



THE MERCURY

THE STUDENT ART & LITERARY MAGAZINE OF GETTYSBURG COLLEGE

Year 2008

Article 9

1-1-2008

Silly Yaks

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Class of 2008

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Cox, Jessica G. (2015) "Silly Yaks," *The Mercury*: Year 2008, Article 9.

Available at: <https://cupola.gettysburg.edu/mercury/vol2008/iss1/9>

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Keywords

creative writing, non-fiction

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Jessie Cox is a senior majoring in Languages and Linguistics and minoring in Writing. Her interests include traveling, puppies, the Beatles, and various combinations of the above. She would like to thank her family and friends for supplying her with chocolate and putting up with her subsequent sugar highs all these years.

Silly Yaks

Passover is coming up again, which means I'm ready to go grocery shopping. So is most of my family. We're a mixture of Catholics, Lutherans, perhaps a few discreet atheists and some undecided college students, but Passover brings us to crowd around the kosher/international foods aisle in late March like it's the second coming of *something* holy. It's for physical health reasons, though,

"I go up with the old people and drink the wine before anyone gets crumbs in it," she says...

not spiritual. We can't eat wheat. We can't eat wheat at any time in the year, but during Passover Jewish people don't eat wheat either, so there's a sudden influx of wheat-free cakes, macaroons, egg noodles, and potato pancakes in grocery stores around the country. We're always ready for additions to a diet that easily gets to be repetitive.

My dad was the first to be diagnosed with celiac disease, an autoimmune disorder that makes one's body treat the protein gluten as a poison. He had been so sick that we – my mom, sister, and I, as well as the extended family – were all glad to find this out. Certainly it was better than other test results had been:

"Well, Colonel Cox, I have good news and bad news," a doctor at Walter Reed Army Hospital once told him, no doubt under the harsh glare of institutional lighting. "The good news is you don't have cancer. The bad news is we don't know what you do have." We were all glad to see the good old taxpayer dollars at work there, taking care of career Army officers who had been serving their country since 1971 and suffering from gastrointestinal distress since 1985. Dad could scarcely believe it when, in April 1994, a doctor newly transferred to Walter Reed told him all he had to do was stop eating wheat, barley, rye and oats and he'd be fine. The gluten in those grains was irritating the villi in his small intestine. Villi are the parts of your small intestine that absorb the nutrients from the food you eat into your blood stream. When they're irritated, they lie down against the wall of the intestine, drastically diminishing the surface area available for nutrient absorption, hence his persistent diarrhea, malnutrition, and irritability. He was lucky the malabsorption had kept his cholesterol levels down or he would've had fifteen heart attacks by then, he was so touchy.

In the beginning, celiac disease made my dad the odd one out in the family. He ate special pasta, pizza and cookies made from rice, corn, or even potato. He chose where we went if we went out for dinner. (When he was out of town, my mom, sister and I ran to the local Bertucci's to eat pizza and tortellini like half-starved wild women.) He was also picked on a lot.

"Whoops, did I drop bread crumbs on that plate? Sorry, Dad...not trying to poison you or anything," we (mainly my sister and I, the bratty kids) would say as we waved our toast around the kitchen.

This is perhaps why he decided that we all had celiac disease too, and just didn't know it yet. It wasn't an entirely irrational idea – it is a genetic disease – but we were youthful and naïve and the current statistics just didn't back him up. Neither did his methods of diagnosis.

"What, your throat's sore? That's it, no more bread for you!" he crowed whenever anyone so much as sniffled in front of him. While the symptoms of celiac disease can vary from person to person, the biggies are gastrointestinal distress, extreme emotional sensitivity, migraines and a dry skin condition called dermatitis herpetiformis. A sore throat is not one of them. No wonder I still hesitate to tell anyone if I feel like I'm coming down with something. Especially because it turns out that Dad's intuition was better than the medical profession's.

