

SIGHTLINES

Changing “WON’T” to “WANT”

Luke was supposed to be patching, but his parents were at their wit’s end at trying to get him to do it. He’d been diagnosed with *amblyopia*, the most common vision problem found in young children before the age of 9 when their visual cortex is fully developed.

Amblyopia affects 2-3 of every 100 children. The good news is that if the condition is found early enough (before age 7) and patching therapy is used (covering the strong eye and correcting the vision in the weaker one to give it a chance to develop),

vision can develop normally. The bad news is that if left undiagnosed or untreated, vision impairment can progress to permanent blindness.

Luke would reluctantly patch at home for short periods of time, but never outside the house. And when he was wearing the patch he didn’t want his parents or siblings to even look at him. He was self-conscious and embarrassed. Did having a *lazy* eye mean *he* was lazy? Was his eye bad? He wanted to fit in with other kids, not stand out and be teased as different.

But all that changed when his parents brought him to a fun kids club at ForSight Vision. There he met Danielle Crull, an optician and founder of A Child’s Eyes, who runs the Amblyopia Support Group with her daughter Jax, also an optician, and Leora Wiest, ForSight Vision’s Director of Prevention Services.

“When Luke came to the patching group four months ago,” Danielle said, “he wasn’t wearing a patch. But he went up to one of the other boys, James, and asked him if he liked wearing a patch. James said, ‘I LOVE IT!’—he was so enthusiastic—he was the best kid to ask about it. The following week, I saw Luke and his mom in my office and his mom said, ‘Luke’s just decided he’s going to wear his patch!’ He was here last night, super excited. He brought some of the games that he does at home when he’s patching to show his other friends.”

In fact, Danielle said, “Peer acceptance is *the number one* best motivation for getting kids to accept patching.” To that end, she has also written a book, *Apple Patty Patches*, that children can read and bring to school to spread understanding



Interaction with other group members helps take the stigma out of patching.

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Message from the President



Helen Keller said:

“Life is either a daring adventure or nothing. To keep our faces towards change and behave like free spirits in the presence of fate is strength undefeatable.”

At the Pennsylvania Association for the Blind, we are very proud of the changes we have helped Pennsylvanians to create—changing lives, changing perceptions, and changing limitations. Whether we are working with an older adult seeking to learn the skills necessary to continue living alone after vision

loss, a high school student who needs help making the transition from high school to college, a working-age adult who needs training with access technology to obtain employment, or a family member trying to cope with the challenges brought on by vision loss in a loved one, we are there to help with these critical life changes.

Every day, people experiencing vision loss deal with change. Every trip to a new doctor, a new grocery store, restaurant, or shopping mall brings change. And yet, every day

our clients deal with this change, they overcome their fear of it, and they succeed. The Pennsylvania Association for the Blind is here every day to help Pennsylvanians acquire the skills they need to rise to the challenge.

Like the people we serve, each day brings change for all of us as well. We are continually challenged to create new programs and meet the changing needs of our community. But we don't do it alone. We do it with the help of a dedicated staff of volunteers and with the help of people like you. Thank you for your support.

Sincerely,

Elaine Welch
President/CEO

Throughout July 2015, across the state of Pennsylvania, several of the member agencies of Pennsylvania Association for the Blind will present the inaugural Vision Bowl. This event will not only raise funds to support services provided to blind and visually impaired individuals in Pennsylvania, but will provide information to participants about visual impairment and enable them to bowl with a simulated impairment.

The following agencies will be holding Vision Bowl events:

- Beaver County Association for the Blind
- The Blind Association of Butler and Armstrong
- Bucks County Association for the Blind and Visually Impaired
- Community Services for Sight (serving Carbon, Southern Luzerne, and Schuylkill counties)
- Fayette County Association for the Blind
- ForSight Vision (serving Adams and York counties)
- Lackawanna Association for the Blind (serving Lackawanna and Susquehanna counties)
- Venango County Association for the Blind (serving Clarion, Forest, and Venango counties)
- VisionCorps (serving Chester, Lancaster, Lebanon and Somerset counties)
- Vision Resources of Central Pennsylvania (serving Cumberland, Dauphin, Franklin, and Perry counties)

In addition to awarding prizes to the winners of the individual events, the agencies will be competing for the Vision Bowl trophy which will be presented at the PAB fall conference.

For dates, locations, and links to registration materials, please visit the events page of our website at www.pabind.org/event/vision-bowl.



Take a Chance!

Rick Roth is a man on a mission. He wants to help people who are newly blind or visually impaired overcome their fears and regain confidence in their abilities. He wants more employers to open their doors to them.

He speaks from personal experience. He was just 43 and working as a furnace operator for a train car axle manufacturer when he had a freak accident: he plunged from six feet, landing on his back. From that moment, his life was forever changed.

When the drugs and anesthesia wore off from a grueling 11-hour surgery spent facedown, he discovered he had lost all of his sight.

He had worked hard to build a life for himself. In addition to his job at the steel mill, he also ran a small used car lot and a pizza shop. Now, in addition to losing his health and vision, he lost his work and businesses.



Rick's O&M training allows him to navigate the aisles like a pro.

Like many people who go through traumatic experiences, it took him time to adjust. He was angry and despondent. And being independent and self-motivated by nature, he resisted help at first. But then, he *saw the light*, and decided to *learn how to be blind*.

