

Pam LeBlanc
goes whale
watching in
Cape Cod.
Travel, D10

Figure out what
fun you want to
have this week.
Planner, D2-D3

PROFILE

FINDING HIS VOICE



Keli Thorsteinsson is nonverbal autistic but he composes music and writes poetry using a letterboard to get his message across. The 16-year-old is the subject of a book by actress Kate Winslet and a documentary made by his mom. His parents also started the Golden Hat Foundation, which is having a walk for autism awareness on Saturday at the Dell Diamond.

Teen with autism shares his journey from not being able to communicate to writing poetry and music

Story by Nicole Villalpando nvillalpando@statesman.com ■ Photos by Ralph Barrera rbarrera@statesman.com

“I am real, and I am nice.” That was Keli Thorsteinsson’s first sentence. He was 10.

His ability to share his thoughts had been locked away by autism. But when Keli was 10, his parents brought him from their town in Iceland to Austin to meet with Soma Mukhopadhyay of the Helping Autism through Learning and Outreach (HALO) center. She has helped other nonverbal children with autism, including her own son, learn to communicate by using a letterboard, a simple piece of wood with the alphabet cut out.

Slowly Keli, who is now 16, began to tell his parents and others what they always wanted to know about him and his struggles with autism.

What does autism feel like? “I don’t know,” Keli points out using a letterboard. “What does being ‘normal’ feel like? I have nothing to compare it



Keli, with his mother, Margret Ericsdottir, taps out what he wants to say using this letterboard. He learned to use it when he was 10. It was the first time he could communicate.

to.”

He sometimes feels disconnected from his body. Like other people with autism, he does what is called stimming, short for self-stimula-

tory behavior. It might mean flapping his arms or playing with string. “It is strange. In my head sometimes I think, ‘Stop stimming ...,’ but my hands don’t seem to hear my

brain. It’s like I’m not in control. Someone else is driving, but I’m sitting in the driver’s seat and (have a) view with no controls.”

He and his parents, Margret Ericsdottir and Thorsteinn Gudbrandsson, founded the Golden Hat Foundation, based on a poem Keli wrote in 2009. The poem inspired actress Kate Winslet to create a book featuring self-portraits of actors wearing a simple black hat with a quote about something that is important to them. Winslet first got to know the family when she narrated a documentary about autism Ericsdottir made. The book came out last year and its proceeds go to the foundation.

The Golden Hat Foundation’s goal is to first bring worldwide awareness of autism, which now affects 1 in 88 children (1 in 54 boys and 1 in 252 girls). The dream is to build a center where adults

Golden Hat continued on D6

‘Requiem’ a dream for choral director



Jeanne Claire van Ryzin
Seeing Things

For Brent Baldwin, good music is good music. It doesn’t matter what century it came from.

In his role as artistic director of the Texas Choral Consort, he’s decided to feature Brahms’ mighty German Requiem as the centerpiece of the chorus’ upcoming concert.

But Baldwin has also put something new on the program: The premiere of a piece by 30-year-old Caroline Shaw, this year’s winner of the Pulitzer Prize in Music and one of only a handful of female

BRAHMS’ ‘GERMAN REQUIEM’

When: 7:30 p.m. Aug. 17, 3 p.m. Aug. 18

Where: Northwest Hills United Methodist Church, 7050 Village Center Drive

Tickets: \$20 (\$15 students)
Information: 512-900-8517, www.txconsort.org

composers to net the prestigious award.

“I like to mix it up,” says Baldwin recently over coffee while taking a break from annotating a score.

Baldwin has amassed more than 140 singers and a 38-piece orchestra to tackle Brahms’ vocal masterpiece in two performances Aug. 17 and 18.

Seeing Things continued on D5

THEATER

Play takes soul-searching trip to Mexico

Man’s bicultural issues focus of ‘Confessions of a Mexpatiate.’

By Nancy Flores
nflores@statesman.com

It’s easy for Oaxaca’s magical energy to seep into a visitor’s soul and invigorate the spirit. For Austin-based playwright Raul Garza, who traveled there last fall for a writing residency, the charm and mysticism of the city helped bring to life his first one-man show, which is partially set in the southern Mexican cultural gem.

