Gluten-free baby: When parents ignore science

macleans.ca/society/health/gluten-free-baby-when-parents-ignore-science

Aaron Hutchins Jan 11,

2017

The first time Daniel Bissonnette saw Goldfish crackers, Fruit Loops and blue Jell-O, his mother recalls, he mistook them for art supplies. He was three years old and his preschool teacher had just served the kids snacks. Daniel began smearing the Jell-O on a piece of paper as if he were painting the ocean. The Fruit Loops were going to represent bubbles and the bright orange crackers, obviously, fish. But he was really confused when the teacher handed him a spoon. Then Daniel looked around the room and saw the other kids eating their materials.

"He'd only seen food in its unrefined raw form," says Ilana Bissonnette from their home near Coquitlam, B.C. "Then he saw that things out there in the world were very different."

That story may seem incredible, but for the first six years of his life, she says, Daniel was raised on a raw, vegan, non-GMO, unprocessed diet, which means he only ate uncooked, unprocessed foods, and no meat or products of animal origin. The diet stemmed from llana's experience trying to get pregnant. When she went off birth control, her menstrual cycle wasn't getting back to normal. She and her husband sought out solutions through conventional medicine, without success. Then, a year later, she switched to a vegan, mostly raw diet. She says her cycle resumed and she got pregnant with Daniel. So when it came time for him to start eating solid foods, she decided it was best to start him off on the same diet—despite objections from both doctors and relatives.

"My parents thought I was insane for <u>going vegan</u>, for going raw, and for breastfeeding as long as I did," Ilana says—three years for Daniel and four years for her second son, Adam. It wasn't just the extended breastfeeding. "It was pretty much exclusive breastfeeding for the first two years. My approach was to put the best nutrition in me so I could produce the best breast milk and feed it to my children."

Bissonnette didn't stop with her own sons; she created "Raising Raw Babies," a three-hour audio program for interested parents (cost: US\$75), which covers topics such as conception, pregnancy, breastfeeding and feeding children. Bissonnette acknowledges she's not a nutritionist or a doctor. "I found the experts that I knew would have the answers and I did the research," she says.

Bissonnette is among the growing number of parents discounting conventional nutrition—and in many cases, conventional medicine, too—to carve their own path in raising their children. It's difficult to know just how many parents are raising their children sugar-free, gluten-free, or on raw-food or paleolithic diets. But browse your local bookstore, or

Amazon, and you'll find an abundance of literature on the subjects, from *Well Adjusted Babies: A Chiropractic Guide for Holistic Parenting from Pregnancy Through to Early Childhood*, written by Australian chiropractor Jennifer Barham-Floreani, to *Eat Like a Dinosaur*, which offers tips and recipes to raise kids on a paleo diet. Online there is a plethora of blogs, such as *The Raw Food Mum*, *The Vegan Momma*, *Fruit-Powered* and *The Paleo Mom*, whose author, Sarah Ballantyne, has published a book, *The Paleo Approach*, and claims the diet can help manage and even reverse autoimmune diseases like rheumatoid arthritis and psoriasis.

Ballantyne discovered the benefits of going paleo first hand. A Canadian expat who got her doctorate in medical biophysics at Western University in London, Ont., but who now calls Georgia home, she was seeking help for her psoriasis and eczema five years ago, so she did what comes naturally to her: research. Ballantyne found her answer in "the caveman diet," as it is often dubbed, which gives the green light to fruits, <u>vegetables</u>, meats, seafood, nuts and seeds, and shuns all dairy, grains, legumes, and vegetable oils as well as refined or processed foods.

"I thought it sounded really extreme," she admits. But she gave it a shot, and not only did her skin soon clear up, her migraines disappeared and her irritable bowel syndrome was gone. She felt so good she followed through on the diet with her kids—first making the shift to cut out gluten and then transition them to the paleo diet.

Ballantyne insists she relies only on reputable research, but many of the alt-parenting books and blogs draw from a wealth of popular yet contested work in alternative nutrition and health.

