

Middle-class FAS: a silent epidemic?

'One glass of wine won't hurt,' we often say -- but the latest research suggests alcohol in the womb is more damaging than we guessed, even in low doses. As MARGARET PHILIP reports, Canadian stereotypes that link fetal alcohol syndrome with poor and native mothers are misleading. It's the well-off who are most likely to drink during pregnancy

By MARGARET PHILIP

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Janet Christie was drunk when her son was conceived. In her first few months of pregnancy, she would cure the morning sickness with a nip of gin. And as her belly strained against her clothes, she was pouring stiff drinks almost every day.

Even then, in the 1970s, before stacks of science warned of alcohol's toll on the unborn brain, she knew drinking during pregnancy was frowned upon -- like smoking or junk-food binges. She cut down, but for an alcoholic with a fierce case of denial, quitting seemed about as easy as stopping breathing.

It would be years before it returned to haunt her as the searing regret of a lifetime.

"I came from a loving family, a nuclear family, mom and dad, brothers and sisters," Ms.

Christie, now 46, says of her ordinary upbringing in British Columbia's Fraser Valley. But she always felt she didn't fit in. "There is alcoholism in my family, if I go back a few generations. I believe I was born an alcoholic."

Her son was to struggle in school, humiliated by teachers convinced he was lazy and taunted by classmates who thought he was thick. By the time he was 13, the year she quit the bottle at last, he was running with thuggish older boys, out until all hours.

About a week after Ms. Christie knocked back her last drink ever, a police officer called late one night to report that her son had been found huddled in a closet during a bust at a crack house. "I thought he was a good little boy who didn't even play with matches, and there he was into crack cocaine."

Soon, he would descend into stealing, living off the proceeds of prostitution, sleeping in his car.

"For four years, not a day went by that I didn't receive a phone call from a police officer or a landlord or a neighbour or a probation officer or another parent."

She sometimes wondered if her drinking had caused her son's troubles, but would push the thought away. Not until he was 20 were her fears confirmed: He was diagnosed with fetal alcohol syndrome (**FAS**) -- a declaration that his brain was irrevocably damaged by alcohol exposure in the womb.

The profile of **FAS**, once an obscure diagnosis, is on the rise. A generation ago, even most doctors did not understand it; now, there is research aplenty to describe the smaller, malformed brains and lifetime of struggle that result when alcohol floods across the placenta into the womb.

Yet the label is still pinned most often on the children of poor and, in Canada, native women, living in squalid inner cities and remote reserves. Invisible are the middle-class mothers who drink during their pregnancies, whose problems with the bottle are shamefully concealed behind closed doors.

They are hardly a rare breed, and they are not just alcoholics like Ms. Christie. In fact, the expectant women most likely to imbibe are educated, older and of higher income -- women with stylish clothes and decent jobs who are the patients doctors least suspect.

"It costs a lot to drink," says Peter Selby, assistant professor in the University of Toronto's

department of family and community medicine and psychiatry. "Someone who has wine daily with meals has to afford that money to do it. We know that **FAS** doesn't necessarily happen to alcoholic women."

In fact, with no conclusive findings on the number of drinks a pregnant woman can consume without harming her baby, the experts conclude that no alcohol -- not a drop -- is safe. But when half of Canadian women drink and half of all pregnancies are unplanned, plenty of expectant mothers are exposing their fetuses to alcohol, if only for the short time before discovering they are pregnant. Nobody can say for sure that their children are born unscathed. The lion's share of federal funding for **FAS** is poured into programs exclusively for native children, a richly deserving population, but hardly alone. And at the same time, Ottawa has steadfastly resisted pressure to label wine and liquor bottles with warnings about the dangers of drinking while pregnant.

"Alcohol is not racist. It's not sexist. And it's certainly not classist," says Christine Loock, a developmental pediatrician at Vancouver's Sunny Hill Health Centre for Children, one of Canada's leading experts on **FAS**.

