The smallest babies face the biggest risks

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Hamilton Spectator – Born: A Code Red Project

Deep in the heart of Brantford is a neighbourhood of boarded-up buildings, a few rough-looking bars and a couple of pawn shops — “Welcome to the People’s Bank,” says a sign outside one.

A casino hasn’t helped its fortunes. Some say it’s been harmful.

Even the newspaper, the Brantford Expositor, pulled out of its historic downtown site for a new commercial strip plaza on the edge of town.

There are signs of life, to be sure. New buildings for Wilfrid Laurier University’s Brantford campus sprout like mushrooms along Dalhousie Street, but only make the irony all the more striking.

In a neighbourhood being slowly nursed back to health by the growing presence of two universities — Nipissing University also has a campus here — none of the 190 adults between the ages of 25 and 34 who lived here had a university degree, according to data from the last census. On top of that, nearly four in 10 adults over the age of 25 don’t have a high-school diploma.

By almost any measuring stick, this hunk of Brantford’s downtown can be counted as one of the most hurting neighbourhoods in all of Ontario.

Three-quarters of the children under age 18 live in poverty, according to census data. The median household income is $21,700, about one-third of the provincial average.

More than a quarter of all income is from government handouts, 27 per cent of families are headed by a single mother, and the unemployment rate is almost twice the provincial average.

When the social factors that help determine health collide with such ferocity, the wreckage looks a lot like this downtown Brantford neighbourhood.

It’s not surprising, then, that mothers and babies are paying the price, according to the results of a groundbreaking new Spectator analysis of 535,000 Ontario birth records.

Between 2006 and 2010, one in six babies in Brantford’s downtown was born with low birth weight — the second-worst performance of 2,100

neighbourhoods across the province.

On top of that, the rate of births to teenage mothers over that time was 17 per cent, which also ranked Brantford's downtown among Ontario's worst neighbourhoods. There is also a significant link between the rates of low-birth-weight babies and teen mothers.

Four out of five expectant mothers in Brantford's downtown neighbourhood received prenatal care in the first three months of pregnancy. While that sounds impressive, it's below the provincial average and well below the levels in the wealthy suburban municipalities of the Greater Toronto Area.

These are some of the findings uncovered by a massive Spectator examination of four years of birth outcomes and maternal health factors across Ontario.

The data has been broken down not just to the level of municipalities and communities but also to the level of neighbourhoods.

The project is an extension of The Spectator's landmark Code Red series last year, which explored the health of Hamilton at the neighbourhood level and showed the strong connections between poor health and areas of the city with high rates of poverty.

Low birth weight — considered less than 2,500 grams or 5.5 pounds — is associated with increased risks for lifelong health problems and significantly increased costs to the health-care system.

A major 2007 report on low-birth-weight babies from a not-for-profit health institute described the problem as "a complex issue with profound short- and long-term consequences for individuals, families and society (with) significant cost implications."

One Alberta study showed premature babies required five times more in direct health costs than full-term babies over the first seven years of life, while a report from Ontario's health ministry says hospital costs for caring for a small-for-gestational-age infant were 11 times higher than caring for infants born with healthy birth weight between 2005 and 2006.

In addition to those extra costs, "weight at birth is considered a key determinant of the chances for survival and good health," says a federal government document.

It's estimate that three-quarters of all deaths and illnesses in newborns occur in those with low birth weight, "and those that survive are more likely to experience learning disorders, visual impairment, respiratory illnesses

and cerebral palsy," according to an Ontario report.

The results of The Spectator's new investigation show many of the same social and economic problems that influenced health in Hamilton are also contributing to poor pregnancy-related outcomes in disadvantaged neighbourhoods across Ontario.

"It might be that many of these people do not have access to a family physician," said Dr. Neil Johnston, an expert in analyzing health data who has collaborated with The Spectator for both Code Red and this latest BORN project. "It might be they can't afford or aren't motivated to attend prenatal care sessions. It could be that coincident with all that, they may have domestic situations which preclude them from attending prenatal care.

"There could be a litany of things," Johnston added. "They might be less adequately nourished or have behaviours that are unhealthy.

"It's not a single smoking gun. It's almost a conspiracy of things that preclude them from ensuring the child they're carrying will be as healthy as possible."

