

Girl on Fire: Ann Arbor Pioneer hockey player Lauren Chapman perseveres through rare skin disease



Lauren Chapman, 18, ices her hands during a break between period in a game against University Liggett February 10. Chapman has Erythromelalgia, a rare neurovascular disorder that causes her skin to turn red and creates a sensation of burning pain.

(Brianne Bowen | The Ann Arbor News)

*By Kyle Austin | kyleaustin2@mlive.com
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When she steps off the bench and onto the ice, Lauren Chapman feels normal

The Pioneer senior hockey player can skate, pass and shoot as one of her team's top players. The speed of the game supersedes all else.

It's when she comes back to the bench that the familiar feeling returns.

Her hands turn bright red and feel like they're being burned from the inside. Inside her skates, her feet are the same.

She keeps ice packs on the bench to cool her hands. During breaks in practice, she'll take off her gloves and soothe her hands on the ice. After games, she's the first player to take off her equipment, as she tries to bring her body temperature down.

She competes in a refrigerated warehouse, but she can't keep cool.

Chapman was diagnosed last summer with erythromelalgia, a rare disease that makes her immune system unable to regulate body temperature. The result is periods of intense pain and swelling on and off the hockey rink.

She keeps playing hockey even though playing hockey makes her disease worse. The exercise raises her body temperature, which triggers more episodes.

But despite the added pain, playing hockey makes her life better.

So she steps back onto the ice for those few moments of normalcy.

"I try not to let it define me, I guess," Chapman said. "I don't want that to be the reason why I don't want to be like everyone else."

'An internal third-degree burn'



Lauren Chapman, 18, applies a ketamine compound cream to help manage her Erythromelalgia before a Pioneer High School hockey practice Thursday, January 30. (Brianne Bowen | *The Ann Arbor News*)

Chapman's diagnosis last summer began a quest to learn more.

She had been dealing with erythromelalgia her whole life, but had only just learned its name after a University of Michigan rheumatologist looked up the disease in a medical textbook. He had never diagnosed a case before -- a 2008 study found it affects approximately only one in 100,000 people -- and had little more information to offer.

Most of that learning took place on a trip to the Mayo Clinic soon after the diagnosis. And after watching a video about another erythromelalgia patient, Chapman decided she wanted to pass along everything she learned, so she might help others with the disease. So she made a documentary of her own about her trip.

She **released it last month**, and has watched as teammates, classmates and friends have learned about what she's been going through these last few years.

"I'm just tired of holding it in," Chapman said.

In the documentary, Chapman explains her 50-70 episodes per day in which at least one part of her body heats up and turns bright red. The episodes vary in length and severity, and often run together.

She found out at the Mayo Clinic that her skin temperature goes up by 20 degrees during an episode. During a bad episode, she said, she could take a pan out of an oven and feel no additional pain.

That's because the pain is already there -- and it can dominate her day.

"You know when you have a migraine, and that's like all you think about? It's like that," Chapman said. "It's really difficult to get through the day

"It's like an internal third-degree burn every day."

Some episodes force her out of the classroom and into the school bathroom, where she will splash cold water on her face to try to cool off.

Some force her to drive home from school to go to bed.

Some wake her up at night and keep her awake for hours.

"It's excruciating pain," Chapman said. "It almost travels up your leg and it feels like you're being burned by like an iron or something."

An iron is an interesting simile. While getting ready for a date last fall, Chapman grazed her face with a hair straightener. But since she was having an episode, she didn't notice.

Hours later, she walked out of a movie theater and noticed blisters forming on her face.

“I was so freaked out,” Chapman said. “I didn’t know what I had done.”

She was in the emergency room by midnight, and months later still wears makeup to mask the scar of a severe burn she never felt.

Road to a diagnosis



Lauren Chapman, 18, talks with her mom as they watch a movie at home on Thursday, January 30. (Brianne Bowen | *The Ann Arbor News*)

During a practice at age 10, Chapman noticed her feet starting to feel hot. When she took off her skates after practice, they were bright red and burning. She had never seen it before

For years, attacks were infrequent, but always during or after hockey. Visits to the doctor proved fruitless.

“By the time you get an appointment, she’s not having any symptoms,” Chapman’s mom, Rebekah Shepherd, said.

Chapman learned last year that she has a progressive type of erythromelalgia, and in the last few years she’s seen her attacks increase substantially, from every few days to multiple per day. More doctor visits produced diagnoses from Raynaud’s disease to lupus. One doctor told her to seek counseling.

After years of the disease being painful but manageable, her attacks went to a new level last year. They kept her out of the classroom, her grades slipped as she missed more and more days of school. Chapman thought her friends didn’t want to hear about her disease anymore, so she started withdrawing socially.

“I was just sick and tired of not knowing,” Chapman said. “I was just tired of the pain all the time, so I was kind of like ‘Screw it, I’m going to be like this forever, and I kind of just fell into a pity stage.’”

She got a cell phone for the first time that year, and through text messages Shepherd found out just how much pain her daughter was in throughout the day.

“It was a really rough year, just emotionally,” Shepherd said.

Her fortune changed after, of all things, a concussion.

Chapman suffered the head injury during hockey game in February 2013. During a follow-up appointment with a sports medicine specialist, she finally had an attack while sitting in front of a doctor.

The doctor called in three colleagues. None had ever seen anything like it.

That appointment got her a referral to a rheumatologist at the University of Michigan, where she finally got a name for her disease.

There was plenty of bad news to go along with that disease. Erythromelalgia is incurable, and the multiple creams and patches Chapman has been prescribed seem to have no effect.

Patients often end up wheelchair-bound later in life, and the suicide rate is high.

But as bad as that information is, it’s better than the unknown.

“It was a huge relief,” Shepherd said.

Always on the ice



Lauren Chapman, 18, talks with her friends Anna Humes and Mercedes Reyes during lunch at Pioneer High School on Thursday, January 30. (Brianna Bowen | *The Ann Arbor News*)

When Chapman's grandmother took her to an ice rink when she was younger, it wasn't the graceful skating that caught her eye. It was the hockey players, and all the cool equipment they wore.

When her mom got her the full ensemble for Christmas soon after, Chapman started crying she was so happy. She put on her new hockey pants and ran around the house.

Soon, she was diving headfirst into the sport, with no shortage of energy. Her family gave her the nickname "Fire on Ice." Chapman laughs about it now.

After playing for years on club teams, Chapman and her mom moved from Adrian to Ann Arbor before her sophomore year so Chapman could play for Pioneer, the only high school girls hockey team in the area. Shepherd commutes to Adrian every day for work.

In three years in a Pioneer uniform, Chapman's become one of the team's top forwards, with eight goals and seven assists on the year.

"She has a sniper snapshot," friend and teammate Mercedes Reyes said. "Probably one of the fastest in the league."

But after the diagnosis and documentary, many were shocked to learn what she's been dealing with for the past three years.

"When she describes the severity of it, it's like 'How do you do this?'" Pioneer coach Sandy Hurd said. "And the fact that exercise brings it on and she still comes and does it is just amazing. I don't know how she does it."

Chapman plans on attending Eastern Michigan next fall and transferring to Grand Valley State to play in their club hockey program.

She knows her disease will keep getting worse as time goes on.

But she'll keep stepping out onto the ice.

"I think hockey makes it a little bit better, because it gives me something to strive for," Chapman said.