Pennsylvania Association for the Blind member agencies taught him orientation and mobility skills so he could get around safely using a white cane. He found he was really good at it. He learned braille and independent living skills so he could cook, do laundry, and other tasks. "You have to go in with the right attitude," he said. "If you have a negative attitude, you won't get anywhere. I'm not afraid to take a chance on something, and I just kept trying. When I succeeded, it gave me the confidence to try the next thing."

When he finished preliminary training, he got an apartment and volunteered cooking at his church's funerals for two years. He attended a week-long cooking course and they encouraged him to come back to take the full course and become a chef. "If you don't try something, you'll never know if you can succeed," he said.

When his mobility teacher suggested he consider becoming a licensed massage therapist, he found his calling. "They taught me how to start my own practice. But when I graduated, they hired me! After a year and a half, I went into private practice and created *Out of Sight Therapeutic Massage*. I've been doing massage for eight years now, and I love it! I love helping people. I can feel their trigger points and work out the knots in their bodies to reduce stress and pain."



He's not stopping there, though. He's passionate about helping others deal with the challenges of disability. He speaks publicly, and may one day write a book, or even go into politics. "All doors are open," he said, "It just has to come together, one step at a time. There's always room to expand. You have to sit down, look at your skills, plan out what you want to do, and then keep pressing on. You can always keep on learning. The thing is, we all need to come together to help one another. We come into this world with nothing, and we're leaving with nothing. Instead of focusing on material things, we should be helping our brothers and sisters as much as we can. We need to encourage them, pat them on the shoulder, and say, *Hey, you can do this...one step at a time.*"

PAB member agencies assisting Rick were: Blind and Vision Rehabilitation Services of Pittsburgh, VisionCorps, and the Blair/Clearfield Association for the Blind and Visually Impaired.



Changing “WON’T” to “WANT” *(continued from page 1)*

and acceptance of patching among their peers.

“The *second* biggest motivator, my parents tell me, is PIP,” Danielle said. “Our Patching Incentive Program reinforces the behavior by rewarding kids with a sticker every time they patch. When they fill up their page with stickers, they can bring it in and choose a prize. I’ve had parents say, ‘Thank You, Thank You, Thank You for this program!’ It changes the family dynamic from one of nagging and punishment to positive rewards and fun.”

Bill Rhinesmith, President and CEO of ForSight Vision, said the partnership with Danielle opened his eyes to gaps in blindness prevention efforts. “ForSight has had a screening program for 30 years. We screen 3,000 children a year, but I’ll be honest with you, we were referring children with amblyopia to professionals and just assumed their vision problem would be taken care of. We learned that was not the case.”

“Doctors have lots of patients to see and a limited amount of time to spend with them,” Bill said. “The doctors are familiar with amblyopia, but the parents aren’t. The parents hear ‘*There’s something wrong with your child!*’ and go directly into: ‘*Is my child going to go blind?*’ ‘*What did I do? Is it my fault?*’ ‘*Will my child need surgery?*’ without really understanding what they are being asked to do.”

“The real work happens — or doesn’t — when the parents get home. It’s a serious problem,” Danielle said. “There are studies showing that around 20% of parents are patching the wrong eye! They are

unclear on the concept that they should patch the strong eye so the weaker one will get used and develop. They go home from the doctor’s office and try to Google *amblyopia*, and don’t know how to spell it. They may not see the doctor again for 3-4 months, and when they do, the doctor is alarmed by the lack of progress and the child’s eye is one step closer to permanent damage.”

And then there is the lack of understanding from classmates and the public. Danielle said, “I’ve had parents tell me that *well-meaning* strangers will come up to them in the grocery store and say, ‘Oh, that’s such a shame about your child’s eye!’ Other kids will say, ‘Do you have an eye under that patch?’ That can be hard for the parents and the child to hear, and it makes patching in public harder to do. I like to empower both parents and kids by giving them everything they need to deal with a situation.”

The support group provides patching themes and fun activities for the children, with graduated games so every child can both succeed and be challenged. It also offers Danielle the opportunity to explain the condition in depth to parents and answer their questions. And it gives parents a chance to compare notes, suggest tips, and offer encouragement to each other.

Without vision screening programs, amblyopia is sometimes misdiagnosed in schools as a cognitive or learning disability. Children fall behind in their studies and may become at risk of dropping out. Scarce teacher time, funding, and special program resources are wasted without

addressing the real problem. And then, when blindness occurs, expensive surgeries, drugs, and programs to assist the blind take over — a situation that could have been prevented cheaply and effectively.

Recognizing the value of childhood screening, the Pennsylvania Association for the Blind worked to close the gap. “PAB secured statewide funding from the Bureau of Blindness and Visual Services to conduct a children’s eye safety program called Prevention of Blindness. We were able to increase the capabilities of our member agencies and together were able to offer eye screening free-of-charge to 65,000 people throughout Pennsylvania,” said PAB Executive Director Elaine Welch. “ForSight Vision’s Amblyopia Support Group takes that effort one step further, and is a wonderful model.”

“When health care professionals, nonprofits, government agencies, families, and communities collaborate, we can close the gaps in care, change people’s perceptions on health and disability, make the very best use of resources, and ensure that every child has what he or she needs to succeed in life,” Elaine said.



Parents are encouraged to participate in the group’s activities.