Johnston is a health research faculty member in McMaster University's department of medicine and he's also associated with the Firestone Institute for Respiratory Health and St. Joseph's Healthcare.

Where poor social and economic conditions collide with high rates of low-birth-weight babies, Johnston said he expects less access to prenatal-care programs plays a role.

Which means, he added, any solutions to the problems of high rates of teen mothers or low-birth-weight babies or poor access to prenatal care will require a broad range of initiatives.

"We can throw all the money we want at health services — which we do anyway — but until such time as we take seriously these kind of gradients, particularly those that affect the health of children, frankly we may as well be pissing into the wind," said Johnston.

"You can fix people up to some extent but by the time they reach adulthood, in effect the die is cast.

"They may change their behaviour, they may give up smoking, they may do this, they may do that, but fundamentally, from that point on, their life is going to roll out in a fairly preordained fashion."

Of the 20 neighbourhoods in Ontario with the worst rates of low-birth-weight babies, three of them are found in the lower part of the former City of Hamilton.

In the neighbourhood bounded by Wellington and James streets between King and Cannon streets, nearly 15 per cent of all babies born between 2006 and 2010 had low birth weights.

That's more than twice the Ontario rate of 6.5 per cent, according to The Spectator's analysis.

This forlorn chunk of the city faces the same social and economic challenges as the downtown Brantford neighbourhood.

In this part of Hamilton, 74 per cent of children live below the poverty line, a rate four times higher than the provincial average.

More than a quarter of all income comes from government sources, the median household income is just $25,500, according to census data, and nearly 28 per cent of families are headed by a single mother.

A few blocks east, it's pretty much the same story.

GRAPHIC: Birthweight in Hamilton

In the neighbourhood marked by Sherman and Gage avenues, between Cannon Street and the rail line north of Barton Street, nearly one in seven babies is born with low birth weight, which puts it in 17th place among 2,100 Ontario neighbourhoods.

Nearly half of all children in this neighbourhood live below the poverty line. The unemployment rate is more than 15 per cent and nearly one in three families is headed by a single mom.

In fact, the low-birth-weight story is similar to the story in last Saturday's opening instalment of The Spectator's BORN investigation.

Much like the concentration of teen mothers, the distribution of low-birth-weight babies is disproportionately high in Hamilton's inner city, where incomes are lower and poverty is heavily concentrated.

In the area bounded by Queen Street and Kenilworth Avenue, the rate of low-birth-weight babies is 8 per cent. For the rest of the amalgamated City of Hamilton, the rate is 6.1 per cent.

In Ancaster, for example, the low-birth-weight rate is 5.9 per cent. In Dundas, it's 5 per cent; in Stoney Creek, it's 4.5 per cent; and in Glanbrook

the rate is 4.1 per cent.

The 18 Hamilton neighbourhoods with the highest rates of low-birth-weight babies are all found in the former City of Hamilton, and 14 of those are in the lower city.

Smoking during pregnancy is one significant risk factor that can lead to low-birth-weight babies.

Smoking rates are also inversely related to income — the lower the income, the higher the rate of smoking — so it's not surprising there's a connection between smoking, poverty and increased rates of low-birth-weight babies in Hamilton's lower inner city.

According to a 2007 report prepared by Hamilton's public health department, there were parts of the city where the rates of smoking by pregnant mothers may have exceeded 40 per cent.

"It wasn't that long ago that women would smoke to have a smaller baby so they'd have an easier delivery," said Dr. David Price, chair of McMaster's department of family medicine.

He's also the founding director of the Maternity Centre on James Street South, which counts a high proportion of low-income and at-risk pregnant women among its clientele.

About one-quarter of the women treated at the centre were smoking at the beginning of their pregnancies, Price said.

With a lot of intervention, he added, the centre has been able to reduce the smoking rate to below 20 per cent — an improvement, he noted, but still worrisome.

Since the original Code Red series last year, the city has been developing a strategy to deal specifically with the problem of low-birth-weight babies.

"This is one where I would hold every level of government and every major institution in our community accountable," said Dr. Chris Mackie, a Hamilton associate medical officer of health. "We haven't handled this issue.

"We haven't solved this problem and it's been known for some time that it's a major problem.

"We're looking for opportunities to partner with the community," Mackie added.

“We really think that government can’t do it alone because the issues are so embedded in the culture of those communities.”