My older sister, Alexis, was the next Cox to bite the glutenous cookie dust. After a year or so of having doctors tell her that she was a young female mechanical engineer trying to cope in the big, bad, male-dominated real world, so of course she was feeling run-down, and suffered from migraines and emotional meltdowns, she decided that she knew what was really going on (she always does). She cut the gluten out of her diet and lo and behold, an emotionally stable, energetic Alexis emerged. She now incorporates horseback riding, yoga, Pilates and ballroom dancing into her week, every week, while still protecting American citizens from technology gone awry full-time. Her miraculous recovery was enough to convince my two aunts, my dad's only siblings, that their various health problems could be celiac-related, too. They had the blood tests done, which came back positive. They stopped eating gluten and no longer had aching joints, "nervous stomachs," or chronic fatigue.

Last summer I stayed on campus, working for a professor and living in a dorm with Lisa, another student. The first time that I spent a weekend in the bathroom, I knew what was up. Even though I was cooking for myself for the first time, it never took more than a spoonful or two of cereal for me to realize the milk was bad, so I knew spoiled food wasn't to blame. These were classic celiac disease symptoms, and so I ignored them. They didn't ignore me, though, and the symptoms started to pile up: I slept nine to twelve hours a night, every night, despite not ever doing anything other than going to work (which consisted of sitting in front of a computer and transcribing interviews) and coming home to watch movies with Lisa. I lost weight despite surviving off of pizza, pasta, cereal, and ice cream. I cried at least once a week during our movies, whether it was *Superman* ("I'm always around. Good night, Lois"), *Thank You for Smoking* ("The great state of Vermont will not apologize for its cheese!") or *Lilo and Stitch* ("Ohana means family, and family means nobody gets left behind"). But when I went home in August and was out-walked by my fifty-seven-year-old mother and an equally aged friend of hers in a flat botanical garden – and by out-walked I mean I later took a nap all afternoon and then slept all night while they continued visiting people and going places – I knew I had to 'fess up to what was going on.

I cried when I told my mom that I wanted to be tested for celiac disease. Given my health by that point in the summer, that might not mean much except she cried, too. When I told my dad the same thing that night at the dinner table, he didn't cry or lecture or even gloat. My tests came back negative, but given

my family history, my doctor and I decided it would be dumb not to try the diet. Unsurprisingly, I too, have celiac disease. (In case you're wondering, while the emphasis on wheat-based products in my summer diet may have helped my symptoms become severe enough to be noticeable, they didn't create the disease.) Once I changed my diet, I was back to normal, at least as normal as I ever have been. Now weepy, sleepy Jessie only appears when I accidentally get "glutened," which makes following the diet entirely worthwhile, although not always easy. It took a few weeks of getting sick after Sunday brunch before I found out that the eggs in the buffet at my college's dining hall are made from powdered eggs, which have had some sort of wheat product added to them. It makes me mad when they add barley to a perfectly good tomato vegetable soup, and don't even get me started on products that list "modified food starch" as an ingredient but don't say whether it comes from wheat or corn. I feel awkward when pizza or cakes are brought into class. I look at normal pizza and remember the bloated gut, crying while curled into the fetal position on my bed in the middle of the day, and don't mind passing it up, but I don't want to offend anyone or stand out, or have to go into details about what my gut will be like if I do eat it.

"Lisa, what flavor do you think that is?" I asked as we checked out the ice cream selection on our way out of lunch one fine Thursday. One of the six cartons wasn't labeled.

"Dunno," she said. At four foot-eight inches tall, she had to peer in to get a closer look. "Looks like there's chocolate in it."

"Eat some and tell me if you think it's cookie pieces," I said, but she decided she didn't want ice cream that day. So, I didn't have any either.

Most of the time it's not that bad, though. Even when I do eat gluten, there's no anaphylactic shock involved, and I've always preferred margaritas to beer and grits to oatmeal. My mom is always forgetting or losing her glasses so I've been reading labels in grocery stores practically since learning to read. In fact, even before diagnosis I was known to pick up the soy sauce on the table in Chinese restaurants and read the ingredients out of idle curiosity. (Almost all of them contain wheat.) I've eaten gluten-free breads, pizzas, and pasta on and off throughout my life whenever my mom wanted to do Italian but didn't feel like cooking two meals, so the dryness of the bread and the mushiness of the pasta didn't faze me much. I can even appreciate how far these substitutes have come since my dad was diagnosed thirteen years ago.

