Making Beautiful Music

Written by Betsy Penturf, Tulsa Kids Magazine

A violinist since age 5, young Madison Ingram began having problems seeing her music during violin practice when she was around 8 years old. In most cases, a prescription for glasses would be the solution for children needing vision correction.

“I thought she was wanting to quit violin, but she just couldn’t see it,” said Yoriko Ingram, Madison’s mom. “We took her to the eye doctor and thought with getting her glasses, she would be fine.”

A trip to Dean McGee Eye Institute in Oklahoma City resulted in a diagnosis of Stargardt disease, the most common form of inherited juvenile macular degeneration that causes progressive vision loss in children and young adults.

Stargardt disease, like other forms of macular degeneration, does not yet have a cure. It affects one in 10,000 children. Vision loss generally stops progressing in the late teen years.

Madison was then referred to NewView Oklahoma, where she has been a patient of Judy Riley, O.D., for two years.

“My daughter loves Dr. Riley,” Yoriko said. “She explained everything so well so that we could understand. Dr. Riley is really good with kids and is so patient. She takes time to answer all of our questions.”

Madison uses bioptic telescopes to see more clearly and give her the ability to see much further away, especially her violin music. The telescopes are attached to her glasses and work like miniature binoculars to make images larger and easier to see.

Yoriko highly recommends NewView to other parents. She said they will even visit your home to check to ensure nothing is dangerous for a person with limited vision or blindness.

“They were so helpful, especially since we didn’t know anything about Madison’s disease,” Yoriko said. “They just make you feel better, feel good...like a blanket.”

Madison is in fifth grade and part of the gifted and talented program at her school. She maintains a 4.0 grade point average and is in an Individualized Education Program. She and another girl in her class who also has been diagnosed with Stargardt disease have the assistance of an aide during school hours.

For more information on our services for children, visit NVOKlahoma.org or call (855) 811-9699 to speak with one of our low-vision specialists.
Youth Programs

Every child and teen deserves to experience summer camp, but for many visually impaired youth, summer camp is out of reach. Camp has been proven to enhance self-confidence, encourage personal growth, and foster teamwork skills—and camp experiences often play a major role in identity formation.

In 2000, NewView held the first ever OWL Camp (Oklahomans Without Limits). Since then, we have expanded camp to include one week-long camp for younger children and another for teens. Our OWL Camps are the only camps of their kind in Oklahoma, and over the past 19 summers, our OWL Camps have grown to host campers from across the state of Oklahoma.

At both of our OWL Camps, we challenge societal and self-imposed limits through a variety of activities including rock climbing, kayaking, horseback riding and more. Our teen campers have the opportunity to water ski, tube and enjoy other lake activities—just like their sighted friends. Each activity is designed to encourage collaboration and improve confidence and independence.

OWL Camp is free to campers, many of whom are low-to-moderate income. Support from donors like you makes these camps possible. Please consider contributing to our OWL Camps today—your generosity will change the life of a visually impaired child.

If you would like to support a child at camp, or your organization would like to sponsor our OWL Camps, please contact Sarah Frey at SFrey@newviewoklahoma.org or fill out the enclosed donation form and mail it back.
Globe Life Donates Lake Tenkiller Facility to NewView Oklahoma

On Monday, January 28, Globe Life and NewView leadership and Board members met at Lake Tenkiller in Cookson, Oklahoma as Globe Life handed over the keys to their 3-acre waterfront property.

Globe Life has donated their corporate meeting facility, complete with a caretaker’s cottage and guest house on a 3-acre waterfront property that is valued at $1.8 million. The donation is one of the most significant gifts in the history of Globe Life.

“We became aware of NewView’s mission to serve sight-impaired children through various summer camps at lakes throughout Oklahoma, and the donation of the Globe Life property at Lake Tenkiller seemed like a perfect fit,” said Globe Life Direct Response President and CEO Bill Leavell. “Globe Life has used the lodge as a meeting and teambuilding facility for over 50 years. As the company has grown, we’ve outgrown the space, so we are thrilled to be able to pass it on to support NewView Oklahoma. We believe the property will be a terrific venue for NewView’s programs. We can think of no better organization to use the facility to support Oklahoma children.”

This incredibly generous gift will allow NewView Oklahoma to hold our OWL Camps (or Oklahomans Without Limits) for blind and visually-impaired youth and teens on the property for many years to come.

