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## MUSIC LIGHTS A FIRE



Twelve-year-old Ben Monkaba belts out *Do-Re-Mi* from *The Sound of Music* during a Broadway-style revue for parents and staff on the last night of camp.  
[Times Photo: Jamie Francis]

**People with a mysterious disorder attend a Massachusetts music and arts camp every year to revel in music, which for them is not just a pleasure but a passion.**

By **DAVE SCHEIBER**

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LENOX, Mass.

**H**ere in the gently rolling Berkshire hills of Western Massachusetts, the landscape blossoms with lush foliage and a legacy of music.

This is the picturesque region James Taylor sang of in his classic *Sweet Baby James*. It is the area where Arlo Guthrie drew the ire of police for littering, inspiring his legendary anti-war saga, *Alice's Restaurant*. It is the place the Boston Symphony Orchestra calls home each summer at the internationally renowned Tanglewood festival.

But for the past five years, the musical personality in these parts has evolved

with new depth and significance.

Nestled on a wooded ridge in the 200-year-old town of Lenox, Belvoir Terrace Fine & Performing Arts Camp has become a magnet for professional musicians -- and leading geneticists.

That is not because Belvoir Terrace, with its world-class instructors from Juilliard to Berklee School of Music and beyond, ranks as one of the country's top music and arts camps. The intense interest is tied, instead, to a one-week gathering that follows the regular camp session.

Every August, Belvoir Terrace opens its doors to some 50 people who have a rare genetic condition called Williams Syndrome. They share a unique array of traits that include heart problems, a pixie-like facial appearance, mental ability from low average to mildly retarded, excellent verbal skills, a gregarious demeanor. And one more thing: a passion for music.

The man who identified the syndrome in 1961, a New Zealand doctor named J.C.P. Williams, knew nothing about the music characteristic. Several years after publishing his paper on Williams Syndrome, he was spotted boarding a train in England, never to be seen or heard from again.

But while mystery enshrouds Williams himself, scientists are painstakingly peeling back the mystery surrounding Williams Syndrome. What they have found is critical not only to helping people with Williams; the research is providing important insights about how the brain works, how we learn to speak, how our personalities are formed.

Scientists are fascinated by the remarkable verbal skills of most Williams people. They are confounded, too, by the music connection. Many Williams individuals have perfect or relative pitch. Almost all have a love of music that approaches the spiritual.

"Music lights a fire in me and I feel it go right through my system!" says Christian Lawson, 24, a pianist from Connecticut. "It's like I'm in paradise."

## Paradise



For enlargements  
click on photos.

[Times photos: Jamie  
Francis]

Beneath a thick canopy of maple, white birch and pine trees at Belvoir, landscaped in part by the man who designed New York's Central Park, the hills truly are alive with the sound of music.

In bungalows, with little signs outside practice rooms labeled "Carnegie Hall" and "Lincoln Center" and "The Bottom Line," voices singing pop and classical mingle in the cool New England air with echoes of piano minuets, clarinet solos and rhythmic drum riffs.

The spacious drama studio bustles as Williams Syndrome Music and Arts campers work with professional instructors to rehearse adaptations of Broadway hits *My Fair Lady* and, fittingly, *The Sound Of Music*, for a Saturday night grand finale.

Sitting in the bleachers during a rehearsal, Terry Monkaba watches her son Ben, 12, on the floor below and smiles. Monkaba is executive director of the 7,500-member Williams Syndrome Association. Ben, an adorable orange-haired boy with boundless enthusiasm, had multiple heart surgeries before he was 2. He is small for his age, fragile-looking.

But Ben stands tall musically. As a drummer, he handles complex 5/4 beats and advanced stylings. As a singer, he projects joy and presence. Finishing his solo of *Do-Re-Mi*, Ben displays a stage persona as big as P.T. Barnum, yelling, "Yeah!" and thrusting two thumbs skyward.

"I look around here this week and there are 57 kids," says Monkaba. "Are there 57 ultra-talented kids here? No," she says. "Are there 57 kids who really are touched by music? Absolutely. And I think that's the key."

Ben and his fellow campers have just breezed through their parts with one of several film crews hovering over them. The campers are at home before the barrage of film crews -- from *Nightline* to French public television. Most are hams at heart with ample media experience. Last year, *60 Minutes* filmed a segment. Two years ago, noted neurologist Dr. Oliver Sacks was here to film a BBC documentary. Sacks, whose PBS special *Oliver Sacks: The Mind Traveler* will feature Williams Syndrome on Sept. 15, told the *Boston Globe*: "I haven't seen this much group enthusiasm for music since seeing a Grateful Dead concert."