Sometimes people even envy me. At the beginning of this past year, my RA, Jenna, was planning a soft-pretzels-and-movie night and stopped by my room to ask me what she could get for me to eat.

"I can eat pretty much any ice cream," I said. "How about a Klondike bar or something like that?"

"Great," Jenna said.

"Aw, I want a Klondike bar!" my roommate said as soon as Jenna was gone. I only managed to resist the impulse to ask her what she would do for one because I already knew there was no way I was giving mine up. Plus, you have to be nice to the person who licks your envelopes shut for you. (Yes, that glue has wheat in it. Thank the gluten-free gods for self-adhesive stamps.)

I've introduced multiple friends to the wonders of the peanut-peanut-butter-M&M cookies the dining hall has recently started stocking in their gluten-free fridge. I love the doughnuts, cookies and bread they keep in that fridge, although as breaks approach, it seems to get emptier and emptier without getting replenished, making me wonder if they're trying to starve us celiacs out, perhaps in an attempt to strengthen the world's gene pool. People are often curious about what I'm eating, and I'm happy to offer them samples.

"Just let me finish what I want of it and then you can stick your contaminated fork in," I told a friend after she expressed a desire to try my spaghetti in red sauce.

"Hey, this is better than what they give the rest of us!" she said. That night must've been a pretty bad one for normal folks, but I wasn't going to argue with her. Still, the best comes out at family get-togethers.

"You know, I was tested and I didn't cause this," my grandmother says at every gathering after she's told each of her grandchildren, and any other unsuspecting children that happen to be around, "You're growing like a weed, you're so tall and gorgeous."

"Those tests aren't foolproof, you know," Grandpa Gruber says in return. "Alexis and Jessie both tested negative and they have it." This is from a man who isn't even genetically involved, but has been forced to overhear discussions about gluten for years. Besides, he loves riling people up and knows this will encourage my grandmother greatly. Now she's telling us her family has good genes; we might even be related to Czar Ivan the Terrible. Why you would want to broadcast any sort of relationship to someone who beat his pregnant daughter-in-law and caused his son's death, I don't know. Besides, we've already decided that celiac disease is a Cox gene through and through; the carrier was her husband. My grandfather claimed to get sick whenever he ate something other than steak and potatoes, a fact for which he was unfortunately ridiculed for most of his life. My dad blames the genetic mutation on the fact that his Cox grandparents were first cousins. I'm guessing it goes back a little further than that fateful day in southern Virginia. Surely not all the celiacs in the world have that family history.

Sometimes I feel bad for the in-laws on the Cox side. They didn't know what they were getting themselves into, but in our defense, back when they married in, neither did we. It really isn't supposed to happen this way, you see. Current research suggests odds are supposedly 1 in 10 of first-degree relatives having celiac disease. Four out of my dad's five living first-degree relatives are celiacs. I'm no math major, but that's a pretty big difference. Celiac disease is still largely under-diagnosed. We're not complaining, though: these days there are all sorts of celiac groups and websites, including the one that oh-so-cleverly discovered that "celiac" sounds marginally like "silly yak," but nothing beats having a living, breathing, genetically related support group. When I arrived at college as a freshman and realized that being in German 301 probably meant I should have brought my German-English dictionary with me, my mom sent it to me in a box with a short note and nothing else. This year, she and Alexis came to visit me for a day loaded down with homemade cookies and store-bought soup, cereal, and instant macaroni and cheese. Our disease brings us together, not only with each other, but with

other food-troubled people. Over spring break, two of my friends from high school visited me at my parents' house, bringing the dietary restrictions in the house up to: no wheat (myself and Dad), no meat (a vegetarian), and no sweets (a diabetic). My mom was unfazed and we feasted on grilled vegetables, tofu, stir-fry, homemade soups and chef salads, and fresh fruit.