For weeks now, home away from their Hamilton home has been the neonatal intensive care unit at McMaster Children’s Hospital, after Ella made an unexpected appearance at 3:25 a.m. on Sept. 12.

That was 11 weeks before the date she was due to arrive.

At just 28 weeks of gestation, Ella’s fragile lungs, heart and nervous system were under tremendous stress — as were her parents.

In this case, the tiny apple didn’t fall far from the tree.

Back in 1978, Michelle herself was a premature baby, also born around 28 weeks, and also a patient in McMaster’s neonatal ICU.

She still has a yellowed Spectator clipping, a feature piece about the unit that includes a picture of her own mother, Debbie Beaulieu, pregnant with Michelle.

Michelle was four years old when Beaulieu died, so she doesn’t have the chance now to seek her advice or commiserate.

“I don’t have any history from her herself, so I’m relying on what my father tells me,” she said. “But he doesn’t remember that much, because he’s a man.

“They don’t pay attention to detail.”

Michelle keeps the article close to her daughter’s incubator as a bit of inspiration for both mother and child.

Thirty-three years ago, a 28-week preterm baby was a far bigger challenge for the neonatal intensive care unit.

“I was much larger though,” Michelle said with a laugh. “I was about four pounds.”

Her daughter, by contrast, arrived weighing two pounds eight ounces — just over 1,100 grams. This easily put her into a special category — very-low-birth-weight babies — reserved for those under 1,500 grams.

There were no indications Ella was going to be a premature baby.

The day before her arrival was normal enough, except Michelle did notice when she woke up there was a lot of room between her chest and stomach.

“My stomach had dropped and I remember saying. ‘That doesn’t usually happen until right before you deliver,’” she said. “I just thought it was weird, maybe I need to go eat some breakfast.”

That night, she went to bed and awoke at 11:30 p.m. with cramping. It happened again and then again, and when it happened a fourth time, she roused Mike after she went to the bathroom and noticed some bleeding.

“I’m yelling ‘Call the hospital,’ and he’s like, ‘I don’t know the number,’” Michelle said. “At that point, I was still not thinking I was in labour.”

By 3 a.m., Michelle was told to hand her jewellery to Mike because she was being wheeled in for an emergency caesarean section. “When they said, ‘You’re going into labour,’ I’m thinking, ‘I’m not ready, she’s not ready, it’s too early,’” said Michelle. “I was more panicked than anything.”

“They kept saying ‘Lower your breathing, you’re going to hyperventilate,’ and I’m thinking, ‘It’s too late, I’m already hyperventilating,’” she added.

“I was standing and then sitting and then trying to stand again, trying to keep my composure and comfort her as much as I can,” said Mike. “It was completely unexpected, too, so I didn’t really get to prepare myself for it.

“There she is and it’s my first child, it was the best moment of my life.”

But it was a short-lived moment.

Within seconds of Ella’s birth, Mike said, she was taken to the neonatal ICU.

“When you’re going into labour, you picture this moment where you get to hold your child for the first time — and it never happened,” said Michelle.

“The nursing staff, everyone is saying, ‘Congratulations, congratulations,’ and I’m thinking, ‘For what?’” Michelle recalled. “It didn’t really register that I had had a baby because I didn’t get to see her or hold her or touch her, to know that everything was OK.”

“There’s nobody there to comfort you, to assure you that it’s OK.”

And then the tears flowed.

“When everyone left the room with the baby and it was just you and I in the room by ourselves,” Michelle said, with a nod to her husband. “He looked at me and he started to cry and he said ‘She’s so small.’

“That’s all he kept saying. And I didn’t even get to see her.

“I don’t know what she looked like, I don’t know how small is small.”

No mother expects the first time she sees her newborn will be through an incubator with a jumble of tubes jutting out of such a tiny body.

“The first few days, you just pray she makes it to the next day,” said Michelle. “You don’t know how bad it is. Is she going to live tomorrow?

“You don’t want to call her by her name, you don’t want to have an attachment to her the first few days because you don’t know if she’s going to be there the next,” she added. “You think that in the back of your mind without saying it out loud.”

The next emotional marker was the day Michelle was discharged, because Ella stayed behind.