In their day-to-day lives, the Bissonnettes' primary online health resource is the website of Joseph Mercola, an anti-vaccine, alternative-health physician who often counsels against trusting medical professionals, scientific researchers and government agencies. While Mercola has been a guest on <u>Dr. Oz's TV show</u>, he was presented as "the man your doctor doesn't want you to listen to."

These are arguably boom times for people who fit that description. Alternative therapies are a growing business, while celebrities and bloggers are emerging as authorities on lifestyle and nutrition, advocating for everything from the latest dieting trends to homeopathic remedies. Now, we are witnessing the phenomenon filter down to society's most vulnerable members—children. The parenting choices of Kourtney Kardashian are broadcast to her more than 50 million Instagram followers and become fodder for tabloid news outlets, like her decision to raise her kids on a gluten-free, dairy-free diet. Meanwhile, Rainbeau Mars, a Hollywood yogi and former global ambassador for Adidas, encourages families to go vegan.

But when does out-of-the-box parenting end up going too far? A recent article on *Gizmodo*, the popular tech website, argued, "If you feed your baby the paleo diet you should be in prison." Last summer, an Italian parliamentarian put forward the idea of jailing parents who

raise their kids on a vegan diet, after a spate of high-profile cases of vegan toddlers needing emergency hospital care.

Those are extreme reactions, but dieticians agree that diets can be risky for children. "Once you start restricting food groups or large chunks of food groups, you start running into problems like vitamin and mineral deficiency," says Karen Kuperberg, a registered dietician who works with the Failure to Thrive program at the Hospital for Sick Children in Toronto. "In general, any diets for kids aren't recommended. You want kids to eat a variety of foods from all food groups."

Should parents be left to decide what diet is best for their children, even against the advice of medical professionals? Should they be allowed to impose alternative remedies on their children like chiropractic care or homeopathy? Parents only want what's best for their own children, after all. And yet parents following dubious authorities can go astray despite their best of intentions. As Bissonnette puts it, coming from another perspective: "It's not something you want to play around with. It's your kid's life."



The phenomenon of kids on fad diets is not merely the reflection of recent fashions in dieting, but may rather be the product of a number of broader cultural tendencies. For one, there is the trend toward vilifying or fetishizing components of food, be it <u>sugar</u>, fat, gluten, salt or protein. Consider the gluten-free boom: Despite the fact that only an estimated one

per cent of Americans lives with celiac disease, an autoimmune disorder that would require a gluten-free diet, a 2015 survey found about one of every five Americans actively choose to eat gluten-free foods. Meanwhile the spike in protein consumption is so far-reaching that General Mills created a "Cheerios Protein."

Couple all the nutritional tips and dietary hand-wringing with the influx of parenting advice—via books and blogs on topics ranging from attachment parenting to helicopter parenting to "tiger" parenting—and it's not surprising that what kids eat has become an area of serious focus in North America. A 2013 survey from an independent American advertising agency found that 52 per cent of Millennial parents closely monitor their children's diet, while food-tracking apps like Kurbo allow parents and their children to monitor eating habits via a traffic light system (red: foods to avoid; yellow: eat in moderation; green: help yourself).

Another factor in the rise of the phenomenon is a broader data illiteracy in our culture. "Stories and narratives always win out over the data," says Timothy Caulfield, a professor in law and public health at the University of Alberta and the Canada Research Chair in Health Law and Policy. "One good cover story in *People* magazine about Kourtney Kardashian is always going to win out over a whole body of evidence."

With cherry-picked scientific evidence, it's possible to find support for almost any argument, and medical professionals and scientists—no matter their qualifications—now compete on the Internet with alternative health proponents or bloggers who have little more than a personal success story. A claim on Mercola's website about certain kinds of brassieres potentially causing cancer, for example, cited leaders in the alternative medical field and a 1995 study from an anthropologist. Even though cancer researchers have found no such linkage, the theory circulated far and wide—even ending up on the popular (albeit equally controversial) lifestyle website *Goop*, curated by Oscar-winning health authority Gwyneth Paltrow.