"Poverty does magnify health risks. If you're poor, you have less access to nutrition and health care and likely more psychosocial stressors. So if it's pneumonia, it's worse. If it's fetal alcohol syndrome, it's worse. But poverty doesn't cause fetal alcohol syndrome. Alcohol causes it." Yet rather than be diagnosed, middle-class children with **FAS** are far more often labelled as having attention deficit hyperactivity disorder, and shunted into private schools with other learning-disabled kids.

"I've seen many parents who are well-educated and have full-time, responsible, management kinds of jobs who have affected children. It tends to be a bit invisible because the mindset in Canada is that this is a native problem," says Ab Chudley, a pediatrician in the department of biochemistry and medical genetics at Children's Hospital in Winnipeg who has been diagnosing children with **FAS** for more than a decade.

"You might think for the child who has grown up in an upper-class area that his problems in school are behavioural issues or ADD and not think about the fact that alcohol may be behind it. It doesn't get recognized because it's not the first thing you think. Whereas if the child was native and had these problems, that's the first thing you'd think."

"When he got the diagnosis," Ms. Christie says now, "I was pumped. I wondered, 'Why am I so happy about this?' But I was. It answered so many questions. It was the missing piece of the puzzle."

But never will she escape the guilt. "It's really, really hard to watch your kid struggle through life, not sure whether he's going to make it or not, and knowing deep inside it's your fault."

Joe Margetson is late. There are scraps of paper pinned to the bulletin board above the telephone his mother's apartment in Guelph, Ont., a collage of all the phone numbers on the circuit of his life. They are mostly there for Joe, who struggles with the telephone book, but when he is late or forgets appointments altogether, his mother and older sister start dialling until they track him down.

Joe often forgets. At 23, he has outgrown the facial traits of his **FAS**, except for his razor-thin upper lip, a telltale sign. Tall and gangly, with tousled blond hair spilling from beneath a ball cap and a toothy grin, he is a handsome young man whose appearance betrays none of the brain damage that has confused his life for the past two decades.

"Foolish, drunken and harebrained women most often bring forth children like unto themselves, morose and languid." While less than charitable, Aristotle was on to something, more than 2,000 years before the diagnosis of **FAS** was invented by researchers at the University of Washington in 1973.

Since then, dozens of studies around the world have drawn the link between drinking during

pregnancy and neurological defects in children. Now, **FAS** is regarded as the largest cause of mental retardation in the Western world. About one of every 100 children in Canada is thought to suffer from the disorder.

Like thalidomide, the anti-nausea drug that left children born with deformed limbs in the early 1960s, alcohol is a teratogen, a toxic substance that passes undiluted across the placenta from mother to fetus. In the fledgling life, the alcohol damages the central nervous system, often leaving the brain smaller and smoother, stunts growth and subtly alters facial features. Joe's sister Amanda finally finds him at the house of a co-worker he had driven home after work at the Sleeman Brewery, where Joe has stocked shelves for the past 18 months, the longest he has ever held down a job. When he arrives, he insists that he is not late, that he was supposed to come home an hour later than the time his mother remembers.

Chris Margetson is hardly about to argue. When Amanda was born, she was stone-cold sober, but after her marriage crumbled, she started drinking. By the time Joe came along five years later, she had become the kind of hard-core alcoholic her upstanding, middle-class parents had been. Six months into the pregnancy, Chris was admitted into a Toronto hospital for alcohol treatment.

That was in 1979, and she has not sipped a drink since. But the damage was done. Her son has stumbled through life as an outcast in the classroom, seldom grasping the lessons that seemed second nature to his classmates, being ridiculed for his off-the-wall questions and quirkiness. The humiliation still stings.

"People automatically assume something about you because of what they see," he says, with disarming insight. "I get into disagreements sometimes because I feel that people don't respect me or don't respect what I have to say because of the fact that I didn't go to university, or I didn't read that book, or what have you. I've been judged throughout my life by teachers. And because the teachers would judge me, I didn't get a lot of respect from other students."

Today, Joe will never fully escape his maddening impulsiveness, his propensity to live in the moment without a thought to the lessons of the past or the consequences of the future. Money tends to slip through his fingers, with the abstract concepts of numbers and value elusive to the unusual workings of his mind.