So, at Easter, my mom, Uncle Gregg, Uncle Steve, and nineteen-year-old cousin Peter are huddled in one corner of the living room or squashed down at one end of the dining table, eating rolls while at least one celiac is watching to see exactly what they do with their butter knives. It must be like being in an etiquette class.

"Uncle Gregg! Did you just put your knife back in the butter after it touched your bread? I can't believe this," eagle-eyed Alexis calls out from the other end of the table. Sometimes we're nice and just go ahead and give them their own butter. Eating dinner with your whole family is stressful enough without feeling obliged to keep an eye on every stray crumb. My three younger cousins (ages ten, eight, and five) have it slightly easier since the kids' table is entirely glutenous, at least so far. We may come across as paranoid to the non-celiac, but all it takes is one episode of glutening after eating food that you thought was safe to turn you to fanaticism.

Uncle Gregg times us to see how long we can all be assembled before the words "celiac" or "gluten" emerge. I think our record is about five seconds. There are always stories to be told as we dip rice crackers into the gluten-free artichoke dip, like how one of my Gruber cousins diagnosed a roommate of hers with celiac disease while the doctors were stumped, or that Shadow's new dog food, ostensibly for canine sufferers of early kidney disease, also happens to be gluten-free. Every specially made gluten-free dish has to be oohed and aahed over, its ingredients delineated ("Coconut flour? I didn't even know that existed; we've just been making do with white rice flour") and the source of the recipe examined. Sometimes websites are called up and cookbooks are passed around. Pens are whipped out of purses and notes are taken. My mom at times participates in this part of the ritual because although she isn't a celiac, she is the main cook (read: the cook for anything beyond frying an egg or opening a can of soup) in my house. At the end of the meal, Aunt Linda asks to have some of the quiche wrapped up for her to take home.

"Sure thing," Alexis replies and gets out the plastic wrap.

"Who wants a brownie for the road?" I ask, probably unnecessarily.

Everyone wants a brownie, even some of the non-diseased. Celiacs get priority, though. It's a high-status position around here, not something to be ashamed of.

After brunch, we transform the kitchen table into an egg-dyeing station. We like to do Ukrainian-style egg decorating, which involves candles, beeswax, pen-like implements called *kistky* and less-than-kid-friendly dyes. The kids are off hiding Easter eggs for each other in the backyard, though, so it's just Mom, Alexis, Aunt Linda and me sitting at the table when Uncle Steve walks by.

"What is this, a séance?" he asks as we pass matches around the table, each lighting a candle in front of us.

"No, it's an offering to the gluten-free gods," Aunt Linda replies and

picks up an egg. It's not entirely a joke – we take our disease seriously, and our bookshelves prove it with titles such as *The Gluten-free Gourmet Cooks Fast and Healthy* and *The Gluten-free Bible*. Uncle Steve continues on his way, certain that this is no place for the likes of him, and Aunt Lydia is the next to enter the room.

"I go up with the old people and drink the wine before anyone gets crumbs in it," she says when my mom asks if she's still taking Communion. She did for awhile because the Catholic Church insisted that when the bread turned into Jesus' flesh, it wouldn't hurt celiacs. They haven't come out and said that isn't true, but these days celiacs are allowed to take the wine and not the wafer. Meanwhile, a Lutheran pastor I know has started using gluten-free pizza crust in Communion and no one in the congregation has noticed.

"Peter was tested for lupus this year but the results were negative," Aunt Linda says about her son as she dips her egg into the scarlet dye. My sister and I exchange a glance.

"It's probably just celiac disease," Alexis says.

"I'm not a celiac!" Peter yells from the other side of the house. It doesn't matter if he hears us or not, he knows what we're talking about. I smile and shake my head, remembering the days when I too thought I was above the reach of the family disease. He and the three little cousins are living on numbered days, if you ask me. Whether you want to or not, you just can't escape your family.