

## Getting used to the stares is a common burden for those born with facial abnormalities

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By Mark Roth, Pittsburgh Post-Gazette



Mark Roth/Post-Gazette

David Roche and Marlena Blavin of Vancouver, British Columbia.

Several years ago, David Roche was walking to work in San Francisco when he saw a well-dressed man approach him.

The man stopped, made eye contact -- then spit in Mr. Roche's face.

"You are the ugliest thing I have ever seen," the man said, and walked on.

Mr. Roche, who was born with a disfiguring tangle of blood vessels that affects the left half of his face, fumbled for a Kleenex.

"And then," he wrote in his memoirs, "without planning, without thinking, I yelled, 'You are ugly in your heart.' "

Until that moment, Mr. Roche had never stood up for himself when anyone said something cruel or insensitive about his appearance.

But with his defiant reply, he wrote, "I stopped standing to the side."

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Thankfully, most people who are born with facial abnormalities will never live through such an ugly encounter.

But they will have one thing in common: Wherever they go, people will stare.

Mr. Roche, a 66-year-old resident of Vancouver, British Columbia, who speaks all over the world about facial differences, has certainly experienced it.



So have Nick Wiese, a 22-year-old from Marshall, who was born with Apert syndrome, which distorts the shape of the face, hands and feet, and Peter Townsend, a 65-year-old retired probation officer from Collier, who has neurofibromatosis type 1, which has covered his face and body with hundreds of fibrous bumps.

While each man has been through painful medical procedures, their daily social interactions have been their biggest challenge.

"The thing that's difficult is the constant attention," said Mr. Roche. "It's the double-takes, the stares, the averted stares, the comments -- just constant reminders that I'm weird. If you live in that kind of world, you can start taking it on and put up emotional barriers."

An estimated 100,000 children are born in the United States each year with facial abnormalities, said Anna Pileggi, executive director of AboutFace International, a Toronto-based group that educates people about facial differences.

Many of them, even after plastic surgery and other treatments, will have to come to terms with the fact that "this is who I am, and I have to accept this," she said.

Mr. Wiese, Mr. Townsend, and Mr. Roche have all reached that plateau, each in his own way.

David Roche's journey has been the most visible.

Since 1990, he has made public appearances to talk about his face and the lessons it has taught him, sometimes alone, and sometimes with his wife, Marlena Blavin.

His memoir, "The Church of 80% Sincerity," is largely based on his one-man show. The title comes from the idea that we cannot be perfect and should never try to be.

"As a practicing member [indeed, the beloved founder] of the Church of 80% Sincerity," he wrote, "I have come to accept my gifts as well as my flaws. And to see that sometimes they are one and the same."

His goal, he said, is to teach anyone to "learn to accept yourself with your body's perceived imperfections and all your inner ones as well."

In an interview at his home nestled in the woods near Vancouver, Mr. Roche said that when he was born in Hammond, Ind., in 1944, the only sign of his condition was a slight discoloration of his left eyelid.

But at 15 months, "the bottom part of my face kind of blossomed into what my father described as a small bunch of grapes." Doctors diagnosed a venous malformation, a swollen mass of blood vessels that affected his jaw, temple, tongue and palate.

He ended up at the Mayo Clinic in Minnesota, where the treatment of the day was surgery and radiation. In a technique that is no longer used, doctors put several radon



Some people never have the luxury of being average.

If they are among the 100,000 people born each year in America with facial abnormalities, they may never blend into a crowd, even after years of surgery.

In this installment of our continuing series, "About Faces," we look at three people who have faced up to their faces -- and gained wisdom in the process.

• PG Slideshow: [Getting used to the stares](#)

• Yesterday: [Their faces were gone](#)

seeds under his skin, some of which are still there. His disfigurement is the result of both his inborn condition and that damaging therapy.

The left side of his face is discolored. His lower lip is gone. He wears dentures. But none of it is life-threatening.

"There's dysfunction," he says, "but it's not like there's real disability."

He lived much of his life in denial of his facial differences. While his family members encouraged him to be active and to pursue his goals, they didn't talk about his face. He didn't either.

"Without having dealt with my appearance," he says, "I headed into the world with a lot of emotional armor on."

He covered up his pain in obsessive ways. He exercised maniacally. He took up gardening, fiercely eradicating any sign of weeds. And he turned to drinking, to "blot out my fears and doubts."

He also struggled with how to relate to women. After an early, failed marriage, he had only sporadic relationships until he met Ms. Blavin in the late 1980s, when they were both training to do massage for hospice patients.

Falling in love with Ms. Blavin, standing up to the man who spit at him and deciding to stop drinking all marked critical turning points in his life.

That's when he decided to try a humorous one-man show, using the material he knew best: his face and what it means to him and the world.

He now makes his living with these talks. As he's perfected his presentation, he's learned that for the first 10 minutes, people just need to stare at him.

"I often begin by saying I'm a little nervous, even though I've performed around the world, so when I count to three, I want you to say, 'What happened to your face!?' And people do it."

His main message is that we all feel distorted and inadequate in some way.

"Everybody wants to know, 'How do you do it? How do you feel so good about yourself when you look so messed up?'"

"So I feel like I do have some responsibility to answer that question. People with facial differences are given access to a certain part of the human experience, that everyone feels disfigured. And it took me years to realize that."

Mr. Roche and his wife often appear together before groups of middle school students, who are at a point in their lives where the couple's message is especially meaningful.

The girls are particularly fascinated with how Ms. Blavin became attracted to Mr. Roche.

"I kind of take them through my thinking, how what I really wanted to do after I met David was stare at him," she said, "and then I wondered if he had a girlfriend and what would it be like to kiss him, and I make it OK, because they're thinking the same

things."