“Confessions of a Mexpatiate,” which runs Thursday through Saturday until Aug. 24 at the Salvage Vanguard Theater, follows one man’s journey across Mexico in search of answers about his Mexican-American identity, life’s meaning and his place in it.

“You always think the grass



Actor Mical Trejo performs “Confessions of a Mexpatiate,” written by Raul Garza and presented by Teatro Vivo, at the Salvage Vanguard Theater on Tuesday in Austin. CONTRIBUTED BY CHRISTINA BURKE

is always greener,” Garza says. “So this explores the idea of what if you really went for it? What would happen if you escaped?”

Garza’s latest work, which is directed by Ken Webster

and produced by Teatro Vivo, delves into issues associated with straddling two cultures but remains a universal story. The play, which is told mostly

Mexpatiate continued on D8

FINDING HIS VOICE

Teen is a poet and composer

Golden Hat

Continued from D1

with autism can live and work as well as support adults with autism in the community. On Saturday, the foundation will hold its first fundraising walk/celebration at Dell Diamond in Round Rock.

'The Golden Hat'

This boy had a golden hat. The hat was magical. It could talk. The boy did not have any voice. He had autism. His hat was always with him. His hat was lost one day.

Now he had no way of telling them his stories.

His mom and dad became sad.

They taught him spelling on a letterboard. It was hard.

End.
— Keli Thorsteinnsson from "The Golden Hat: Talking Back to Autism."

A noticeable difference

At first Ericsdottir thought Keli was just the same as his two older brothers, Erik and Unnar. The first months he seemed normal. But then, she says, "I started to have question marks."

He didn't feel the same when he was breast-feeding. She couldn't get the same intimacy and pull him close. He was sensitive to sights and sounds and being touched and held.

"I thought he was a genius," she says. "He was so awake and so aware of everything. My other boys just slept."

But Keli didn't sleep. He didn't sleep well for three years until it was discovered that he had reflux and was given medicine to help him. Keli couldn't tell his parents why it hurt to sleep.

When Keli was 6 months old, he and his mom spent some time in the hospital to see if there was something wrong with him and to give her a break; after all, she wasn't



Keli Thorsteinnsson rocks in a dancing motion as he listens to music with his father, Thor Gudbrandsson.

sleeping either.

She was told she was being an oversensitive mom, that this was just hysteria. She was told she shouldn't worry so much about her son. She should relax and drink less coffee and eat less cake, Ericsdottir says.

She was relieved, but yet, she couldn't really believe that there was nothing wrong.

When he was 9 months old, she was told he was delayed. When he was 1, he had a seizure and died and was revived. The few words he did have like "mama" in Icelandic went away.

"He didn't recognize us," Ericsdottir says.

When he was 4, the words "autism" and "metal retardation" were used. Ericsdottir was told he had the mental capacity of a 2-year-old.

And so, Keli watched kid shows like "Teletubbies" and was read children's books. He attended special education classes and learned life skills instead of academics. He was taught to point to a few pictures to say what he wanted.

Keli couldn't tell them that inside this body with limbs flapping and eyes darting was a brain that was composing music and writing poetry. He couldn't tell them



In his work room at his Northwest Austin home, Keli loves to play the piano, but he does his musical compositions by pointing to which clef he wants, length of note and which note one at a time, similar to the letterboard he uses to spell out one letter at a time. RALPH BARRERA PHOTOS / AMERICAN-STATESMAN

he'd learned to read by watching subtitled TV with his parents and that he wanted to read authors such as Mark Twain and J.R.R. Tolkien.

'Praying'

I am praying
Only God can hear my voice
Telling you is no use
Dear God
How many times must I feel sad?
I feel sad when daddy leaves
I feel sad when I don't talk
I feel sad when I can't ask for help
I am autistic
I don't want to thank you for making me

autistic

You are God
I am sad
End

— Keli Thorsteinnsson from "The Golden Hat: Talking Back to Autism."

