

Opening (and Swallowing) A Can of Worms to Treat My Crohn's Disease

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Editor's Note: This article discusses the experience, ingenuity, and determination of Sean Ahrens, a young patient with Crohn's disease who took it upon himself to treat his longstanding, symptomatic Crohn's disease with pig whipworm eggs. Reading this story will make some of you uncomfortable. You might question whether this work belongs in a medical journal or sends the wrong message to readers. However, we recognize that this topic is controversial and that N=1 reports cannot and should not change practice. The purpose of this story is not to encourage the use of pig whipworm or to demonstrate its efficacy (or lack thereof). We firmly believe that patients are uniquely qualified to provide insights into how they view their illnesses, weigh risks and benefits, and ultimately achieve self-efficacy. Stories like this are important for us to acknowledge and understand, even if they do not change our practice.

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A shot glass of parasitic worm eggs sat on the table in front of me. Today was the big day. Today, I was going to intentionally self-dose with pig whipworm, known scientifically as *Trichuris suis ova* (TSO).

The cardboard package I received in the mail was covered on nearly all sides with Thai mailing labels and custom stamps. Luckily, the dozen vials inside had English translations on their Thai labeling.

Into the shot glass, I poured a single vial, containing 15 ml of salt water with over 2,500 pig whipworm eggs. The eggs were invisible to the naked eye, but they were there: minutes earlier I had taken a plastic toyshop microscope and verified their claim.

I was standing. The shot glass was on the kitchen table in front of me (**Figure 1**). My roommate Vincent stood with his back against our stove with a camera in his hands, eagerly recording me, a big smile across his face.

"Hi, I'm Sean. And I'm about to swallow parasitic worms." I said, nervously starting the video. My thinning frame was the result of months of ongoing weight loss. "Why?" I asked. "Because I have a digestive illness that I believe that these parasitic worms might be able to treat. Modern medicine hasn't offered me anything in the way of a cure."

The illness I was talking about was Crohn's disease, a condition I had been living with for exactly half my life, since age 12. At this moment, I was in the midst of a very bad flare: ongoing months of chronic diarrhea, increasingly excruciating gut pain, colonic bleeding, and weight loss. The medication I was on, infliximab (administered intravenously at a hospital every 6–8 weeks at a dose of 10 mg/kg of body weight), was no longer winning my fight. The tide was turning toward my disease.

Trying my chances at the next line of medication (frequently self-injected biologics) would mean that, at best (if they worked), I would forever abandon my dreams of backpacking the world and, at worst (if they did not), that I would be out of medical options, and my only hope would be to progressively cut out parts of my intestines.

I continued speaking to the camera. "Some studies are showing that by intentionally infecting myself with parasitic worms, such as these—the pig whipworm—I can actually improve my condition and maybe put myself in remission." The study I was referring to, conducted at the University of Iowa (1), had shown clinical improvement in 43% of subjects with ulcerative colitis. The theory behind it was the hygiene hypothesis: our overly clean societies of today are a reason why our immune systems are misbehaving. I had even heard of patients, unable to wait for further helminth studies, who had flown themselves to the developing world and walked barefoot in latrines to acquire the worms directly themselves. I preferred mail order.

It was my friends with Crohn's who first told me about helminth therapy. Two of them were self-dosing with human hookworm, which, unlike pig whipworm, could live indefinitely inside the human body. This made their choice of hookworm a riskier (but potentially more effective) option. With pig whipworm, I was not too concerned about risks, because, as being evolved for pigs, the eggs are ultimately rejected by the human body.

Luckily, my friends and I are under the care of the same gastroenterologist; hence, when I told him I wanted to try TSO, he was already aware of patients trying helminths. His assessment was that risks associated with trying TSO were probably low, but he would neither recommend nor condemn the treatment. He told

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Figure 1. Sean Ahrens preparing to ingest the first dose of *Trichuris suis* ova.

Sean's Health Report

Consistency

Solid

Soft Serve

Mushy Pile

Water

Blood?

Choose ▾

Gut Pain

Discomforting

Disruptive

Eruptive

Debilitating

SUBMIT

Figure 2. Google form created for a smartphone to record symptoms every day: gut pain, bowel movements, and presence of blood in stool.

me that, if I took them, he would monitor my health and provide my care as he always had.

Which is how I got here today, with a shot glass of parasites sitting in front of me—a shot glass that, should I mention, was flashing with multi-colored, embedded LEDs; if I was going to do this, I was going to do it in style. “This is probably the creepiest, craziest thing I’ve ever done,” I exclaimed as I nervously wrung my hands. I paused, then took a deep breath.

“Ahhh! Here I go!” I picked up the shot glass to my mouth, threw my head back, and swallowed the salty solution.

In the weeks leading up to today, I had been preparing methods for this experiment. Today was only dose one: 17 March 2010. There were going to be 12 doses, spanned out at 2-week intervals, ending in the final dose on 15 August 2010. My first dose I would refer to as being in week 1; my last dose: week 23.

Rather than just taking the worms as someone would do for any prescribed treatment, I saw this as an experiment, and I wanted to track the data so I could share it with others. I created a Google form on my phone to record my symptoms every day: gut pain, bowel movements, and whether there was blood in my stool (Figure 2). If I had a bowel movement, I would rate its consistency as (in decreasing order) “solid”, “soft serve” (like the ice cream), “mushy pile”, or “water”. If there was blood present in my stool, I marked “yes”, otherwise “no”. If I had gut pain (which commonly accompanied my bowel movements during flares), I marked its intensity as (in increasing order) “discomforting”, “disruptive”, “eruptive”, or “debilitating”. One week prior to the first dose, I began tracking my symptoms to establish a baseline.