“We are incredibly humbled by Globe Life’s generous gift,” says NewView President and CEO Lauren Branch. “This facility allows us to further enhance the unique experience OWL Camp offers to our clients and volunteers.”

To learn more about OWL Camp, visit nvolahoma.org/community-programs.

The Globe Life Lodge is available to rent!
To reserve the Lodge for your next retreat, reunion or gathering, contact Margaret Godsy at mgodsy@newviewoklahoma.org.
Upcoming Activities and Events

**VITAL Monthly Meeting**
April 17, 2019
NewView OKC Clinic (new location)
4301 N Classen Blvd.

May 15, 2019
Peppers Ranch
3172 Peppers Ranch Drive
Guthrie, OK 73044
11:30 a.m. - 1:00 p.m.

VITAL gives social support to vision-impaired servicemen, women and their families by providing opportunities to build community, share stories, and access helpful resources. The VITAL group includes men and women who have served in every major war since World War II. Attendees enjoy a catered meal and guest speakers, and the group takes quarterly outings to military bases, museums and other venues.

Email info@newviewoklahoma.org for more information.

**NewView Oklahoma Technology Day**
April 30, 2019
NewView Tulsa Low Vision Clinic
5350 East 31st Street #302
Tulsa, OK 74135

Join us as we demonstrate the latest technology that can assist those who are blind or have low vision. Representatives from several companies will be on-hand to demonstrate their newest devices. Attendees will have the chance to ask questions and try the technology while enjoying light refreshments. This event is come and go.

Please RSVP by Friday, April 26 to Dr. Judith Riley at drfoureyes@aol.com or Terry Rairdon at Trairdon@newviewoklahoma.org.

**Keys to Work Transitions Institute**
June 2-15, 2019
Staybridge Suites in Oklahoma City (Airport location)
For ages 16-22

Keys to Work is a collaboration between NewView Oklahoma and other statewide agencies to provide comprehensive services including occupational therapy, orientation and mobility, and assistive technology. The curriculum is designed to prepare young adults with blindness or vision impairment as their primary disability for college and employment.

Email info@newviewoklahoma.org to request an application.

**OWL Camp OKC (ages 8-14)**
June 24-28, 2019
University of Central Oklahoma

**OWL Camp Tulsa (ages 15-18)**
July 19-22, 2019
GlobeLife Lodge, Lake Tenkiller

OWL (Oklahomans Without Limits) Camp is NewView Oklahoma’s free summer camp for kids ages 8-18 who are blind and visually impaired. Camp activities are carefully designed to encourage collaboration, improve confidence, and challenge societal and self-imposed limits through a variety of indoor and outdoor activities.

**Eyes Just Talking**
April 24, 2019
NewView OKC Clinic
4301 N Classen Blvd.
3:30 p.m. - 5:00 p.m.

May 22, 2019
Braum’s Restaurant
4020 N Pennsylvania Ave
4:30 p.m. - 6:00 p.m.

Eyes Just Talking is a peer-run activities group for visually impaired and blind individuals as well as their families and friends in the Oklahoma City metro area. Come enjoy refreshments, topic discussions, camaraderie, and exchange information and resources.

If you have any questions, please contact Katy Ng at kng@newviewoklahoma.org.
Why do I keep seeing things that aren’t there?

By Judy Riley, O.D.
Vision Rehabilitation Optometrist
Tulsa Low Vision Clinic

In 1769, Charles Bonnet, a famous Swiss naturalist, philosopher and biologist, noted that his grandfather, Charles Lullin, was having visual hallucinations. Grandpa Lullin had lost his vision to dense cataracts. His mind was alert and he knew that what he was seeing was not real. He described images of men, women, birds, carriages and buildings of various sizes, shapes and locations. There was no sound associated with these images. Years later, when Charles Bonnet lost his vision, he also saw these visual hallucinations.

Charles Bonnet Syndrome is described as the occurrence of visual hallucinations in patients with good cerebral function secondary to visual deprivation. It is estimated to occur in 11% to 15% of patients with low vision. This number may be higher as patients do not always report that they are having this phenomenon as they do not want to be labeled as having dementia or psychotic problems. Typically, the patient is elderly, with the average age of onset at 78.2 years, but children with rapid vision loss may also have this phenomenon.