Awareness of Williams Syndrome is growing. A national convention is held every other July, and a Southeastern regional meeting will be held in St. Petersburg next month.

Much is still new and unfolding. It wasn't until 1993 that the link was established between music and Williams individuals. That, in turn, paved the way to the creation of the camp a year later. Undergirding it all is the notion of discovering untapped potential in any person with special needs.

"We have found ways to understand Williams people and that has allowed us to help them realize potential that was once never thought possible," says University of California-Irvine professor emeritus Dr. Howard Lenhoff, who helped create awareness of the connection between music and Williams Syndrome. Lenhoff's work was fueled by his 43-year-old daughter, Gloria, an acclaimed Williams performer who can sing powerfully as an opera soprano in 25 languages.

"The same principle applies with other handicapped people," Lenhoff adds. "Everybody focuses on what they can't do instead of what they can."

### **The Church On The Hill**

An air of excitement pulses through the well-worn wooden pews inside one of the oldest churches in Massachusetts.

The Church On The Hill is aptly named. Perched atop the main street of town, it has presided over Lenox since 1806. This is a special day for the historic church, whose pastoral, post-Revolutionary War cemetery adjoins the Belvoir Terrace property.

A van has just arrived from the camp next door, and 16 eager people with Williams Syndrome take their seats. It is the first time that Williams campers have staged a public show in Lenox, and several dozen residents have turned out to watch.

One by one the campers happily introduce themselves and perform their pieces. John Libera, a 17-year-old from Massachusetts, studiously grasps his clarinet and eases through Leonardo Vinci's *Sonata No. 1*. The crowd applauds wildly as Libera motions to his piano accompanist from the camp staff. Little Ben Monkaba from Michigan throws his whole body into a spirited rendition of *I've Got No Strings*, and thrusts his thumbs sky-high to a huge ovation.

Christian Lawson announces calmly, "I'm doing the *Skye Boat* song; I hope you like it, it's real pretty." He plays it beautifully on the piano, then stands and salutes his appreciative audience with a full military flourish.

The musical love fest  
continues for an hour --  
Gloria Lenhoff of  
California enchants the  
gathering with Puccini's *O  
Mio Babbino Caro*; Kate  
Bove of Vermont, a pixie-  
ish 10-year-old, dips and  
waves gleefully through  
Rodgers and  
Hammerstein's *My  
Favorite Things*; Meghan

Finn, a Michigan 21-year-old, offers a smooth, sultry adaptation of Bette Midler's version of *The Glory of Love*; and 19-year-old Canadian Lisa Walsh displays a soaring, show-tune voice on another Rodgers and Hammerstein tune, *I Have Confidence*.

It doesn't take long to see that the campers revel in the music and thrill of performing. But the biggest reaction always comes from campers simply watching the show: They high-five and cheer in an uninhibited display of support and pure joy.

"Their expressions when the music moves them are just magic," says Ann Breen, visiting from

Ireland with her husband and their 15-year-old daughter, Karen, a new Williams camper. Breen started her country's Williams Syndrome Association from scratch a decade ago. It has grown from two to 44 families.

"When I came here, I expected to teach, and the remarkable thing is what the kids have taught me in return," Keith Spencer, a professional opera baritone and a camp vocal instructor, says after the show. "Sometimes when you're a professional performer, you're so worried about learning the music and making everything precise. But these students sing for the love of the music."

### **The road to camp**

Of course, there would be no public performance, no music camp at all for that matter, if not for the work of several Williams parents sitting inside the church this day. They weave a story typical of the Williams experience -- of parents pushing for answers when there seemed to be only bleak questions, and finally forging a solution.

Dr. Sharon Libera, John's mother, is camp coordinator and a key reason the camp exists. Libera remembers her son being late for many of the early milestones for a toddler. She didn't think he was retarded but was puzzled that he did not speak until he was



Stephen Picchione, 25, looks forward to sleeping in his bunk at Williams Camp. "I have a bad feeling they are going to paint these bunks, but they can't erase Beethoven," says Picchione. "It reminds of everything when I first came here." [Times Photo: Jamie Francis]

almost 3. When he did speak, his first sentences were verses to *Bah Bah Black Sheep*. Soon she and her husband were getting their son speech therapy and buying him an endless array of toy musical instruments, which he loved to no end.

A doctor, meanwhile, delivered the stark news that their son had Williams. This was the early '80s, when not much was known about it. They were given a grim textbook outline of symptoms. "My husband had immediate back spasms," she says. "It was really terrible." But then the Liberases went to a Williams Syndrome clinic and received a brighter picture, which included helpful therapies.