From then on, every 2 weeks, I took a dose of pig whipworm eggs. After the first, I forewent the flashy shot glass and took them straight from the vial. I continued taking my regimen of infliximab every 6–8 weeks, unchanged. Every day, I recorded my symptoms as they occurred. In week 23, I had taken my final dose of TSO and could reflect on my results.

During the experiment, I intentionally did not review my symptom data (Figure 3). I was trying to blind the experiment as much as I (in a very limited way) could. What I could tell from my own

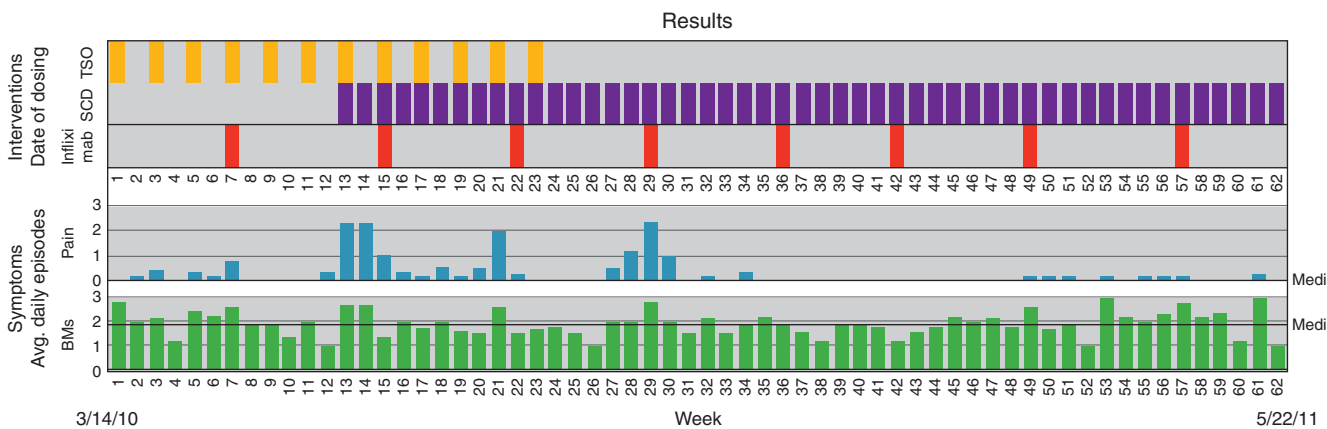


Figure 3. Symptom data over the 62-week collection period. Note, the visualization here summarizes pain and bowel movements into average daily counts and does not include or show their “consistency” or “intensity.” BMs, bowel movements; SCD, Specific Carbohydrate Diet; TSO, *Trichuris suis* ova. Note: Due to normal human circumstances of forgetting to log entries, episodes of pain and bowel movements carry some error of under-report.

intuition was that, during the experiment, I was really sick: I was really sick before the experiment, and I was really sick during it. That did not change much. As before the treatment, I had to frequently stay home because of sudden and unpredictable episodes of drop-everything pain and hour-long sessions on the toilet.

Three months into the experiment, I could not take it anymore. My flare had lasted too long. Despite the fact that it would ruin my shiny, single-intervention experiment, I had to do something. Thus, starting in week 14 (6 June 2010), I began a strict elimination diet called the Specific Carbohydrate Diet (SCD), where I eliminated all grains and refined sugars from my diet. On week 23, I took my final dose of TSO, and I continued the diet and kept tracking my symptoms.

Around week 36 (13 weeks after my final dose of TSO), I noticed something was different. For the past several months throughout this flare, it was common for me to experience extreme abdominal pain and increased stool frequency before my regular infliximab treatments. However, this time before my infliximab treatment, pain was virtually absent. Then before my next treatment at week 42, the same thing happened. In fact, from week 35 onward, I became virtually pain-free, and remained so throughout the entire span of data collection ending on week 62. Somewhat surprisingly, the frequency of my bowel movements did not seem to change significantly during the experiment. This was okay. Pain matters most to me. Being pain-free, for me, is a proxy for good health or at least for moving toward remission.

Why did I get better? Was it the pig whipworms (TSO)? Was it the SCD? Was it the natural course of the disease (i.e., Was I going to return to normal from my flare regardless of these inter-

ventions)? I do not know. I do not have the statistical power to tell you. Maybe TSO was responsible but had a highly lagging effect. I suspect that one or both of the interventions (TSO and SCD—and I am leaning toward SCD) assisted in my return to health. However, I cannot tell you that for sure. I am actually not entirely sure if it is possible to be conclusive in an experiment of one person. I do believe that if I had more baseline health data before starting the experiment, it would have helped these analyses. I am not sure, however, that it would make them conclusive.

Now it is 2016, and it has been about 5 years since I did this experiment. Since then, I have experienced some other flares, but my health generally has been on an upward trend toward stabilization, which I have continued tracking on Crohnology (a website I built to track my health with other patients). I have continued routine infliximab and continued the SCD diet with varying levels of adherence (tightening when symptoms return). In November 2013, a routine colonoscopy showed signs of “remission with no visible inflammation” with microscopic inflammation found in biopsies.

CONFLICT OF INTEREST

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Potential competing interests: None.

REFERENCE

1. Summers RW, Elliott DE, Urban JF Jr *et al.* *Trichuris suis* therapy for active ulcerative colitis: a randomized controlled trial. *Gastroenterology* 2005;128:825–32.