—Slug:.....COMM-0875.wc.kiah_coble_ALS

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—For section.....News

—Format.....News feature

—Dateline.....St. Albans

—Article Number:.....44020

Notes from editor (not for publication):

HEADLINE ELEMENTS:

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Living fully: A Vermont mother's journey with ALS

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Kiah Coble, diagnosed with ALS at 33, is embracing motherhood, advocacy, and adventure while raising awareness of the disease's outsized toll on Vermont

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TEXT BODY:

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Kiah Coble was talking on the phone with a parent at NewBrook Elementary School in Newfane, where she worked as a school counselor, when her left hand suddenly cramped.

"It was very odd," Coble says. "It was like all of a sudden being plunged into ice water."

It happened again. And again. Her hand grew weaker.

What followed was a nearly two-year odyssey through primary care doctors, physical therapists, a nerve specialist, an unsuccessful wrist and elbow surgery, and finally neurology — before Coble, then 33, received the diagnosis that changed her life.

She had amyotrophic lateral sclerosis, or ALS, also known as Lou Gehrig's Disease.

"Diagnosing ALS is a process of elimination — there is no test for it, so you have to eliminate all other possibilities," Coble says. "We don't have a good system for diagnosing ALS."

As described by the ALS Association, a national nonprofit advocating for awareness of the disease and advancement toward treatment, "Amyotrophic lateral sclerosis is a progressive, fatal neuromuscular disease that slowly robs the body of its ability to walk, speak, swallow, and breathe. The life expectancy of a person with ALS averages two to five years from the time of diagnosis.

"ALS can strike anyone. There is no known cause of the disease, and it costs loved ones an average of $250,000 annually to provide the care people living with ALS and their families need."

Now 36, living in St. Albans, and soon to move to the Burlington area, Coble grew up in Brattleboro and Provincetown, Massachusetts. Her family still lives locally.

She is approaching four years since her diagnosis. In that time she has gotten married, given birth to a son, Fen, continued working part-time until her recent retirement, and traveled to Patagonia — all while her body has steadily changed around her.

A body in transition

Coble's left arm is now largely paralyzed. Her right hand is following the same path, taking with it the fine motor skills she once relied on for writing, art, and cooking. Her left leg has weakened too, curtailing the hiking she has loved.

"I am an avid hiker and I can't hike much anymore, and that's difficult," she says. "We try to get out and do what we can."

Coble recently won a mobility scooter in a giveaway — "the first giveaway I have ever won for the least fun item I can imagine," she says with characteristic good humor — and the family is eyeing an off-road wheelchair for beach and trail access down the road.

Despite the losses, Coble described her progression as comparatively slow.

"I'm progressing quite slowly compared to a lot of others, thank God," she says, though she acknowledges a recent shift.

"It does feel like we're in a new era of my ALS, where I am no longer working," she says. "I am needing more assistance. We're noticing it more."

Even so, Coble exhibits acres of quiet strength, courage, and determination. Post-diagnosis, she added a small, new image to her tattoos: two wild horses.

"They're running," she says with a smile.

Living with the diagnosis

Coble and her husband, Ryan Karb, married and had Fen, now a year and a half old, after her diagnosis.

Rather than letting ALS define those years, the couple made a point of living fully within them — including taking a trip to Patagonia with friends not long after Coble learned she had the disease.

"We kayaked up to a glacier," she says. "We touched icebergs — it was incredible. For a while, we kind of lived our lives alongside the diagnosis. We got married, we had a baby, I continued working."

She retired from full-time work this past June after spending her final year as a part-time paraeducator in a kindergarten classroom — a switch from her previous role as a middle school counselor.

"I loved it — it was really fun," she says. "The kids are really adorable and weird and ask great questions."

The cost of care

Coble is candid about the financial strain of both illness and inadequate family leave policy. Vermont does not guarantee paid maternity leave, and Coble exhausted her sick days between her diagnosis, surgery, and the birth of her son.