Finding the words

Keli recalls first using the letterboard: "I remember having hope one day I could communicate my thoughts and feelings and not rely on limited pictures, symbols or words on a computer. I knew it would take time to get there, but it gave me hope."

His mother's quest to make a documentary about Keli and other children with autism introduced him to Mukhopadhyay and the letterboard.

In the documentary, "The Sunshine Boy," which HBO showed and renamed in 2010 "A Mother's Courage: Talking Back to Autism," Ericsdottir met several families and autism researchers in the United States. One of the families in the film was Jon Shestack and Portia Iversen, founders of Cure Autism Now.

Their son Dov also was nonverbal, but he was communicating with a letterboard that he was taught to use by Mukhopadhyay in Austin.

For the film, Ericsdottir came to Austin to watch Mukhopadhyay use the letterboard and her rapid prompting method. At first, Mukhopadhyay talks to the child about something and asks questions that require him to point to two possible answers she's written on a piece of paper. Then she verbally spells out his answer and writes it on a piece of paper. Eventually the child works up to using the letterboard and to pointing out each letter of a word. Some children eventually move on to using a keyboard or an iPad.

Ericsdottir didn't know if Mukhopadhyay could help Keli, but she had to try. Keli grew up hearing Icelandic and English, and Ericsdottir knew he understood them, but could he read? Could he spell? Or were the doctors correct that he was developmentally a 2-year-old in a then-10-year-old body? There were a lot of questions.

"It is very easy to give up, and I gave up," Ericsdottir explains. Children with nonverbal autism "are totally invisible. You don't know who they are and what they stand for if they don't have any way of expressing themselves or communicating through other ways."

Keli gave them reason to not give up. In the film, you see him using the letterboard in those early sessions and asking, "Can I learn piano?" Mukhopadhyay reassures him that she thinks he can. "I make songs," he points

WHAT IS AUTISM?

The Centers for Disease Control defines autism spectrum disorders as "a group of developmental disabilities that can cause significant social, communication and behavioral challenges. People with ASDs handle information in their brains differently than other people." It is not known what causes autism.

Autism is a spectrum because it can range from very mild to severe and it can affect people in different ways.

Some of the classic signs of autism are:

- Not playing pretend games.
- Not pointing to an object to show interest.
- Not looking at objects when another person points to them.
- Having trouble relating to others or showing an interest in other people.
- Avoiding eye contact.
- Wanting to be alone.
- Having trouble understanding other people's feelings or talking about their own feelings.
- Not wanting to be held or cuddled.
- Appearing to be unaware when other people talk to them, but respond to other sounds.
- Being very interested in people, but not know how to talk, play or relate to them.
- Repeating or echoing words or phrases, sometimes in place of normal language.
- Having trouble expressing needs using typical words or motions.
- Repeating actions over and over again.
- Having trouble adapting to change in routine.
- Having unusual reactions to senses.
- Losing skills they once had such as words they once used.