"I'll know I need a new pair of shoes desperately, but instead I'll buy \$100 of records," he says. "I'll put my wants before my needs. That \$100 shirt looks a lot better than food."

Like many children with **FAS**, Joe was slow in reaching his baby milestones -- late to roll over, sit up, walk or utter his first words. "With each one he missed, I got a little more concerned and take him to the doctor," Chris says. "I was always reassured. I had a pediatrician and a family doctor and an addictions counsellor who I was seeing every few weeks. I was talking openly about my drinking during the pregnancy, and nobody said anything. Nobody raised it as a possibility."

But as Joe grew, so did his problems. As a toddler, he withdrew into a shell, oblivious to people talking to him. "It was like he shut down inside," his mother said. But still, no one connected the dots to his mother's prenatal alcoholic binges.

Convinced that she was deficient as a parent, Chris enrolled in an endless stream of parenting class, but none of the latest child-rearing techniques seemed to work with her little boy. She hauled Joe to a child psychiatrist, until he was collecting ominous diagnoses like marbles -- ADHD, conduct disorder, oppositional-defiance disorder. The Ritalin never worked.

When Joe was 7, Chris unburdened her troubles to the addictions counsellor she has visited for years. The woman turned to her husband, a developmental psychologist, for advice. He was the first to suggest **FAS**. By the time Joe was diagnosed at the Hospital for Sick Children's then-new Motherisk clinic, the first place in Canada to diagnose the disorder, Chris was convinced.

The doctor, however, broke the news that little could be done for children with **FAS**. It was like

an incurable disease.

"Joey and I got into the car, and all the way home I told him what I was thinking," Chris says. "I told him he had this disorder. He's 7, so he's taking in 10 per cent of it. I didn't know what to do. To a certain extent, it was a relief, because now I knew what the problem was. But it was devastating to be told by the doctor who knows the most in Canada that 'you're on your own, baby.' "

In that short drive back to Kitchener, Ont., where she lived at the time, she promised herself never to wallow in guilt that she had damaged her beloved son through her own vice. And, she says, she never has. "I could have gone down that road. One of the things I said to Joey -- I can still hear my voice saying it -- is: 'I did this to you, but there's nothing I can do about that now. I can't change what happened. But I can certainly change what happens in the future. That's the only power I have right now.' "

One thing that sets middle-class women raising children with **FAS** apart from women on the margins is their power to advocate for their children. Research shows that people with **FAS** face daunting odds of dropping out of school, getting fired from jobs, becoming teenage parents, dabbling in drugs, tangling with the police and drifting in and out of homelessness. But those are usually children whose parents were fighting off the child-welfare agencies, children raised in troubled homes or in foster care. It's different when they have feisty parents in their corners.

As soon as Joe was diagnosed, Chris pulled him out of the local public school (where his teacher often would banish him to an empty classroom to finish his schoolwork, even though he never did) and enrolled him in a private school with smaller classes and fewer distractions. At \$8,000 a year, private-school fees were a small fortune for a single parent. But it was the first time her son started to learn.

"Middle-class parents are able to buy what they need for their children to do well," says Chris, who has become an expert in **FAS** since Joe's diagnosis and now holds evening support groups for exhausted parents raising children with the disorder.

"I paid \$1,200 for a psychoeducational assessment to be done. There was a waiting list to get hold of the psychologist at school, so I got a private psychologist to do it. We're able to put in place certain things for our kids that other families can't even think about."

Prenatal drinking is notoriously hard to measure. Researchers have little choice but to rely on the mothers' honesty and their sometimes fading memories. Nonetheless, the two major studies done in Canada both confirm that the heavier drinkers tend to be older, more affluent women.

The National Population Health Survey found that 25 per cent of all women with children under 5 reported drinking alcohol while expecting babies.

But among higher-income mothers, it was 29 per cent, while only 21 per cent of poorer women reported doing so. Just 16 per cent of women under 25 drank, but the percentage among expectant mothers 35 and older was nearly double.

In the National Longitudinal Survey of Children and Youth, a massive Statistics Canada study that has followed nearly 15,000 families since 1994, the figures were a notch lower, but followed the same pattern.