Libera still had no idea about the Williams link to music. No one did. But she knew her son had a musical gift, and arranged piano lessons at a young age. She also noticed letters from other parents in the Williams Syndrome newsletter talking about their own children's love of piano or singing. "Things began to add up for me," she says.

She had a professional video made of John's piano lessons to show other parents. And she got in touch with Dr. Howard Lenhoff. Libera had heard about his daughter Gloria and her opera-singing prowess.

Lenhoff and his wife, Sylvia, had been even more in the dark about Williams. Gloria was born six years before J.C.P. Williams ever identified the syndrome. The Lenhoffs knew their daughter was retarded and set out to enrich her life any way they could. When Gloria was 11, they noticed that she had a nice singing voice. "It was very hard to get a teacher for a retarded girl who didn't want or know how to read music, so our first teachers were disasters," Lenhoff says.

They finally found the right teacher, a woman who taught singing to prisoners. She taught Gloria by ear, starting with Mozart and Handel, with Lenhoff eventually hiring foreign instructors to teach her works in other languages. He also bought her a small accordion.

"So help me God, she just picked it up and started playing it," he says. "She knew how to chord it and everything."

A 1988 documentary about his daughter, *Bravo Gloria*, spread the word. After the documentary aired, Lenhoff was flooded with calls from scientists and parents telling him his child had Williams. "Essentially we said, so what?" he recalls. But he and his wife attended some Williams meetings and heard similar musical anecdotes. "I said, 'This is kind of spooky,' " he remembers. Yet he wondered if Gloria was just an anomaly, who excelled because she was talented and well trained.

Then Lenhoff met more Williams children who were musically gifted. A 1993 trip to England's Williams convention convinced him that it was no fluke. "We saw more kids, English kids, and I

said, "Sylvia, it's real." Lenhoff had just started trying to convince people of the musical connection when he got a call in California. It was Libera, phoning from Massachusetts.

Libera suggested they meet to discuss their music observations. During a family visit to his native Massachusetts, Lenhoff met with her. She proposed a Williams music camp; he proposed a Williams music college. Discussion of the latter continues, but the former plan fell into place rapidly, almost by chance.

Before catching his flight home, Lenhoff had breakfast with an old pal who happened to sell food to an elite girls music camp nearby. It was Belvoir Terrace. Within hours, Lenhoff had pitched the camp idea to Belvoir director Nancy Goldberg. She liked it.

Her mother, Edna Schwartz, has owned Belvoir Terrace since 1954. She had buildings, chairs, tables and other accoutrements painted shades of her favorite color, purple. To this day, she rides around the campus in a purple golf cart, always dressing in purple outfits. Schwartz recalls the day in 1993 Lenhoff brought Gloria to meet her and Goldberg: "We listened to her sing and sat there with our mouths wide open."

The Williams board still had to be convinced. The association wasn't certain of the musical connection, and didn't want to set up other children and parents for disappointment.

"We were skeptical," says Williams Syndrome Association chief Terry Monkaba. "We were not willing to say these kids just have astonishing talent. Many of the board members had younger children who hadn't been exposed to music and weren't sure. But we went ahead with it.

"In the years since, it's become so clear how much they're all touched by the music, and how kids who don't seem that musical can make so much progress when they're immersed in it."

### **The genetic mystery**

Well before there was talk of a Williams camp, there was talk of Williams genes. Specifically, missing genes.

Scientists had been studying the genetic makeup of Williams people throughout the '80s. The breakthrough came in 1993, when scientists determined that Williams individuals all were missing a tiny portion of genetic material in one of the two copies of chromosome No. 7 that are found in each cell of the body.

That missing portion includes at least 15 individual genes. One of them is a gene that produces Elastin, a protein that is vital for helping elastic fibers develop in major arteries, the lungs and skin. Individuals who have fewer Elastin genes may develop

heart problems, intestinal disorders, high blood pressure and joint problems.

The absence of sufficient Elastin does not explain all aspects of Williams Syndrome, a random chromosomal disorder affecting 1 in 20,000 births. Scientists hypothesize that other missing genes correspond to certain traits of the syndrome. One of the other missing genes, LIM kinase-1, may hamper spatial awareness. That may be why simple activities such as drawing shapes, arranging blocks, even walking without bumping into something can be a major challenge for a Williams person.

