Like her sisters before her, Val Mowatt needs a new liver. But women are more likely to die waiting for a transplant than men—and being First Nations and living in a rural region make getting one even harder.

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FIRST, THEY LOST JUDY. The youngest sister in a large family from the Gitxsan Nation in northwest British Columbia, she was in her 40s when she died. She was diagnosed with primary biliary cholangitis (PBC, which was previously known as primary biliary cirrhosis), an autoimmune disease that destroys the liver, and put on the province’s wait-list for a transplant. She died waiting, in 2014.

Next, Veronica. She found out she had the same disease in 2020. By fall, her liver was failing. She was put on the wait-list for a transplant. She also died waiting, on January 20, 2021.

A few months before Veronica’s death, her younger sister, Val, learned that she, too, has PBC. Val doesn’t want to die waiting.

Val Mowatt is 60, a retired paralegal with four children and seven grandchildren. She lives in Prince George, a city in central B.C. Since her October 2020 diagnosis, she has grown sicker and sicker. She suffers from ascites, a painful buildup of fluid in her abdomen that is a common complication of late-stage liver disease. She is tired all the time. Her body is fading; her voice is slow and starting to quaver. In February, her doctor told her she had perhaps three months before complete liver failure.

Mowatt would do anything to see her grandchildren grow up—but she’s running out of time. And she’s fighting not only the disease but also the health care system she must rely on to save her life. Part of the difficulty Mowatt faces is shared by anyone needing a liver transplant in Canada, that there just aren’t enough donor organs to go around. But there are added challenges for her because of the disease she has—and because of who she is: a First Nations woman living in a largely rural region.

PBC is genetic, seemingly triggered by some kind of environmental exposure. Nine out of 10 people with the disease are women, mostly between the ages of 40 and 60. If it’s caught early, medication can slow its progression. But once the liver stops functioning on its own—as was the case for Mowatt and her sisters—a transplant is often the only option left that can prolong life.

Across Canada, kidneys are by far the most common organ transplanted: About three-quarters of people waiting for a transplant at the end of 2019 needed one. In that same year, liver patients made up about 15 percent of those on waiting lists, and yet that group comprised nearly half—107 of 249—of those who died waiting.

JOANNE BURCHELL

“WOMEN ARE 14.4 PERCENT LESS LIKELY TO RECEIVE A DECEASED-DONOR LIVER THAN MEN.”

In February, Mowatt was told it would be a two-month wait for an appointment with specialists at Vancouver General Hospital to be considered for a transplant. By mid-April, she still hadn’t heard anything. BC Transplant, the provincial health agency responsible for organ donations and transplants, replied to a request for an interview with an email saying that wait times vary depending on clinical status.

Patients are prioritized using a system called Model for End-Stage Liver Disease (MELD). The sickest patients generally receive donor organs first, though other factors also influence allocations, such as blood type, geographic proximity and size. That’s one reason women are more likely to die waiting: They tend to be smaller, narrowing the pool of available organs. But researchers also suggest that the MELD system underestimates disease severity in women. A study in the peer-reviewed journal *JAMA Surgery* last year found that women are 8.6 percent more likely to die waiting for a liver transplant and 14.4 percent less likely to receive a deceased-donor liver than men.

At a support group, Mowatt learned of an alternative to waiting for a deceased donor: a living-donor transplant, during which surgeons remove a portion of the liver from a healthy person to replace the recipient’s failing one. If it’s successful, the liver regenerates in both people within a few months.

But living-donor transplants can’t currently be done in B.C. Five hospitals in Canada perform these operations: one in Edmonton, two in southern Ontario and two in Quebec. If B.C. refers patients out of province, it covers in-hospital costs but not travel and accommodation expenses, not to mention child care or any unpaid time away from work. (B.C. also doesn’t provide funding for patients, like Mowatt, who must travel within the province for specialized care.)

While rare in the general population, PBC is the top reason Indigenous people in the province need liver transplants. Researchers have examined the high rates of this disease in the province’s First Nations population and found that patients were referred for PBC-related liver transplants at a rate eight times higher than others. Clusters of the disease are particularly common along the Pacific coast and on Vancouver Island. “There is definitely a genetic basis for this,” says Dr. Eric Yoshida, a gastroenterologist and former medical director of B.C.’s liver transplant program, who has co-authored numerous studies on the prevalence of PBC among First Nations people.

The research has helped change medical culture, he says. “Historically, there was this widespread belief that liver disease in Indigenous communities was because of alcohol,” says Yoshida. “Now, instead of
assuming that any Indigenous person with severe liver disease is a [heavy alcohol consumer], they look for other causes, including autoimmune liver diseases.”