“I cried the whole way home in the car,” Michelle said. “He’s telling me ‘I think you need to see some help,’ and I’m like, ‘I’m allowed to be sad.’ He’s like, ‘You know, I’m really concerned, you’re awfully sad.’

“He’s thinking I have depression issues, and I’m saying ‘I’m not depressed, I’m sad and I’m allowed to be sad. I’m going home without my baby, that’s not the way it was supposed to happen.’”

“I didn’t know what to do,” Mike interjects, a bit sheepishly. “I just wanted the best for you.”

In hindsight, Mike is advised, it’s probably not wise to tell a woman who has just given birth to a severely premature baby still lying in a neonatal ICU incubator that she might need psychiatric help.

“I learned that right after I said it,” Mike noted with a laugh. “I was, like, ‘Oh wait, this is a bad thing to say.’

“I attribute that to no sleep, too,” he added in his defence. “It was probably about 72 hours with maybe one hour of sleep.”

He turned to Michelle. “You forgive me, right?”

“He’s forgiven for that one,” Michelle said.

Ella went home from hospital Nov. 7. As of Wednesday, she weighed seven pounds six ounces.

The Carniellos hope that now

their life as a family will begin in proper fashion.

“I’m always going to picture her as this little baby,” said Mike. “Always.

“She’s going to hate me for it.”

Kristina Walker, a nurse in the neonatal ICU at McMaster Children’s Hospital: “When you’re dealing with an adult, an adult can advocate for themselves most of the time, and even if you do have a confused adult, they can yell at you if you’re doing something that hurts them.

“Babies cannot do the same. They cry and they can be upset but they can’t advocate for themselves. They can just show us signals.

“You’re always thinking, ‘This is the rest of someone’s life.’ The big difference from adults to babies is that with adults, it’s sometimes at the end of their life.

“They’ve grown up, they’ve had a family, they’ve had experiences. This is at the beginning of life and you do think ‘This is going to affect them for the rest of their life,’ and you hope everything goes well.

“Like I say to people, no one plans to come here. No one has us in their birthing plan. So when they come here, it’s a shock.”

The Spectator’s analysis of birth data shows Ontario’s largest cities have some of the worst rates of low-birth-weight babies.

The combined rate of low-birth-weight babies for Ontario’s 10 largest municipalities — which account for about 60 per cent of all births in the province — is 7 per cent, compared to the Ontario average of 6.5 per cent.

For the rest of Ontario’s smaller municipalities, the combined rate is 5.9 per cent.

Brampton’s rate of 8.1 per cent is the highest of all municipalities with at least 500 births between 2006 and 2010. Ajax is right behind at 8 per cent.

The neighbourhood with the highest rate of low-birth-weight babies in Ontario is in Vaughan, a wealthy Toronto suburb that also has one of the lowest rates of teen mothers in the province. There, 16.4 per cent of babies born in that four-year period had low birth weights.

Toronto, Mississauga, Kingston and Markham are also above the provincial average for low-birth-weight babies.

There aren’t always simple explanations for these anomalies.

Social and economic factors clearly play a role in the rate of low-birth-

weight babies born in Ontario.

But they don’t play the only role, which explains why the rate will never drop to zero. Some of the causes of low birth weight cut across all socioeconomic strata.

It’s important to distinguish between two categories of low-birth-weight babies. There are those babies who have low birth weight because they don’t grow and develop in utero to the appropriate level, and those who have a low birth weight because they are born prematurely.

Up to 30 per cent of low-birth-weight babies can be attributed to the social and economic factors that might affect a pregnant mother, according to surveys conducted in the U.S. and U.K.

That still leaves two-thirds of cases that fall into physiological categories that aren’t directly connected to the mother’s social or economic situation.

Maternal age, for one, can contribute. Young first-time moms, such as teens, are more prone to having low-birth-weight babies. So are women on the opposite end of the spectrum — first-time moms older than 35.

This expanding segment of society — the birth rate among Ontario mothers between the ages of 35 and 39 grew by a third between 1995 and 2004 — helps to explain why the province’s low-birth-weight rate has actually risen slightly in past decades.

The growth of in vitro fertilization and other fertility treatments could also be factors. According to a provincial report, women undergoing IVF treatments are nearly 14 times as likely to have multiples — twins, triplets or otherwise — which are closely linked to higher rates of low birth weight and premature deliveries.