"Health insurance in America is terrible; incredibly unjust," she says.

Friends started a GoFundMe campaign for the family while she was pregnant. Coble said it has been essential — and that she has seen a recent resurgence in donations.

The family is also preparing to renovate a bathroom in a new, single-story home they're moving into, a necessary but costly accommodation.

"Expenses for ALS add up," Coble says. "As people progress, there is no way to know what somebody is going to need when. It really depends on how your body goes. The unknown part can be difficult."

A local epidemic, and a mystery

Coble says one of the most striking things she's learned since her diagnosis is that Vermont reports the highest number of ALS cases per capita in the country.

Vermont public health statistics say the state's ALS prevalence is about 2.9 patients per 100,000 residents, higher than the U.S. national average of about 2 per 100,000 people. (The statistics are age-adjusted to compensate for different rates of the disease among different age ranges and the demographics of individual states, which yields a more relevant basis for comparison.)

About 15 new people with ALS are served annually, according to the Vermont chapter of the ALS Association.

"When the neurologist said ALS, it just didn't even seem within the realm of possibility for me," Coble says. "And now that I am in it, I am realizing that we have so many community members who are living with this disease, and it is a local issue."

The cause remains largely unknown. ALS is more common among veterans, Coble said, and researchers point to possible environmental factors, like air and water pollution.

She has her own theories, too, wondering about Vermont's agricultural practices and the state's characteristically low vitamin D levels during its long winters.

"A high percentage of cases are what they call 'sporadic,' which means there is no known cause for onset of disease," she said. "Mine is sporadic."

A smaller share, she said, is genetic — roughly 10%.

That distinction has been a source of both relief and frustration.

"It made me feel more confident in having a child," she says of her diagnosis.

But treatments being developed target specific genetic mutations, leaving patients like Coble hopeful but on the sidelines.

With emerging research, "folks are regaining lost function with the treatment for a specific genetic mutation," she says. "The rest of us are sort of hoping that there are advances for everybody."

One such treatment, Tofersen, targets the SOD1 gene mutation, one of more than 150 linked to ALS.

"I'm unfamiliar with the science of how it is working, but I know that it's working," says Coble.

Community support

Coble says she draws strength from a support group called Her ALS Story, made up largely of women diagnosed with ALS before age 35.

She describes herself as spiritual rather than religious, with hiking and time outdoors serving as her form of worship — which makes the disease's toll on her mobility especially painful.

"One of the very hardest parts of ALS is losing my ability to go hiking," she says.

Still, Coble feels buoyed by her adopted home state.

"I find Vermont to be so community minded and lovely and helpful," Coble says with a heartfelt smile. "I don't feel ostracized. I feel embraced. It's just been so lovely."

Raising awareness

This fall Coble will serve as an ambassador for the ALS Association's annual Walk to Defeat ALS, set for Saturday, Sept. 26 at Oakledge Park in Burlington.

"Every dollar raised at the walk goes towards research for a treatment to make ALS livable, which is what we're holding on to," she says.

Looking ahead, Coble and Karb are hoping to take Fen on a major family trip — debating between Iceland and Alaska, where a visit to Katmai National Park, home to some of the best grizzly bear viewing in the country, could be a fitting destination, given their son's current fascination with bears.

"Whether or not he'll remember the detail of the trip when he's older, we'll have photographs," Coble says. "Just building that experience as a family — I think it would be so incredible."

Asked what else she wanted people to understand, Coble pauses before returning to gratitude: for her family, her community, and the life she has built since her diagnosis.

"I am grateful to be in Vermont," she says.

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To support Coble and her family, visit the GoFundMe campaign. Learn more about the ALS Association's Sept. 26 walk (the Walk to Defeat ALS Vermont: The Coyote Pack) at Oakledge Park in Burlington, where Coble is serving as this year's walk ambassador, at bit.ly/875-alswalk.

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