Yoshida was quick, however, to point to a November 2020 report on the province’s medical system that shows that discrimination and stereotyping are still pervasive. In Plain Sight: Addressing Indigenous-Specific Racism and Discrimination in B.C. Health Care noted a staggering 84 percent of Indigenous people experienced discrimination when accessing health care. More than a quarter reported health professionals always assumed they were drunk or asked them about substance use.

Mowatt’s genetics and gender made her vulnerable to PBC. Now she and her family wonder if racism is why the other sisters weren’t screened when medication could have slowed the progression, and why they all struggled to get a transplant. Her brother Kelly Morrison questions why the family didn’t hear about the possibility of a living-donor transplant while Judy or Veronica were waiting, and why Mowatt learned about it from a support group rather than a doctor. “We didn’t know what options we had,” he says. “[Judy and Veronica] could still be alive today.”

Early this year, at the hospital in Prince George, a technician asked Mowatt how long she’d been drinking. Having been instructed to stay well hydrated, she began describing her water intake. “He looks at me and says, ‘No, what happened to your liver? How long have you been drinking alcohol?’” she recounts.

She answered that the disease is genetic, that she’d already lost two sisters to it and that she didn’t drink alcohol heavily. He apologized, but the incident left her frightened. “If I end up in the emergency [room] again…. I worry that they’re going to treat me differently,” she says.

For many years, most jurisdictions in Canada required those who needed a liver transplant for alcohol-related reasons to abstain from drinking for six months before being considered eligible. In recent years, advocacy and legal challenges have led many provinces, including B.C., to backpedal on those policies.

In Ontario, the Selkirk Liver Society was founded in memory of a man who died in 2010 after being denied a transplant. Its members say that while transplant centres may no longer have an official abstinence rule, many still exclude patients who had previously been told to stop drinking and weren’t successful. In B.C., health officials say its six-month abstinence policy was mixed in 2019, but an unspecified period of abstinence “is still needed because the natural recovery of liver function can occur, reversing the need for a transplant.” Transplant patients must also be deemed low-risk for future alcohol use.

In 2019, David Dennis, a Nuu-chah-nulth man with end-stage liver disease, launched a complaint before the B.C. Human Rights Tribunal, arguing the abstinence policy “discriminates against Indigenous peoples, who have disproportionately higher rates of alcohol use disorder, linked to the centuries of violent colonial practices of all levels of government in Canada and the intergenerational trauma of Indian residential schools.” Since Dennis’ death in 2020, the Union of British Columbia Indian Chiefs (UBCIC) has taken on the complaint. In April, UBCIC contacted Mowatt to get involved and applied to amend the case to include another aspect of potential discrimination. Mowatt’s affidavit argues that First Nations women in B.C. suffer disproportionately higher rates of PBC and suggests MELD scores are biased against those with the disease, which “has the effect of discriminatory denial of liver transplants for Indigenous people.” (B.C.’s Ministry of Health said in a written statement that it would be inappropriate to comment “[out] of respect to the process of the B.C. Human Rights Tribunal.”)

A 2016 study in Transplant International that examined the outcomes of more than 81,000 patients in the United States with liver disease found those with PBC have a higher wait-list mortality rate than most. The authors suggested that PBC sufferers waiting for a liver transplant should be considered for “exception points” when their MELD scores are assessed.

“They won’t even look at you until you’re sick enough,” says Linda Morrison, Mowatt’s sister-in-law. “But then you have to stay stable and strong enough for a transplant [or] they’ll take you off the list.”

“I watched two sisters die of this,” says Keith Morrison. “I can’t wait around for another to die.”

In early April, Mowatt gave up on B.C. Her doctor referred her directly to the Edmonton centre that performs living-donor transplants and, within a couple of days, she had an appointment for an assessment in mid-June, or sooner if necessary. For the first time in months, she was hopeful. But then, Mowatt says, the Ministry of Health refused to approve paying for the treatment in Alberta because she hadn’t been referred by BC Transplant. The agency wrote in an email response that “ideally” patients see its team first. For patients referred out of province directly by their specialists, funding requests “would need to be assessed and coordinated with the B.C. Ministry of Health.”

Mowatt is determined to go to Edmonton. Her daughter and brothers are ready to undergo tests to determine if they are eligible donors, and the family is fundraising for travel costs—including a GoFundMe, Facebook raffles and virtual garage sales. “I don’t want to be stuck at the last minute and say, ‘I’m sorry, I don’t have the money to go,’” she says. The family is hoping that Mowatt will stay strong enough, long enough, to make it there.

They’re also hoping that B.C. will change course and agree to pay for the in-hospital costs. Mowatt has been contacting officials and politicians, asking for help. “I get really angry with them,” says Mowatt. “I told them, ‘Are you going to make me do the same thing that my sisters did—sit and wait to die?’”