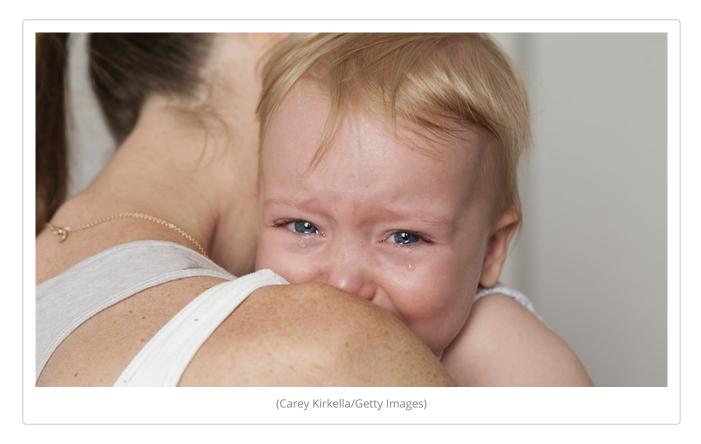
One frequently cited source for going raw (he pops up on Bissonnette's website) is Gabriel Cousens, a holistic nutritionist who claims to have a cure for diabetes through a 21-day program where insulin is no longer needed after as little as four days. Another popular figure is Brian Clement, a nutritionist who boasted that his alternative therapy health spa in Florida has cured everything from leukemia to multiple sclerosis. (He was ordered by the Florida Department of Health to stop calling himself a medical doctor after treating leukemia-stricken Ontario First Nations girls with Vitamin C injections, laser therapy and a raw food diet.)

In a more mainstream vein, the paleo diet has come under plenty of criticism from experts. An evidence-based review of the diet for the Dieticians of Canada led by Tanis Fenton, a dietician and epidemiologist at the University of Calgary, concluded that "several of the premises of the paleo diet are not supported by evidence." Harvard's medical school came

to the same conclusion in a 2015 article: "There is no strong scientific evidence at this time for claims that a paleo diet helps prevent or treat many medical conditions." Yet interest shows no signs of ebbing.

For children, following a strict paleo diet does offer some benefits: it means eating whole foods as opposed to the prepackaged kind, long relied upon by hurried parents. But it can also potentially lead to serious dietary deficiencies. "A child would have to consume five cups of cooked spinach to get the same amount of calcium as in two cups of milk," says Fenton. "A couple of cups of milk is possible in a day. I've never met a child that would eat five cups of cooked spinach a day." Fenton adds that shunning grains and legumes isn't recommended either because those foods can be rich in important vitamins, minerals and nutrients.

It's not that restrictive diets—such as raw, vegan or paleo—can't be followed; it's just easy to get them wrong. They're also often unnecessary for parents looking for ways to raise healthier kids.



Kuperberg, the nutritionist at Sick Kids hospital in Toronto, has seen children in her clinic with everything from cognitive delays to rickets, a softening of the bones due to lack of vitamin D or calcium. One family, she remembers, had a diet that encompassed basically fruit, nuts, seeds and homemade almond milk—and the child came in with vitamin D deficiency, vitamin B12 deficiency, and, well, "the list was endless," Kuperberg says. Some families dutifully follow Kuperberg's advice to get their child's diet back on track. For parents who fail to provide their kids a healthy diet, under worst-case scenarios, she says, Children's

Aid has had to step in.

Professionals like Kuperberg, of course, can only help the kids who end up at a hospital or clinic in the first place. Families with nutritionally starved children can easily fly under the radar. "When the kids are at home, there's no way of knowing—especially infants or toddlers who aren't even at school," Kuperberg says. In which case, parents are at risk of their own misinformation hurting the ones they love.

"It's an interesting question: when does it cross over from reasonable parenting to almost abuse?" says Caulfield. "When is that line crossed? When you're compromising the health of a child in some way, I think that's when it becomes an issue."

Caulfield thinks more science is the answer. "We need better information about what basic nutrition is," he says. "We need to have a science-literate society and a food-literate society. The best we can do is work with the best evidence available."