And when academics questioned middle-class pregnant women about their drinking habits in Fort McMurray, a prosperous oil-sands town in northern Alberta, nearly half of the expectant mothers confessed to drinking even after learning they were pregnant; 43 per cent of women said they believed it was unharmed.

British Columbia mother Carrie Prentice, now 36, never drank when she was pregnant with her eldest child, daughter Jessie, 14 years ago. She knew almost from the moment she conceived, and she quit the bottle and her packs of cigarettes without a second thought.

Growing up in a middle-class family near Kamloops, B.C., with a rye-drinking father prone to

abusive slurs, she had longed for the white-picket-fence happiness of the families she saw around her. Her standard was set by *Little House on the Prairie*, her favourite television show as a little girl.

"I wanted to do it right," she remembers. "I knew you shouldn't drink or smoke. And I wanted to be one of those people you see on TV. I didn't have that childhood, and it's what I wanted to have."

But the second time she became pregnant, it took her months to notice the missed periods and thickening waistline. Though she was still living with Jessie's father, her drinking had been on the rise -- no longer just a party girl who would reserve her indulgences for the weekends, she was getting drunk almost every night, and had acquired a taste for marijuana besides.

When it finally dawned on her that she was expecting a baby, she quit drugs and booze, keeping only her cigarettes as a crutch. "I thought maybe nothing would happen," she says. "I didn't realize the fetus could be affected so small."

But her son Jamie, now 12, was affected. When he was born, listless, with hardly a whimper, he was whisked away from Ms. Prentice's side for a time. In the next few weeks, he never cried, even as he struggled vainly to suck from his mother's breast.

There was no clue that the scrawny, wizened baby was slowly starving, until Ms. Prentice returned to the doctor when he became ill with an ear infection and bronchitis. The alarmed physician discovered that she was producing no milk.

By the time he was a toddler, doctors were predicting Jamie would never walk.

But no one -- neither the doctors, Ms. Prentice nor Jamie's father, who was soon to walk out on the family -- suspected his problems stemmed from prenatal exposure to alcohol.

"I didn't even think of it," she says. "It didn't cross my mind. I thought you had to be falling-down drunk every day. I never thought you could just be sitting on your couch at home."

Like many alcoholics, Ms. Prentice was in a state of utter denial. She drank beer, vodka, tequila -- anything but rye, whose smell she could hardly stand. But while she avoided her father's drink, she was becoming more like him all the time. "I was screaming and yelling at the kids, and they were looking at me like I was some kind of evil monster," she says now with a shudder. "I'll never forget the look on their faces."

Not until she learned her parents were plotting to remove her children from her care did she seriously consider treatment. She was only 26 years old, her children just 4 and 2, when she was ushered into a treatment centre. Ten years later, she has remained sober, returned to college to become a community-support worker and now works in a residence for developmentally disabled children.

She lives in Mission, B.C., with her children and second husband, in a life not far from the one she has always wanted -- only with an unusual twist.

In a workshop at one of her first jobs after graduating from college, working with young offenders, she heard a woman lecture about **FAS** and the toll it takes on children. For Ms. Prentice, it was if she were describing her six-year-old son from head to toe. "She was going through all these things and I'm thinking, 'Oh my God. Oh no.' At lunch, I ran out to my car and started crying. 'This is my son. What have I done?' "

His was a classic case. Aside from his thin upper lip and misshapen palate, Jamie misses social cues and is unduly affectionate with strangers -- he's drawn to stroking the heads of bald men. His intelligence is borderline and he suffers from a severe learning disability that requires a teaching assistant to sit with him in his public-school classroom. His behaviour is erratic and impulsive, with no understanding of consequences for his actions. Even though he is close enough to walk home from school, his mother has arranged for the bus to drive him, lest he wander astray.

At night, he has trouble sleeping. Like a three-year-old, he needs constant reminders to brush his teeth and wash his hands. And he is physically awkward, mastering a two-wheeler without

training wheels only last year.

Last December, Dr. Look at Sunny Hill centre in Vancouver finally diagnosed Jamie with partial **FAS**. He suffered from prenatal damage to his central nervous system, and showed some of the textbook facial features, but not to the degree of warranting a label of the full-blown syndrome.

