josie Kantner at 814-238-0132.

2nd Thursdays is a collaboration between the Bureau of Blindness and Visual Services, North Central Sight Services, and the Sight-Loss Support Group of Central PA. Each month staff members and clients from all three organizations come together and find common ground.

UPCOMING AUDIO-DESCRIBED MUSICALS

- Call 814-238-0132 to reserve your ticket(s).
- Reservations must be made at least two weeks before the show date.

THE FANTASTICKS: Sunday, October 16th at 2:00 pm, Tussey Mountain Lodge

- Presented by the State College Community Theatre.
- Reserve your spot by October 2nd.

"Try To Remember" a time when this romantic charmer wasn't enchanting audiences around the world. *The Fantasticks* is a funny and romantic musical about a boy, a girl, and their two fathers who try to keep them apart. The narrator, El Gallo, asks the audience to use their imagination and follow him into a world of moonlight and magic. The boy and the girl fall in love, grow apart and finally find their way back to each other after realizing the truth in El Gallo's words that, "without a hurt, the heart is hollow." <https://www.mtishows.com/the-fantasticks>

CABARET: Saturday, November 5th at 2:00 pm, The Pavilion Theatre at Penn State

- Presented by Centre Stage.
- Reserve your spot by October 22nd.

Hear some of the most memorable songs in musical theatre history, including “Cabaret”, “Willkommen” and “Maybe This Time”. Leave your troubles outside – life is beautiful at the *Cabaret*, the Tony

awarding-winning musical about following your heart while the world loses its way.

RENT: Saturday, December 3rd at 2:00 pm, The Pavilion Theatre at Penn State

- Presented by Centre Stage.
- Reserve your spot by November 19th.

Rent has become a part of us forever. With its inspiring message of joy and hope in the face of fear, this timeless celebration of friendship and creativity reminds us to measure our lives with the only thing that truly matters – love.

LOUISE VICTOR: Always Learning, Always Teaching, Always Growing

We'd like you to meet Louise Victor, the coordinator of View Via Voice, the Sight-Loss Support Group's audio-description program. Louise is a woman with a mission of making the arts accessible to people who are visually impaired. When she was newly retired, she ventured into the world of audio description, becoming an audio describer for View Via Voice in 2017. Louise is one who sees the world with fresh eyes and can be restless with the status quo. Within a few short years, she was the coordinator of View Via Voice and now serves on the Board of Directors of the Sight-Loss Support Group. Louise has grown the audio-description program with an emphasis on training and recruiting new audio describers.

Louise has a long history in teaching and music education. After receiving her BS and MS degrees in music education from Penn State, she spent 26 years teaching music at Penn State and various schools in the area. Prior to retiring, she served ten years as the Fine Arts Department Head at the State College Area High School where she conducted choirs, orchestras, musicals, and Special Education music classes.

Louise's commitment to learning did not stop with retirement. It found a new outlet in audio description, a relatively new discipline that is growing rapidly. Louise always had a desire to help those with vision loss; a desire which sprang from spending time with her favorite aunt and observing the challenges her vision loss posed.

Not everyone is familiar with audio description even within the vision loss community. Audio description is a narration service for individuals who are blind or have low vision. The audio describer provides an ongoing, concise description of visual events that are taking place on the stage or screen, at the museum, tour or any public event. The describer fills in details that the visually impaired patron cannot see - scenes, settings, costumes, body language, etc. These details all deftly slipped in between dialog and songs. Visually impaired patrons wear an earpiece so they can hear the describer explain the visual events taking place. These details provide context and enrich the theatrical experience.

Louise felt the need to delve deeper and learn more. She began searching for a training program that would allow her to hone her skills and expand her horizons. She found what she was looking for in the Audio Description Training Retreat (ADTR) in North Carolina. It offered an all-inclusive small-group retreat in a beautiful, lake-side setting. Just eight people living together, sharing meals, learning, practicing, and relaxing together. The four-day retreat gave students practice time, peer and expert feedback, and networking with fellow participants and industry professionals.

Several years ago, Louise and long-time audio describer Cindy Shaler headed to North Carolina for the four-day retreat of Level 1 Training. It was a wonderful experience and they brought back what they had learned to their fellow audio describers in State College. Louise and Cindy also pursued the advanced Level 2 training, offered via Zoom during the pandemic. In 2020, ADTR began teaching all its offerings online and has added almost every continent to its roster. The pandemic has dramatically broadened the reach of this valuable training experience.

The digital reach of audio-description training at ADTR brings us to a bright spot of the pandemic which has landed in our own backyard. Louise has recently become an online instructor for ADTR's Level 2 class. Congratulations Louise! This new opportunity melds Louise's commitment to making the arts accessible and providing professional training for our audio describers. It is an excellent step forward for the View Via Voice program and the emerging field of audio description as it finds its professional footing.

Evolving from student to instructor in such a short time is recognition of Louise's energy and depth of experience in education and the arts. She is encouraging the View Via Voice audio describers to pursue this training; several have already done so and more will follow. Louise is passing along her way of being – always learning and teaching, always growing. Thank you, Louise.