Consider the popular gluten-free diet. "It's a restrictive diet that's totally unnecessary," says Peter Green, director of the Celiac Disease Center at Columbia University. "A gluten-free diet is a life-saving diet for those with celiac disease. But if you don't have celiac disease, we don't think it's a healthy diet." Green says that, for children, a gluten-free diet can often be low in both vitamins and fibre, and there is the worry of companies adding unhealthy ingredients so that gluten-free products still maintain their taste. "If parents buy a lot of products labelled as gluten-free, often when they take gluten out of the product, they add more salt," Green adds.

A commentary published last year in the *Journal of Pediatrics* likewise stated that gluten-free packaged foods often have more fat and sugar than the equivalent foods containing gluten. Other studies have found that a gluten-free diet coincided with increases in obesity, caloric intake and new-onset insulin resistance. As for the claims that gluten is toxic or that a gluten-free diet is a good idea for infants at risk of developing celiac disease—all these were labelled as "fiction" by the commentary's author, gastroenterologist Norelle Reilly, director of the Celiac Disease Center's pediatric program.

Green is all in favour of going gluten-free if it's medically required. But therein lies another problem: parents who incorrectly self-diagnose themselves or their children. A 2013 study of people who self-reported as having non-celiac gluten sensitivity found that "gluten-specific effects were observed in only eight per cent of participants." "If children are having problems, they should be evaluated rather than [for parents to] assume that it's gluten," Green says.



But no matter how many decades of research Green has published about why gluten isn't evil, or how many talks Fenton gives on reasons to avoid going paleo, or how many times Kuperberg recommends parents avoid any kind of diet but a balanced one, none of them can compete with the reach of the rich and famous like Kardashian or Paltrow or the market appeals of a celebrity chef like Australian Pete Evans.

Evans's paleo cookbook, *Bubba Yum Yum: The Paleo Way for New Mums, Babies and Toddlers*, was delayed when the Public Health Association of Australia brought up major concerns—namely that his liver-based do-it-yourself baby formula recipe would have 10 times the daily maximum amount of vitamin A considered safe for babies. "There's a very real possibility that a baby may die if this book goes ahead," Heather Yeatman, president of the Public Health Association of Australia, told local media. The publisher pulled the plug on the book, but Evans opted to self-publish with minor modifications. The Dieticians Association of Australia said the reworked recipe could still seriously harm babies, though Evans did give the formula a new name: "Happy Tummy Brew."

It seems unfair to take parents to task for feeding their kids too many beets. Part of the appeal of these new diets is the damage that more conventional eating patterns can do. A gluten-free or dairy-free diet is counter to most nutritionists' recommendations, but so too is taking a child regularly to fast food restaurants or allowing them to fill up on pop or sugary treats at home, as millions of North American parents do routinely. In Canada, 13 per cent of children between the ages of five and 17 are obese, according to a 2016 Senate report, nearly tripling the percentage from 1980. Another 20 per cent are considered overweight, and the health consequences of the excess pounds range from Type 2 diabetes to poor emotional health.

But the failures of the mainstream are not a direct path to alternative nutrition or medicine, notes Caulfield. For alternative medicine proponents who argue some practices in conventional medicine lack scientific evidence, "that's an argument for better science," Caulfield says, as opposed to "alternative medicine saying, 'We want our turn to provide useless therapies too.'"

Parents who are committed to newfangled diets do have an advantage: they are paying close attention to what their children eat; they may also be more vigilant about other health factors, like ensuring their kids get enough exercise. With good science, their dedication would be commendable. With dubious science, though, the results can be disastrous.

That's a lesson Katya Nova learned the hard way. Originally from Edmonton, Nova had plans to her raise her son Zion on a vegan diet—and she had thousands of Instagram followers giving her plenty of love throughout her journey. But trouble struck when Zion's teeth started to come in. One tooth, she recalls, had started to crumble apart by his first birthday. "It happened so fast," Nova says. "His teeth are just really weak."