"I feel like I've ruined his life," Ms. Prentice says. "I took it away. I go through mourning. Mourning for us. I won't see him play ball or graduate from high school or do all of those normal things. Playing sports and having friends and going out independently -- he's not capable of doing these things. If there's trouble, it's going to find him."

Not all babies born to drinking mothers suffer from full-blown cases of **FAS**. Some have the neurological problems and stunted growth without the telltale thin upper lip and narrow eye slits; they are diagnosed with fetal alcohol effects or alcohol-related neurological defects, more insidious because they are serious disabilities that are invisible to the outside world. Many doctors now group these diagnoses as fetal alcohol spectrum disorder.

Researchers know that the more an expectant mother drinks, the more damage she can inflict. But the lingering, unanswered question is how little it takes. What happens to a fetus exposed to alcohol in the womb depends on the mother's nutrition, her age, her metabolism and the flukes of genetics. But every drink is like a spin of the revolver in a game of Russian roulette: It may do no harm, but then again, it might.

"We suggest absolutely no alcohol, because even at very low doses, we find differences," says Paul Connor, a neuropsychologist with the University of Washington's Fetal Alcohol and Drug Unit, where a study that has tracked 500 women and their children since 1975 shows the impact of prenatal drinking on children as they age. "Even small doses can have an effect. Not necessarily a massive effect, but it is an effect. Even at low levels, you still get a few IQ points of difference."

The mothers in this study are middle-class women who sought prenatal care from Seattle hospitals in the mid-1970s, when little social stigma attached to drinking while pregnant. Researchers have compared children born to women who abstained and those who drank various doses.

The more their mothers drank, the lower the children ranked on intelligence tests at the age of 7. By the end of Grade 2, the children of the heavier drinkers were enrolled in special-ed classes and rated by their teachers as disorganized, lacking tact, grammatically poor and easily distracted. By 14, they scored lowest on measures of attention, memory and arithmetic, and were most likely to be experimenting with alcohol themselves.

The University of Pittsburgh recently released findings from a study following 565 mothers and children since 1982, when the women were all four months pregnant. Even children whose mothers drank less than 1.5 drinks a week during pregnancy were a few pounds smaller as adolescents than those whose mothers never touched a drop. At every assessment, those whose mothers drank even lightly were shorter, lighter and had smaller head circumferences than those whose mothers abstained.

"What they see big-time in the fetal alcohol syndrome kids, we're seeing in a much more subtle fashion in our lightly exposed children," says Nancy Day, a professor of psychiatry, pediatrics and epidemiology at Pittsburgh's School of Medicine, the study's lead researcher.

"We're publishing these data, and have been publishing them for a long time, but the message isn't getting through. The women aren't being told and the physicians aren't helping them out with a really clear, consistent message."

Janet Christie was speaking to alcoholics at a treatment centre, as she sometimes does as part of her recovery, when she was approached by a man who had counselled people with **FAS**. He told her about the disorder, but also that her son could be helped -- **FAS** was not an

automatic life sentence of addiction, crime and homelessness.

"I remember the day I told him that," Ms. Christie says. "We were in my car, and he was 20 years old, and he put his head on my shoulder and he started to cry."

"That would be so sweet," he sobbed.

Ms. Christie could blame no one but herself for the mess of her son's life. But she also can take credit for sweeping up the debris. Since his mid-teens, she has always been there when he was scraping bottom and fighting a system that diagnoses only children suspected of suffering from **FAS**, and writes off the adults.

After years of marginal existence, her son has turned around. He no longer smokes crack. He has left his bad influences behind. He lives in his own apartment for the first time. And he's the father of a two-year-old daughter he was determined would not suffer from the disorder that will dog him for the rest of his life.

"When he was going through the hardship in his teens, I kept telling myself that he's going to outgrow this. It was hard days when I came to terms with some of the things he's never going to outgrow. It's really tough watching someone have a hard life and knowing it didn't have to be that way. The lost potential.

"I look at him sometimes and wonder, 'What your life would be like if none of this had happened. Where would you be now? What would you be doing?' "

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