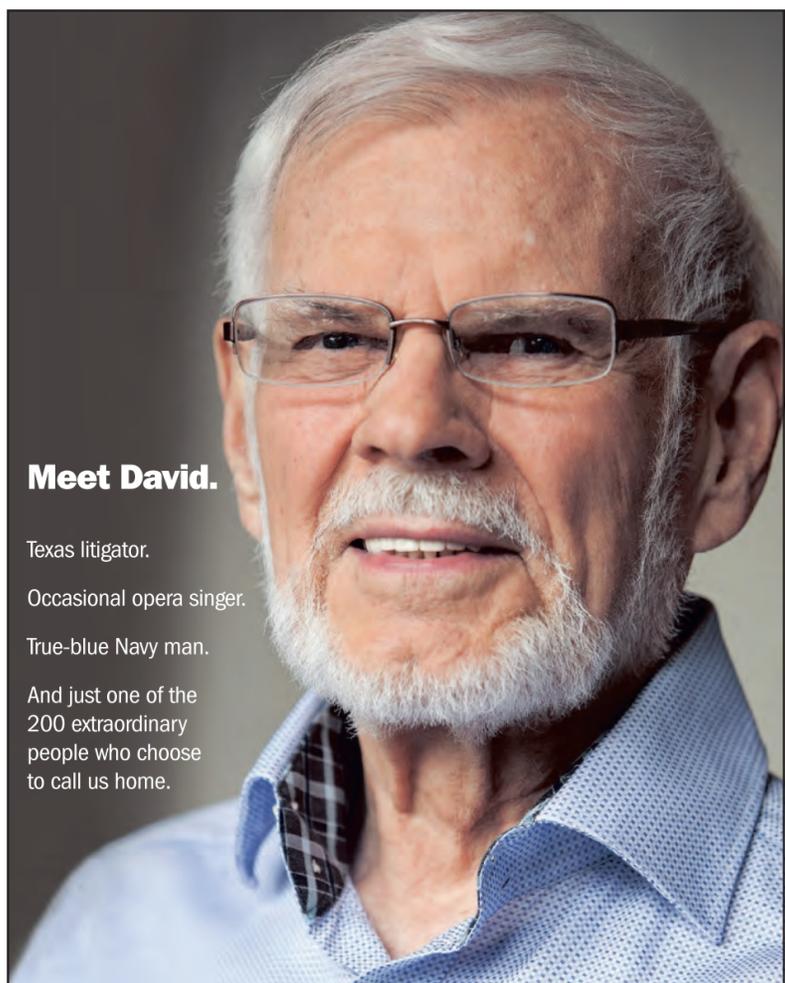
Source: Centers for Disease Control

out. "I began when I was small."

Keli is crying. He can finally tell his parents what he's interested in, what he hopes his career path will be.

"(The letterboard) has meant everything," he points out. "It's been hard but the best thing that has happened to me." Now, he says, he has more freedom and self-esteem. "Just being able to communicate basic things like my foot hurts or my

Continued on next page



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Continued from previous page

stomach, being able to say what food I want or just being able to say what I want to do or don't want to do. Being able to communicate means so much just on the little things."

Ericsdottir realized they didn't know Keli like they thought they did. "We were trying to do our best by guessing; that was the best we could do since we are not mind-readers and he had no way of communicating with us," she says. "And sadly, our guessing on what he wanted or didn't want seldom matched reality."

They soon learned his favorite color is red, not blue. His favorite restaurant is not McDonald's like his brothers; it's Cho Sushi near their house.

Life is a Bigger Puzzle

Most children look like their parents

But my brothers look so different

I want to learn about genes

Life is actually a puzzle People think only autism is a puzzle

But life is bigger puzzle - Keli Thorsteinsson from "The Golden Hat: Talking Back to Autism."

The world opens

The family moved to Austin in 2009 to be closer to Mukhopadhyay and other resources here. It was a sacrifice for Gudbrandsson, who was an investment banker in Iceland, Ericsdottir, who had been a business executive before working on the documentary and starting the foundation, and Erik and Unnar.

Keli wrote in a school assignment last fall: "Without my parents, I wouldn't have anything."

He explains the move in that same school assignment: "My past is Iceland. My heritage, my family line is proud Icelandic. My future though is here. Autism is not understood in Iceland. They are behind in it, maybe because we are an island. That is a joke! I look forward to life here. Already things have changed. I am always working and pointing. Now I write music, too. Here I have met true friends and wonderful people that just want to help me succeed."

In Austin, Keli would start being mainstreamed and attending regular classes. For the first time he was getting an education. Last year, his freshman year at Vandegrift High School in the Leander School District, he finished with a 3.9 grade-point average.

At Canyon Ridge Middle School, Aline Crompton and her staff "made me feel welcomed, included and teachable," he points out. "That continued through (Vandegrift). There are still people that are negative, but my tutor



Keli Thorsteinsson bounces on an exercise ball in his northwest Austin home to the sound of music. Keli loves to listen to music and he writes classical music himself. RALPH BARRERA PHOTOS / AMERICAN-STATESMAN



Keli is allowed to use a scarf to calm and soothe himself whenever he becomes too agitated. He gently feels the fabric by rubbing it across his mouth and face.

tells me to prove them wrong. I'm like any teenager. Sometimes I like school; sometimes I want to stay in bed."