She decided to introduce some animal products into Zion's diet, such as cod liver oil and grass-fed dairy. When she announced her decision on social media, she says, "My Instagram followers dropped by 2,000 in 48 hours. There were a lot of angry vegans who said, 'How dare you use your huge platform to say that a vegan diet may not be suitable to all children?' "

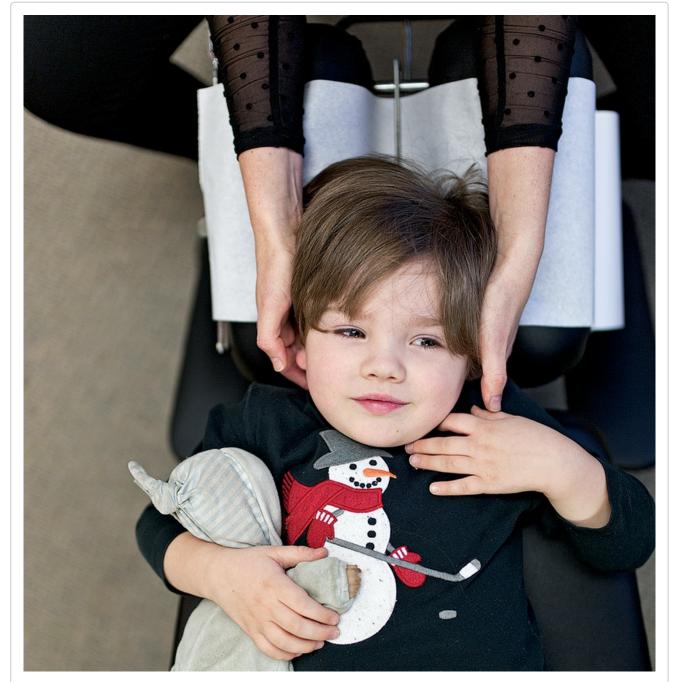
Nevertheless, Nova says her family has dropped the labels and won't get neurotic if their child has cake at a birthday party. "I can understand the danger of a plant-based mama who is passionate about the ethical part of veganism but does not know how to come up with a really balanced diet," she says. "That can be dangerous."



Indeed, the headlines point to the tragic consequences when overzealous ideas about "all-natural" food or medicine—for children, especially, the two are very closely tied—go way too far. In Mississauga, Ont., in 2011, two-year-old Matinah Hosannah died of complications from asthma and severe malnutrition stemming from a vegan diet lacking in vitamin D and B12. A similar tragic outcome occurred in 2012 with 19-month old Ezekiel Stephan of Cardston County, Alta. His parents diagnosed their toddler's meningitis as croup and treated it with natural remedies like olive leaf extract, garlic, hot peppers and horseradish. When his condition worsened—his tiny body was too stiff to settle into a car seat—the parents consulted a naturopath (not a pediatrician) and were given an echinacea treatment. After Ezekiel arrived at the Alberta Children's Hospital in Calgary with abnormal breathing, he was quickly put on life support, but died within two days. David and Collet Stephan were sentenced last summer to four months in jail and house arrest, respectively, for failing to provide the necessaries of life.

If anyone wants to see what living on natural medicine looks like, Michael Rieder suggests, they should go to Afghanistan. "Afghanistan is about as natural as you're going to get in terms of accessibility to 21st-century health care," says the clinical pharmacologist and professor of pediatrics at Western University. For every 10 children born in Afghanistan today, odds are one of them won't see their fifth birthday. "Most of them die before they turn one and most of them die from infection," Rieder says. "That's what happens when you don't have vaccination or antibiotics."

"We're slipping into this 'all knowledge is relative' dark age," says Caulfield. "You don't see this in other areas of science. We don't have alternative physics or people who believe there's a natural healing force that can be utilized to build bridges. But in health, we have this huge tolerance for this alternative, non-scientific perspective."



