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Surgery helps amazing youth

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You can always tell when kids are back in school after Christmas break. They've got on new jackets, new jeans and gleaming white sneakers given to them over the holidays.

When Luke O'Lena returned to Kankakee High School after Christmas break this year, he was wearing a new ear.

Born with birth defects that left him without a right ear, among other things, Luke has undergone well over a dozen surgeries. Four of them were to try to rebuild the tiny stub of an ear that always set him apart from the other kids.

The reconstructions cost the O'Lena family a quarter of a million dollars, but they didn't realize there were other options, until the day Luke and his mother, Karen, were home watching Montel Williams. They learned of a man in Virginia named Robert Barron who was giving people with deformities their lives back.

Stricken by cancer that has eaten away their nose, deformed



from an accident, or burned beyond recognition, patients from across the world have sought Barron's expertise for over a decade now. A former senior disguise specialist with the Central Intelligence Agency, Barron runs Custom Prosthetic Designs, the studio that creates prosthetic eyes, noses, ears and faces.

"There's no better feeling than to give someone back the quality of their life," Barron says.

Especially when it's a kid like Luke. Read about his remarkable story and the new ear that has changed his life in **Accent on Health, page C1.**



Journal/Mike Voss

LUKE O'LENA waits for his friend Jenny Vaughn to catch up with him in the halls at Kankakee High School. Up until Christmas, the St. Anne boy has had to live with a partial "seahorse" of an ear his entire life. Now he wears an auricular prosthetic (top photo) that is nearly identical to his other ear.

Luke's new ear

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Journal photos by Mike Voss,
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KAREN O'LENA OF ST. ANNE did everything right when she found out she was pregnant with twins. She ate healthy, took extra special care of herself, and never missed a prenatal appointment. But a mother's worst nightmare came true for her when Luke emerged from the womb, 11 minutes after Sara.

Nothing Karen could have done would have prevented Luke's birth defects. He was born with a hemifacial microsomia, a rare condition that left the right side of his face oddly disproportionate to the other. His cheek was crooked and caved in, his lip was pulled up tight toward his ear, and a facial cleft left his lip split to his nose and his tongue back to his throat. Worst still, Luke was born deaf, missing a right ear.

Throughout his childhood, Luke underwent dozens of surgeries — several to build a normal-looking ear. He had some of the best surgeons at the University of Chicago, but reconstructing an ear that will stand out on its own is a difficult science. After four surgeries, Luke still had a stub that set him apart — a sliver of skin compared to the well-defined curve of a normal person's ear.

But that was before they met anaplastologist Robert Barron who gave Luke a new ear.

A LIFETIME OF SURGERIES

Luke is just 17, a senior in high school, but he's already undergone well over 20 surgeries. The first was when he was just 9 months old. Most have been done to improve facial symmetry left distorted by the hemifacial microsomia. He has undergone procedures for the cleft lip and cleft palate. He has had septoplasty and rhinoplasty, along with three jaw reconstructions using bone taken from his skull and ribs. Without the surgeries, he would have difficulty eating.

The surgeries on his ear weren't merely for cosmetics, either. Luke started wearing glasses at the age of 5, and without the sturdy ledge of an ear his glasses often sat lopsided. Even with the help of a headband, it made everyday enjoyments like playing soccer difficult.

The operations couldn't restore his hearing — Luke was also born without the ear canal in his right ear — but it would help bring him closer to looking like a normal boy. He was 8 when doctors first started working on the stub, taking skin from his belly, groin and thigh to use like sculptor's clay in forming a new ear. The results were considerable, but the ear remains an



MATH TEACHER Matthew Glenn speaks into a microphone which transmits a signal to the receiver attached to Luke's good ear. It allows Luke, who is mostly deaf, to follow along with the rest of the class.

odd-shaped "seahorse."

The O'Lena family has had its share of suffering. Besides Luke's misfortune, Karen lost both her breasts to cancer several years ago. But despite the hardships, the O'Lenas keep a bright outlook.

Their oldest son, 20-year-old Evan, is in the process of securing a job. Sara, Luke's twin, is heading off to Columbia College in South Carolina to study journalism.

Luke will also be attending college this fall. Over the years, he has missed months of school due to all the surgeries, but he remains an A student, in the top 15 percent of his class. He has won over \$4,000 in scholarships to MacMurray College in downstate Jacksonville. A superb artist, whose work is often seen hanging in the halls at school, he will study architecture. He says he wants to design skyscrapers one day.

Luke is mostly deaf except for partial hearing in his left ear achieved with the help of a device. But he compensates by reading lips fluently, and supplementing with sign language. He uses an interpreter at school, and this will continue at college. Right now, Karen serves as his note-taker during the day.

"All his functional surgeries, we had to do," says Karen. "But if I had known about that man in Virginia, I never would have done the ear surgeries."

Fate led them to Robert Barron. Karen, home recovering from a hysterectomy, saw him on TV. She and Luke were watching Montel Williams, whose guest was a

young girl with the same condition as Luke. She had gone through numerous surgeries to reconstruct her ear, but none had been as satisfying as the auricular prosthesis Barron created for her. It was just a plastic appendage, but it had changed her life.