Keli attends regular classes, but he gets to leave early and come late to allow for more time in the hall. He has an aide with him to interpret his letterboarding. He says no one makes fun of him.

The letterboard is magical, but it is hard work, as is not stimming, which is discouraged in his regular classrooms. "I don't like all my physical obstacles, but I see how far I've come and I know one day they will not be as hard."

Keli does have many physical obstacles. His eyes don't work the way ours do, which is why he relies mostly on his hearing. One day, he started limping like he had when he was little. This time he could communicate his pain and point out on his letterboard: "Emergency, much pain in left foot, doctor today." Finally there was answers. He had a fracture in his left foot and



'I am real, and I am nice.'

Keli Thorsteinsson's first sentence, at age 10

old fractures in his right foot. He has osteoporosis.

The family also has worked on finding a diet that works better for him. They've removed gluten, casein, processed and nonorganic foods. Now he eats only raw foods.

He writes for school: "Now I am stronger, healthier and my system is not in chaos. Even though I miss some foods and freedom from a diet, for now I know it is best. I guess sometimes Mom does know best."

Excerpt from 'To Be Free'

Art is a way to express our thoughts

What is life without art? The art that I have in my head

It has a field of yellow kites

And no strings

It is called to be free - Keli Thorsteinsson, from "The Golden Hat: Talking Back to Autism."

Looking ahead

One of the goals for the Golden Hat Foundation is to build a center in Austin that can be replicated elsewhere. There adults with autism can live and have support with communication, academics and career training as well as dining facilities and a pool the public can use. An architectural plan has been drawn.

Ericsdottir says they realized early on that Keli would outlive them. They had to plan for his future. "I didn't want to have him end up in an institution," she says. "... if I can't think of myself living in an institution, I don't want it for my son."

In a school assignment, Keli created a PowerPoint presentation about his

hope for the future. He sees himself living at the Golden Hat Foundation's campus with his friend Mitch as his roommate.

"I hope one day we will be worldwide changing the way people think, act and feel about autism," Keli points out about the foundation. "I hope that families from all over can find a Golden Hat facility near them and that families can go regardless of cost, like St. Jude's for autism; that no more parents cry endlessly because they don't know how to or where to get help for their child."

In his school assignment, Keli did research on his future career: music composer. He's already composing. Using laminated choice sheets, Keli points to which clef he wants to work on, then length of the note, and which note. His father, using an iPad app, records the results and then plays it back to see if that's correct to what Keli has in his head. Keli and Gudbrandsson work 30 min-

GOLDEN HAT WALK FOR AUTISM

Dress in gold for a family friendly gold-themed parade with kids activities and resource fair.

When: 8:30 a.m.-12:30 p.m. Saturday

Where: Dell Diamond, 3400 E. Palm Valley Blvd., Round Rock

Admission: Free for children younger than 12. Walkers are asked to collect at least \$25 in donations.

To register or volunteer: www.goldenwalkforautism.com.

For more information on the Golden Hat Foundation, go to www.goldenhatfoundation.org.

utes to an hour a day and might only get a few measures done at a time.

"I have learned from Keli," Gudbrandsson says. "I've never been a patient person, but I have to be with him. He has changed me so much."

Keli writes about this gift of patience he has given others in a school assignment: "I am not your typical kid. What I have taught has been a silent lesson. What I have taught is patience. To get to know me takes patience. If you give me time and patience, I will show you my world."

Keli is working on a classical piece called "Skipping in Twilight." He has been offered to debut his music at Carnegie Hall, but the family has not decided whether it will be this November or next, Ericsdottir says. "Now he has dreams," she says. "That's what's so beautiful."

Keli writes for school: "I am so proud of the man I am becoming. I have come so far in the last four years that I can't wait to see what I do in five years."

Contact Nicole Villalpando at 512-912-5900.

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