Four-year-old Cooper Fredrick has an adjustment from chiropractor Dr. Jennifer Wise. (Photograph by Nick Iwanyshyn)

Imposing adult lifestyle choices on infants and children often extends beyond diet and into the realm of alternative medicine. At the Thrive Natural Family Health clinic in Toronto, Jennifer Wise tries to dispel all the preconceived notions of her job as a pediatric chiropractor, where she's treated newborns as young as a day old on their way home from the hospital. "There's a common perception that a chiropractor is going to crack your bones. It doesn't work in that kung-fu style," she says. "With little ones, we're certainly not doing those gross manipulations. It's very gentle contact. Usually it's just holding the area, light touch, light force." She equates the amount of force to what someone might do to a tomato at the grocery to check its ripeness.

But other chiropractors might not be as gentle, as seen in <u>a video posted by Australian chiropractor Ian Rossborough</u> (and subsequently watched over a million times), who loudly cracked the back of a four-day-old as an attempt to treat her colic. The newborn immediately screamed. Amid swift online backlash, the Australian Health Practitioner Regulation Agency quickly banned Rossborough from working on the spines of anyone under six years of age or any kind of chiropractic work on children under the age of two.

Wise says patients come to her for various reasons: maybe the baby is having trouble latching during breastfeeding or consistently sleeps with the head facing one direction. "Sometimes I'll find jaw misalignments so I'll do some cranial work, and within a few adjustments babies start nursing more effectively," Wise says.

In some instances, Wise adds, the results of her work can't be seen for decades, if at all. "So you have a baby that's born in a traumatic situation and as a result maybe the top two bones in their spine are slightly twisted," she offers as an example. "As an infant or child, they don't get any chiropractic care. They end up 35 years old in the workplace and have chronic migraines, sinus issues and allergies."

Of course, there are no longitudinal scientific studies to back up a claim that pediatric chiropractic care prevents hypothetical migraines decades later; even short-term, double-blind, placebo-controlled studies on infants, Wise will readily admit, aren't abundant in her field. And the studies that do exist have mixed results. A clinical trial of 86 infants from 2001 —one of the few studies co-authored by both pediatric researchers and a private practice chiropractor—found that chiropractic spinal manipulation therapy was no more effective in treating colic than a placebo. A 2008 study from the Anglo-European College of Chiropractic, of 43 infants younger than eight weeks old who typically cried more than three hours a day, did find two weeks of spinal manipulation and occipital-sacral decompression "appear to offer significant benefits to infants with colic." But in this study there was no control group, which is often a requisite for researchers to eliminate potential variables or bias that can influence results.

Reliable studies can be especially hard to conduct when infants are concerned, according to Brian Gleberzon, a Toronto-based chiropractor who conducted a review of the scientific literature regarding the use of spinal manipulative therapy for pediatric health conditions. "It could just be that over time, the [baby's] teeth erupted or they just grew up a little bit," he says. "You try to control for these variables but sometimes you can't. And they're babies, so they can't really fill out a form. The only outcome is what the parent perceives in how much crying time is related to what they thought as colic."

And yet, Gleberzon still believes chiropractors should be allowed to treat for colic, though parents should know it's no sure-fire solution to their sleepless nights. "It's the same principle with your dentist or your chiropractor or psychotherapist," he says. "There's no guarantee they can help you. You pay your money and take your chances."

Others aren't so sure. "I don't think any amount of spinal manipulation cures colic," says Rieder, the Western University professor. "I think it's insane. It's a bad idea. As a pediatrician, you don't want my advice on building bridges. I stick to my domain. Chiropractors shouldn't be going into areas like colic."

Britt Marie Hermes is even more critical of alternative medicine than Rieder. That is because she has seen the issue from the other side. She has no idea how many serious diagnoses she missed in her three-year career as a naturopath, but she can think of a few. Hermes does not have an M.D.; after an almost lifelong interest in natural medicine, she completed the doctoral program in naturopathic medicine from Bastyr University—an accredited American university specializing in alternative medicine—which allowed her to use the "doctor" designation in a few states, including Washington, where she later worked as a naturopathic pediatrician.