Patients report seeing persons, faces, animals, figures, shapes and earlier images of themselves. Some of my patients have recurrent images they see, and the images become comforting. One patient reported a scene of people by a river having a picnic. One patient saw a handsome man on the ceiling. These images may last seconds to minutes to hours. The image is always clearer than the patient’s normal vision because it is reconstructed from the vision they had before their vision loss.

The brain is very busy with vision. We think anywhere from 50% to 70% of the brain is involved with creating vision. When vision is lost, the brain misses the stimulation from the visual input and starts replacing it with hallucinations or dreams.

Visual acuity of 20/60 or worse puts us at risk for this syndrome. Other risk factors are social isolation, shyness, vascular disease, fatigue and stress. Making sure our lives are balanced with rest and interaction with others while maintaining good general health is important. When having these hallucinations, reaching out to touch them, talking to them, moving your eyes and changing lighting can help them go away. I have one patient who finds looking at a ceiling fan helps fade his images.

If you are having these symptoms, be sure to tell your physician so that proper diagnosis can be made. This is not something to be embarrassed by, but a normal phenomenon from vision loss.

Call 1-855-811-9699 to speak with a low-vision specialist or email info@newviewoklahoma.org.

OKC Luncheon

More than 430 people gathered at St. Luke’s United Methodist Church on April 10 for the 10th Annual OKC Envision the Future Luncheon. Cindy Batt and her mother, Betty Batt, served as our honorary chairs.

In OKC and surrounding areas, more than 30,000 people are affected by vision loss, and that number grows every single day. Our annual luncheon helps educate the public about NewView’s programs and helps raise funds to continue our services throughout the state.

If you weren’t able to join us in Oklahoma City, save the date for our 5th Annual Envision the Future Tulsa Luncheon on October 2, 2019, from 12:00 p.m.-1:00 p.m. at the DoubleTree by Hilton in Downtown Tulsa. To RSVP, or if you are interested in hosting a table or sponsorship opportunities, please contact Tiffany Henley at thenley@newviewoklahoma.org or at (918) 933-4075.
Congresswoman Kendra Horn Visits NewView

On Wednesday, February 20, 2019, Congresswoman Kendra Horn spent time touring NewView’s facility and speaking with employees. We were able to talk with her about NewView’s involvement in advocacy and policymaking as well as our hopes for Oklahoma City’s blind and visually impaired community. She also learned about the comprehensive services we provide including our rehabilitation services and community programs. She then toured our manufacturing facility and saw firsthand the extent of our in-house manufacturing process.

After the tour, Congresswoman Horn shared with our employees her commitment to hearing from and advocating for her constituents who are blind and visually impaired. She also held an open question and answer forum, where she responded attentively to each question.

When asked why he continues to give and serve NewView’s mission, Graves replied, “The NewView team exhibits great creativity in pursuing new opportunities.” He continued, “I know when I give to NewView, my contribution will be used wisely and will go a long way to empower the vision-impaired community.”

Beyond his involvement with NewView, Graves is the founder of the Shining Honor Project, a nonprofit initiative that funds the cleaning and restoration of veterans’ headstones while employing adults with developmental challenges. To learn more about this project, visit ShiningHonor.org.

We are grateful for Sarah and John Graves’ deeply humble commitment to serve NewView and are consistently astounded at John’s ability to take an idea and create extraordinary results. We can’t wait to see what he does next.

To receive more information about giving opportunities at NewView, please contact Sarah Frey at sfrey@newviewoklahoma.org.

Why I Give

For Sarah and John Graves, generosity is a way of life. John Graves is the founder of a Tulsa-based valve manufacturing company and The Shining Honor Project nonprofit, and he has been involved with NewView’s board and mission for six years. “John’s involvement with NewView is transformational,” said NewView President and CEO Lauren Branch. “When he gets involved on a project, he takes full initiative, and his generosity comes with priceless counsel.”

Graves was an instrumental partner for launching the groundbreaking Tulsa World workforce development project, where several people with visual impairments are now employed. He says he is drawn to NewView because of its commitment to provide valuable life skills and resources that allow people to thrive, despite the daily challenges that accompany blindness and low vision.

“You have to have a reason to get out of bed in the morning,” Graves said. He believes NewView provides that reason for many Oklahomans living with visual impairments. Whether that means staying in the workplace or aging in place at home, Graves is inspired and compelled by NewView’s comprehensive and age-ranging services that empower people to live full and independent lives.

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