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Like Mr. Roche, Peter Townsend has had a lifetime to adjust to his condition and gain some wisdom about it.

In high school, he could cover the few tumors he had on his body and arms with a long-sleeved shirt. The bumps on his face didn't appear until he was in his early 30s.

There are two types of neurofibromatosis, said Amy Goldstein, a neurologist who directs the neurofibromatosis clinic at Children's Hospital of Pittsburgh of UPMC.

NF 1, the type Mr. Townsend has, results in scores of fibrous, noncancerous tumors all over the body, multiplying particularly when patients are middle-aged. NF 2's tumors are internal, she said, and can be much more damaging, causing everything from hearing loss to epileptic seizures to partial paralysis.

With NF 1, Dr. Goldstein said, one of the more dangerous threats is tumors growing on the optic nerve, which usually occur in the first 10 years of life.

Mr. Townsend has been through that.

Doctors removed his right eye at age 3, and when he was in elementary school, they removed larger tumors on his shoulder and neck. Later, in high school, doctors removed a tumor on his spinal cord that threatened to paralyze him.

Since then, he has faced no serious problems from his neurofibromatosis. His burgeoning tumors don't usually cause pain, although he occasionally has had doctors remove some of them when they become infected or start to bleed.

He credits his ability to handle the way people react to his appearance to his strong-willed, supportive mother, a group of close friends while growing up in Ben Avon, and his wives -- Wanda, who died of cancer in 1997, and Marilyn, with whom he now lives in the Nevillewood subdivision.

Mrs. Townsend, a retired second-grade teacher whose own husband died in 1991, met Mr. Townsend through a personal ad. As he had done with other women he dated, Mr. Townsend told her about his condition during their first phone call.

The next night, she invited him to a concert. She looked up neurofibromatosis on the Internet, but couldn't find any pictures.

"So I have to say I was stunned when I first met him," Mrs. Townsend said, "and I was aware of people looking at us, but once I got beyond that, I was fine, because that night was special."

Mr. Townsend thinks his wife's reaction says a lot about how men and women respond to people's looks.

"I know two women with NF, and neither one is married. I think the impact is much more on women than on men. I guess most men view women as sex symbols, and

women, like Marilyn, see more than beauty, like my charming personality ... "

"Anything you say, Pete," Mrs. Townsend said, laughing.

In their nine years of marriage, Mrs. Townsend said she has become "very protective" of her husband.

"If people start to stare, I give them my 'teacher look,' " she said.

Young children are the most open in their curiosity. On a recent vacation in Alabama, they said, a 4-year-old girl approached Mr. Townsend at a museum and immediately began to stroke the bumps on his arms, much to her mother's consternation.

"I held her hand and told her mom it was all right for her to talk to me this way," Mr. Townsend said. "I told the girl that kids who have NF say it means 'no fun,' and she said to me, 'I bet it was no fun for you.' "

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Mr. Wiese also can't escape the attention of young children.

He works as a ticket taker at the Cranberry Cinemas on Route 19, where he faces a steady stream of customers of all ages.

Mr. Wiese's face doesn't attract as much attention as his hands, which consist of a thumb and two digits on his right hand and a thumb and one digit on his left.

"Mainly it's little kids who ask me, 'What's wrong with your hands?' because I'm ripping their tickets for them. Usually before I can answer, their moms yell at them for asking the question.

"But if I get a chance to answer, sometimes I'll say it's the way God made me, or it's the way I was born."

Apert syndrome is one of several conditions that cause premature fusing of the bones of the skull. It also causes malformations of the feet and hands and a sunken midface, which gave Mr. Wiese a severe underbite.

His unusual appearance made it hard for some children to accept him when he began school in the North Allegheny district, but over the years, he became close to many of his classmates.

In his senior year of high school, he wore a metal apparatus on his head to help align his jaws, and even had it on during his graduation ceremony.

The procedure he went through, known as rigid external distraction, has been the fastest-growing surgical technique in recent years for young people with facial abnormalities, said Charlene Smith, executive director of the Children's Craniofacial Association in Dallas.

A semicircular hoop was screwed into his skull, and a vertical piece was then attached to his upper jaw, pulling it forward over several weeks to let new bone grow in behind

it.

In recent years, Mr. Wiese has become active in the craniofacial association, attending several of its annual retreats. The actress Cher is a sponsor, motivated by her award-winning role as the mother of a boy with a severely malformed skull in the 1985 movie, "Mask."

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Jeanne McDermott, a Boston area science teacher and author and the mother of 19-year-old Nate, who also has Apert, has thought a lot about the way people treat children with facial differences.

"When I had Nate, I lost my anonymity as a parent," said Ms. McDermott, who wrote a 2000 book, "Babyface -- A Story of Heart and Bones," about his birth.

"The experience I had going around with a little baby with a facial difference was exactly the same experience I had as the first woman in the carpenter's union in New York or being the only white woman in a neighborhood that was completely black.

"The majority stops and stares, which is entirely what you would expect, and what I learned was that the stares stopped once they got to know you."

People who encounter a person with facial disfigurement often go through four levels of fear, Mr. Roche believes.

The first is "What do you say to someone who looks different? There's a fear of being socially inept."

Some people worry about whether the person has a contagious disease. Others may unconsciously associate facial abnormalities with evil, he said, because "most every disfigured character in the movies or TV has a chainsaw and that feeds into the idea."

"But the deepest fear," he said, "is that there's something wrong with them. The one thing I feel that I've learned is that everybody feels disfigured. It doesn't have to be a facial or body thing, but it relates to the fear of being unworthy.

"That's what makes our work powerful," he said. "I'm someone who has that difference right out there full blast, and yet I have confidence in myself, and that's redemptive."

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