NON-24, A CIRCADIAN SLEEP DISORDER

At our May support group meeting Maggie Felton, a clinical nurse educator from Vanda Pharmaceuticals, spoke on sleep health/sleep hygiene and the visually impaired. She focused on Non-24, a circadian rhythm disorder, that affects blind individuals. Here is some additional information on the topic.

You may have seen commercials for a blindness-related sleep disorder called Non-24. It's a very rare condition affecting many (but not all) people who are totally blind and have no light perception. Our bodies and brains operate on a circadian clock which regulates many biological systems, including sleeping and waking. For most people the clock is approximately 24 hours and resets everyday by the perception of light. Totally blind people with Non-24 have circadian clocks that become out of sync due to the total lack of light perception. These individuals have trouble going to sleep at night and staying awake during the day. The condition can wreak havoc on their lives, especially those in school, working, or caring for a family.

But what about people with retinal degeneration: age-related macular degeneration, retinitis pigmentosa, Leber congenital amaurosis, Stargardt disease, and choroideremia? Are they at risk for developing Non-24 sleep disorder? To answer this question representatives from the Foundation Fighting Blindness spoke with sleep disorder experts Steven W. Lockley, PhD, at Harvard and Helene Emsellem, MD, medical director at the Center for Sleep Disorders in Chevy Chase, Maryland.

While many people with retinal degenerative disease have severe vision loss, a vast majority maintain some level of light perception and are, therefore, not at risk for Non-24. Even people who have lost all of their rods and cones to a retinal degenerative disease may not get Non-24. That's because the cells in the retina that regulate the circadian clock – the photosensitive ganglion cells – usually survive after photoreceptors are gone. So even if light perception is no longer present, there is a very good chance that the photosensitive ganglion cells are still functioning and still capable of sending signals back to the brain to synchronize the person's circadian clock.

So, who is at risk for Non-24? It's blind individuals who have advanced conditions or diseases which affect retinal ganglion cells, and/or the optic nerve, the cable that sends signals back to the brain. People with traumatic optic neuropathy, advanced retinopathy of prematurity, severe retinal detachment, and retinoblastoma (a cancer of the retina) are at greater risk for developing Non-24.

AN EPIDEMIC OF MYOPIA

The information in this article is taken from the article, "The Eyes Have It", The Economist, June 11, 2022.

Over the past few decades, the rates of myopia (short-sightedness) have soared across East Asia. In Taiwan and China, the percentage of students leaving high school with myopia is 80%. In the 1960s the rate was 20-30%. In Korea, Hong Kong, and Singapore things are even worse - 97% of school leavers have myopia.

The public health community in East Asia is beginning to wake up to myopia as a problem. These spikes in rates of myopia are beginning to attract official attention. In 2018 Xi Jinping, China's president, made controlling childhood myopia a national priority. Crackdowns on the country's private tutoring and video-games industries were begun in 2021, motivated partly by worries about children's eyesight.

Most myopia is caused by misshapen eyeballs. A properly working eye focuses incoming light precisely onto the retina. In a myopic eye the eyeball is distorted in a way that causes the light to end up focused short of the retina. One can see normally up close, but distant objects are blurred. And the condition is generally progressive, with vision worsening throughout childhood before stabilizing in adulthood.

For decades researchers thought myopia was mostly genetic. There were early hints, though, that this could not be the whole story. A 1969 study of the Inuit in Alaska found that myopia was virtually unknown in those middle-aged or older, but rates were above 50% in older children and young adults. Such a change is much too fast to be purely genetic, and it happened just as the Inuit had begun to adopt a more settled, Westernized way of life.

Short-sightedness is stereotypically an affliction of the bookish, and a procession of studies has confirmed a strong, reliable link with education. The more educated you are, the higher your grades, the more you participate in after-school classes and tutorials – the more likely you are to be myopic.

The dominant hypothesis currently is that exposure to daylight is the main variable. A study of Californian children published in 2007 found that time spent outdoors was strongly associated with a lower risk of myopia. A three-year study of 4,000 children in Sydney, Australia came to a similar conclusion. Researchers have found that exposure to light appears to stimulate the production of dopamine, a neurotransmitter in the retina. Dopamine, in turn, seems to help regulate the rate at which the eye grows. Too little, and the eye grows too long to focus properly.



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The daylight-exposure theory explains why myopia seems to be a “disease of affluence”, like heart disease and diabetes, that is more common in rich countries than poor ones. Economic growth brings with it more education, which means children spend more time inside. It explains why rates are high in East Asia in particular; the ubiquity of private tutoring and after-school classes mean schoolchildren there work routinely longer days than their western counterparts.

So now we have all the more reason to tell our children and grandchildren to put down their book, turn off the TV, power off their video game and go outside into the great outdoors.

“Earth and sky, woods and fields, lakes and rivers, the mountains and the sea, are excellent schoolmasters, and teach some of us more than we can ever learn from books.” – John Lubbock

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