The genetic work could go a long way toward explaining why Williams individuals usually learn to walk and talk late, around 2; have poor fine motor skills; and are highly sensitive to loud noises, such as thunder or fireworks. Despite delayed speech development, many have a facility with language and surprisingly good vocabularies. This has hindered some Williams children in school, because teachers over-estimated their potential. It also has drawn great interest from Dr. Ursula Bellugi and her colleagues at the Salk Institute.

Bellugi's findings show that the area of the brain that accounts for language ability appears not to be damaged. Another brain area spared is tied to emotions and memory -- two strong characteristics with Williams individuals. A compelling implication of her research is that language and reasoning ability do not necessarily go hand in hand.

But what about the music?

Lenhoff offers an explanation that stems from the findings of Bellugi and others.

"They show that the brain of Williams people is 20 percent smaller than our brain," he says. "The part that seems to be enlarged in professional musicians who have perfect pitch is called the left planum temporale. With some Williams kids, the left planum temporale is either the same size as normal humans, which means it may occupy more of the brain relatively speaking, or even bigger. The missing gene may lead to promoting and stimulating other genes that are involved in this. But we really don't know. In fact, we know little enough of the normal brain, let alone the Williams brain."

Lenhoff is testing Williams individuals for perfect and relative pitch -- where a person can determine any note if given another note. One problem in testing is that very few Williams people read music, and most don't know the names of musical notes. That doesn't hamper them, says Lenhoff, but it makes it hard to determine if they have relative or perfect pitch.

"So far, I've found five kids who know the names of the notes -- and all five have perfect pitch," he says. "That's at least five of

the 57 campers here. In a population of normal people, there's usually only one in 10,000."

### **The Williams people**

"I found out I had Williams Syndrome when I was 3, when my mom went to the doctor and he told her to watch a tape about it," says Catherine Alcuri, an outgoing 16-year-old from Utica, N.Y.

"I didn't like that I had it. I had to go to the hospital a lot when I was little. It made me cry that I had it. Some kids would tease me in school and make fun of me, but my mom would say, 'Don't worry, you're the better person.' Then when I came here to camp, I cried too. But they were good tears, because I had never been around other people with Williams. I was just so happy."

Many Williams people spent their early years undergoing multiple heart surgeries. Many have endured teasing from classmates, stares and feelings of loneliness or not fitting in. They know enough to know that they are indeed different.

"People don't understand it mostly," says Melynda Grace Pawulak, 30, of Maryland. "Sometimes I'll walk up to them and say, 'Do you want to know what's wrong with me and why I walk this way and why I talk this way and look like this?' Some people look at you weird, and it hurts me sometimes and makes me upset, but you can't control what people think and do."

For many, the camp is the only time they are around other Williams individuals. That dynamic adds to the cathartic one-week experience. There are new social relationships and a renewed sense of self, support and confidence.

Sarah Catalanotto, 18, of New York has attended all five Williams camps, and was too shy to sing her first year. Now she loves the spotlight and has one of the camp's best solo voices. Ditto for Lisa Walsh, who came to camp as a keyboard player three years ago, and now is such a talented singer that she performs in church and adult choirs back home in Montreal. Alec Sweasy, a 13-year-old from Minnesota, was only 8 at his first camp and a piano novice. Today he is regarded as the next big musical standout in the Williams world. You could see why as he played a 10-minute version of Mozart's *Concerto in C Major* at the student recital -- entirely by ear.

Then there is Meghan Finn, who has the presence of a pop star on stage, with all the hand gestures and facial expressions to go with her smooth, evocative voice. Meghan's story is intricately bound to the story of her mother, Liz Costello, and shows the immense strain that can accompany a search for answers.

Like many other Williams campers, Meghan developed slowly and suffered from a heart condition. Costello and her husband took Meghan to hospitals all over the country. Neither parent had heard of Williams Syndrome when their daughter was diagnosed at 18 months.

The early diagnosis was a blessing. They started Meghan on an infant stimulation program, sensory integration therapy, occupational therapy, physical therapy, speech therapy. "That's how I spent most of Meghan's childhood, driving from therapy to therapy, and hoping," Costello says.

At age 3, Meghan started plonking on a keyboard, drawn almost mystically to the sounds it made. She would play endlessly, repeating songs she heard on the radio.

Meghan, whose Williams symptoms were fairly mild, progressed well in school, though she only learned to read when her mother bought her a record phonics program that taught through music. At 8, she started Suzuki piano lessons. Costello had heard of the Williams Syndrome Association but says, "I didn't want anything to do with it. You go into denial. I was just trying to keep my head above water, and I didn't want to hear anything else I should be doing."

The stress took a personal toll, as Costello's marriage broke up. She finally turned to a woman in the association for advice. "I don't remember this woman's name, but to me she was an angel. She was the person on the other end of the phone who, when I thought I wasn't going to make it, was there for me. So I feel that's my job now. To be an angel for others."