Ethnicity, too, plays a role. A 2010 report from Peel Public Health showed women of South Asian, Caribbean and African heritage who gave birth between 2002 and 2006 were as much as one-third more likely to have low-birth-weight babies. This could help to explain elevated low-birth-weight rates in Mississauga and Brampton, two communities with growing South Asian populations.

For Mackie, the Hamilton associate medical officer of health, it’s important to distinguish between the socioeconomic and physiological causes. It’s also important to distinguish between potential outcomes.

“They’re almost polar opposites,” Mackie said. “In the case of in vitro fertilization, you’re almost always talking about a couple that is

economically well-to-do, older, established in their careers, so they have some stability in their lives.

“(These babies) are going into families where, statistically speaking, they’re much more likely to get the support they need to grow up healthy and well.”

Meet Dr. Christoph Fusch

He’s the chair of McMaster’s neonatology division.

“I love this medicine,” said Fusch. “I would never do anything different.

“I think it’s one part of medicine that has really improved in terms of survival rates and quality of survival.

“Neonatal medicine is a very challenging medicine, very intense and it needs a lot of commitment but I think it’s one of the most rewarding types of medicine you can do because it’s so nice to see a baby survive and survive in a good way,” Fusch added.

“The good thing is it happens much more often than the disastrous cases.”

In his experience, the advances in neonatal medicine over the past four decades have been nothing less than stunning.

“Forty years ago, about 50 per cent of 1,500-gram babies died,” said Fusch. “The other half survived but with major complications.

“Now, today, a 1,500-gram baby? They should not have a problem.

“It should be smooth care here, and then they go home after a couple of weeks, maybe three or four weeks,” Fusch added. “This baby can grow without any health problems in later life, live a normal life and become a valuable member of society.

“What we are interested in is disease-free survival, and that is increasing more and more in neonatal medicine,” said Fusch. “It’s not only important that more babies survive but the babies survive in better shape.”

A quarter of a century ago, Fusch was associated with the University of Tubingen, one of the world’s top medical schools, near Stuttgart, Germany.

He can recall the excitement in the neonatal unit at that time because premature babies delivered at 29 weeks were about to arrive, and

everyone was praying for successful outcomes.

“Now, today, a 29-weeker is not a problem,” Fusch said.

Fifteen years ago, when he was in Bern, Switzerland, the hospital wouldn’t deal with 25-week babies and some deliveries of 26-week babies.

“Today, a 26-weeker has a 90 per cent chance of survival and about a 78 per cent chance to survive without a problem,” said Fusch.

But there is a cost attached to these miraculous advances, and Fusch admits intensive care for newborns is not cheap.

The average length of stay for a baby in McMaster’s neonatal ICU is 10 to 20 days, and that could result in hospital costs alone ranging as high as $34,000 because the McMaster unit is considered a Level III, which means it handles the toughest and most complicated cases.

“And for the very tiny babies, it’s easily up to $80,000 or $100,000 each,” said Fusch.

“So what do we get for those costs?” he asks. “Or let’s do it the other way — what do we get if we don’t provide this intensive care?”

For one thing, there would be more deaths. Strictly from the perspective of a cold-hearted bean counter, that might be acceptable because deaths are cheap, when it comes to the bottom line.

But there is still a natural survival rate for low-birth-weight and premature babies, even for those at the tiniest end of the spectrum.

“If we say ‘You know what, this is too expensive for us, we won’t do neonatal intensive care anymore,’ then the mortality would go up,” said Fusch, “but what’s more important is that the quality of survival for those who do not die is much lower.

“There will be more babies with lung damage, more babies with gut damage, more babies with brain damage.

“The number of babies who might be handicapped is much higher at the end,” he added, “and each handicapped baby that survives will cost between $500,000 and $1.5 million in lifelong costs.

“You can easily see that if this unit prevents 10 babies from becoming handicapped, it has easily earned its costs.”

Despite the stress, despite the sad cases stuck in his mind for as long as a

decade, Fusch said, the wonder of dealing with the most fragile of humans has never waned.

“The longer I’m in the job, the more a miracle I think it is that a 24-weeker — who is not supposed to be in the open air — is able to breathe, is able to cry, is able to digest and continue to develop,” said Fusch.

“The longer I’m in the job, the bigger the miracle. Not the mystery, but the miracle.”