But Hermes has since emerged as a fierce critic of naturopathic medicine, via her blog and as a regular contributor to *Forbes* covering medical pseudoscience; she is now pursuing a master of science in biomedicine at the University of Kiel in Germany.

Her four years at Bastyr University, Hermes says, included more of a focus on homeopathy than pharmacology. She was confident when it came to taking blood pressure and drawing blood, but when it came to managing prescriptions, for example, she had no clue. "I never learned how to prescribe insulin, which was a major problem when I saw patients with diabetes," she says. "I became friends with a pharmacist. So what I would do is step out of the room, look up the information on a physician database and then I'd call the pharmacist and run it past her to see if I calculated the dosage wrong. I depended on her a lot."

So why would any parent take their child to a pediatrician who is so unprepared? Hermes said there were two groups of patients: The first sought her out specifically because she was as a "naturopathic pediatrician" and thus they believed she would have a different philosophy toward vaccines or antibiotics compared to most pediatricians. The second group blindly trusted Hermes when she said she was trained as a medical doctor. After all, "doctor" and "pediatrician" were in her title.

One missed diagnosis that stands out was a little girl just over a year old, who Hermes had been seeing since birth as her "primary care doctor." The child started to get persistent diarrhea and rashes. "I was seeing her in the office a lot and I was getting the impression the mom was hyper-concerned about her daughter's health," Hermes remembers. "Mom seemed to be panicked all the time and I brushed it off as new-mom nerves. I spent most of my time in those visits trying to reassure mom, but not doing so much physical examination of the child because I thought she was healthy." Food allergy testing didn't resolve anything, nor did the dairy-free or gluten-free diets the young girl was asked to try. Hermes prescribed supplements like probiotics and L-glutamine to help with the girl's gut inflammation.

"I think I diagnosed her with something like tummy aches or diarrhea," Hermes explains. Turns out the girl had cancer, something Hermes found out later—indirectly, through social media; she never learned what type.

"Sadly, there are probably other cases," Hermes says. "Maybe not missing cancer, but I think about it all the time: maybe I missed childhood diabetes or maybe I missed some tumour. Maybe I missed growth or developmental problems because I was doing my best to play doctor."

When it comes to kids, Hermes now argues there should be an outright ban on naturopaths treating minors. "I think adults can make whatever decision they want regarding their health, but I don't think parents should be allowed to voluntarily take their children out of the medical system."

If gluten-free and raw-food diets have something to teach the rest of us, alternative medicine does have some lessons for doctors. One reason Hermes says she had such a good rapport with her patients is because she took the time to listen to them. A visit with each patient could last upwards of 90 minutes, where she asked about their family life, their diet, what time they were waking up. The minutiae may not have pertained in any way to what health concern they came in with, but "it just feels good to know that someone is listening to you."

Engaging more with parents is a way to actually serve their health needs better. It's also one way to ferret out families trying out restrictive diets—or those feeding the kids fast food three times a week, often because of socio-economic factors.

"It would be lovely if pediatricians questioned a little bit more about what the child's diet is like at home," says Kuperberg, the nutritionist. "That'd be a perfect place to start screening these families." If a doctor learned a family is instilling a gluten-free or vegan diet, for example, Kuperberg says that would be an opportunity to do some nutritional blood work to ensure the child is getting all the required vitamins and nutrients.

Back in B.C., Daniel Bissonnette is now 12 years old and appears to be a healthy, energetic and well-spoken boy. His mother says he gets tested to make sure he isn't missing any vitamins or minerals from his diet. He has his own breakfast book, speaks at anti-GMO rallies and has a weekly "Ask Daniel" segment on his YouTube channel, offering tips on topics like cold therapy and dieting choices. The Bissonnette family has also since relaxed from being strict raw vegans; Daniel's diet is now described as being whole foods, organic, non-GMO, unprocessed and primarily vegan, and his mom says it's extremely important to do one's homework to make sure children stay healthy.

"It's okay if you're an adult and go on a diet. If it doesn't work, you switch," says Daniel's mom, Ilana. "But you cannot afford to make any mistakes when it comes to your children."