Costello is that. She gives seminars on coping with a special-needs child, and another titled "Don't Forget the Marriage."

"It can be overwhelming and take you over. It can take over your life and your marriage and your other children and your identity," says Costello, who has remarried and recently received a master's in social work.

As for Meghan, she's excelling beyond her mother's dreams. Though she never sang before her first camp five years ago, she is the acknowledged pop-singing Williams star.

"I love to show how I feel when I sing," she says. "It connects with my whole body, my soul, my spirit and my heart."

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Williams Syndrome campers go crazy for Meghan Finn after she and Williams Camp staffer Sha-Ron Kushnir (back left) performed "As Long As He Needs Me" during a campers recital.

[Times Photo: Jamie Francis]

## The music train

In late June, researchers at the University of Connecticut held a ground-breaking Williams Syndrome program called "Music and Minds." Sixteen Williams individuals spent 10 days singing, playing and learning about mathematics and fractions through music.

The program is run by Sally Reis, a professor of educational psychology -- and cousin of Williams pianist Christian Lawson.

"They have so many gifts," she says. "Empathy. Compassion. Concern. Deep feelings of love, deep understanding of when people are sad or upset, and, of course, social ability."

Her most powerful memory from the program is a hand-written poem by one of the Williams participants, Blake Middaugh, 29, of Venice. The poem was shown on an overhead projector at the music camp during a gathering of parents. It read:

*Music is about what life should be  
and it's what sets you free because  
what comforts the soul is a little  
bit of rock 'n' roll! Music travels  
like a train on its track and when  
the journey begins, there is no turning  
back because music is also about  
friendships-peace-laughter-love  
and family! God gives us each special  
gifts to use and when you make a  
big difference in someone else's life  
you know you can't lose!*

The poem could have spoken for all the Williams campers. You could see it in the way they swayed and sang along when Arlo Guthrie's former guitarist, David Grover, staged a rocking concert. You could see it at the annual disco dance, with campers, parents and counselors twirling and boogie-ing up a storm, shaking the place enough to make the deejay's CDs keep skipping.

You could see it in the private music lessons: One shy camper, Evi Papazoglou, a 21-year-old from Massachusetts, brightened noticeably when her Berklee-schooled teacher improvised with her on a song by her idol, Paul McCartney. And drummer Steve Sesny, a 24-year-old from Maryland, was ecstatic as he traded complex riffs with Arlo Guthrie's ace drummer, Terry A La Berry.

"I've played a lot of dual drummer things, but I've never had chemistry with anybody like it works with him," says the Lenox-based musician. "He gets this big beaming smile and we connect. We don't have to talk about what we're doing. I've never seen anything like it in my life."

You certainly could see it on the final night: At the talent show, music counselors on bass and guitar backed up student bands in songs from *Wipe Out* to *Margaritaville*; and at the Broadway finale, campers delivered show tunes from *Get Me To The Church On Time* to *Edelweiss* with the gusto of giddy stage veterans. A hearty curtain call ended the show amid huge cheers, followed by hugs and tears, awards and emotional speeches. The Williams people knew the week was all but over, that they would soon be returning home to the real world.

In the darkness, campers walked slowly down the hillside, many clasping a parent's arm or a railing for balance. They laughed and talked in the glow of the New England starlight, and somehow you knew, the music was still moving inside them, like a train on an endless track.

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The author's younger brother, Robert Scheiber, 41, has Williams Syndrome and was a speaker at the last national convention of the association. Robert, of Rockville, Md., has worked for the U.S. Government Printing Office for the past 18 years. He is an avid pianist and drummer.

### **St. Petersburg to host conference**

The Williams Syndrome Southeastern Regional Conference will be held Oct. 23-24 in St. Petersburg and will feature national speakers and medical experts.

The conference, at Tyrone Elementary School, 2401 66th St. N, will include a "sibshop" for Williams siblings ages 7 to 18, teaching strategies for WS children, and the teaching of math through music.

The cost is \$25 for adults, \$10 for adults with Williams Syndrome and \$8 for children. For information, call Southeastern regional director Debby Johnson of Treasure Island at (727) 360-1099 between 9 a.m. and 5 p.m. Reservations must be made by Oct. 1.

The Williams Syndrome Association Web site is <http://www.williams-syndrome.org> and the phone number for the Williams Syndrome Association national office is (248) 541-3630; the Williams Syndrome Foundation site is located at [www.wsf.org](http://www.wsf.org).

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