Karen called the producers of the show, got Barron's e-mail, and he responded the very next day. They sent him Luke's senior picture, and soon after learned the good news. Barron could create a new ear for Luke, too.

THE TRIP TO VIRGINIA

Barron began work as a senior disguise specialist with the Central Intelligence Agency. It was an important job — agents' lives depended on him to give them an entirely new identity.

Born and bred downstate and a Southern Illinois University graduate, Barron worked for the CIA for nearly a quarter century. When he retired in 1993, he knew exactly what his next "assignment" would be. A few years earlier, he had attended a biomedical sculptors seminar where he learned how his disguise skills could help restore severely disfigured faces of people. He knew he "could give them their life back."

Today, Barron runs Custom Prosthetic Designs, Inc. out of his Ashburn, Va., studio. He works strictly with burn victims, cancer patients and kids like Luke. Many of his clients are people so horribly disfigured it has robbed them of all their pride.

"There's no better feeling than to give someone back the quality of their life," Barron says. "I know that I'm going to change this person's life. They don't know it, but I know it."

His work has been featured in magazines like *People* and *National Geographic*, and on television shows like *Oprah* and *Montel Williams*. He has created eyes, noses, fingers, ears and even full facial masks, and he was determined to give Luke a new ear.

Barron was particularly interested in helping Luke because he believes reconstructive ear surgery should be abolished, particularly on children. Reconstructions seldom look like a normal ear because of insufficient tissue and cartilage needed to get the ear to stand away from the head, the abnormal color of tissue, and the possibility for scarring.

"The outcome always falls short of everyone's expectations," he believes. "You cannot recreate an ear."



Luke's left ear, his real one.



Luke's prosthetic ear, his right one.



Hyland Collins, left, and Luke O'Lena talk soccer in the Kankakee High School library. Luke, born without a right ear, recently received an auricular prosthesis that has helped him feel like any other kid.



Photo courtesy Custom Prosthetic Designs, Inc.

ROBERT BARRON creates prostheses at his Ashburn, Va. studio. A former senior disguise specialist with the Central Intelligence Agency, Barron makes all kinds of body parts, from noses, eyes and full faces to ears, like the one Luke O'Lena of St. Anne now wears. Barron's work has been featured on Oprah, in *National Geographic* magazine in *People*.



LUKE O'LENA of St. Anne listens intently during his precalculus class. Luke was born without a right ear, but now has a special prosthesis that is a near replica of his normal ear. He has partial hearing out of his left ear with the help of a hearing aid.

Luke

continued from C1

Unless one is reproduced using plastic. In October, the O'Lenas traveled to Ashburn, a suburb of Washington, D.C., for the initial impressions. Barron duplicated Luke's healthy ear using a mold and then reversed the image and created a clay sculpture. The sculpture was molded and an elastic material cast to replicate the image.

Once set, a prosthesis is hand-painted and tinted to resemble the patient's skin tone. They're all made of a soft, durable silicone, and usually attached with an adhesive.

Barron says Luke's ear took about three weeks to create. It cost which Karen says will be mostly paid for by her husband John's insurance through Arm-strong. That's just change, though, she says, compared to the \$250,000 it cost for the four reconstructive surgeries. Factor in recovery time, and the intangible costs are even higher.

The O'Lenas returned to Virginia in December for the fitting. The silicone prosthesis attaches to Luke's head with adhesive and looks unquestionably real. The shape and size is a near replica of his normal ear — right down to the pores and the veins. It was hard to describe the joy the family felt when Luke first glued it on.

"I was in shock. I was speechless," Luke says. "The way he matched it and the way he fit it was amazing — a jaw dropper."

BACK TO SCHOOL

While many of the kids at Kankakee High returned from Christmas break wearing new jeans and sneakers, Luke returned wearing his new ear. His mother says it is the best Christmas present he's ever gotten.



Journal/Mike Voss

INTERPRETER MARY SMITH signs during class for Luke, who is hearing impaired. Luke has to rely on help during school, but thanks to an ear prosthesis he doesn't have to worry about unwanted stares because he was born without a right ear.

► **For more info on Barron's work visit www.prosthesis.com**

Luke's easy-going nature, wit and charm have allowed him to make friends easily over the years. But there have always been — and always be — kids that are cruel.

His new ear has given him a clean slate as he heads off for college. Already, he's noticed more students walking with him in the halls or chatting him up during study hall.

"Most people have been talking to me," Luke says, showing his school pride in a MacMurray sweatshirt.

Karen thinks perhaps it's also because Luke is more comfortable with himself. She notices he carries himself differently. He's more confident and sociable. He's

even started talking to girls.

In reality, Barron wishes he'd never had to make that ear for Luke, or any of the other noses, fingers or full faces he's made for clients. The prostheses, he said, are more for the outside world than they are for the patient.

"People just can't look at a disfigured face, and that hurts," Barron says.

If society would accept those who are different, there really wouldn't be a need for his services, he believes. But there is, and truth be told, he says it can be very gratifying — especially when you're working with a boy like Luke.

"He's so intelligent," Barron says. "When he came in here he didn't have that smile on his face, but when he walked out, he had a smile."

A smile, if you will, from ear to ear.