

**JENNIFER KRISTEN FOUNTAIN**

2412 Swansea Road | Columbus, OH 43221  
[jennifer.k.fountain@gmail.com](mailto:jennifer.k.fountain@gmail.com) | 614.306.3309  
[www.linkedin.com/in/jenfountain](http://www.linkedin.com/in/jenfountain)

February 22, 2017

Rep. Mark Romanchuck  
Chair, Health & Human Services Subcommittee  
Ohio House of Representatives  
77 South High Street, 11<sup>th</sup> Floor  
Columbus, OH 43215

**Subject:** HHS Subcommittee Hearing – Public Testimony (Written & Verbal) on March 23, 2017  
**Name:** Jennifer Fountain, mother of Hudson Crosby Goff (Pre-B Cell ALL) diagnosed February 18, 2014  
**Legislation:** Governor John Kasich’s State Operating Budget SFY 2018-19 (House Bill 49)  
**Issue:** Opposition to Changes within the Bureau of Children with Medical Handicaps (BCMh) Program

Dear Chairman Romanchuk and Members of the Health & Human Services Subcommittee:

Thank you for the opportunity to provide public testimony re: the State of Ohio’s Children with Medical Handicaps Program (CMH), formerly known as “BCMh”. My name is Jennifer Fountain and I’m here today as one of the many families voicing concern about how the proposed changes in Governor Kasich’s budget will negatively affect our ability to care for chronically ill children, like my son, Crosby Goff.

**As a parent of a chronically ill child served by the CMH program, I feel strongly that our kids deserve to be protected by the safety-net provided in the current Department of Health program and not moved into a Medicaid system as it will dramatically reduce the availability of services and limit income eligibility.**

As you are well aware, for almost a century, the CMH program has had great success providing assistance through the medical home model, keeping low- to moderately middle-income families like ours, privately insured, contributing to the Ohio economy, paying taxes and owning homes – all the while caring for one or more chronically ill children.

I am here today to put a face to the 40,000 children served by BCMh under the current configuration. I represent the new face of today’s Children with Medical Handicaps program, counting myself among the fresh contingent of more than half of this population whose future household income now falls just out of reach and above the new guidelines of 225% of the federal poverty level (down from 500%)—a change many Ohioans with sick kids cannot personally sustain financially as the cost of care continues to rise. **I am here today because I do not want to see hard working parents, like us, nor their CMH-dependent children, like mine, fall through the cracks.**

But first, by way of background, here is our family's story:

I am a stay-at-home mother and full-time "momcologist" living in Upper Arlington with my husband (a small business owner) and two children (ages 10 and 7). At age four (4), my son was diagnosed with Acute Lymphoblastic Leukemia (ALL) after a simple blood test at our pediatrician's office detected the presence of cancer cells or "blasts". Weeks prior, Crosby showed unusual signs of fatigue (napping mid-day after already growing out of this stage) and had bruises on his abdomen that wouldn't heal after a weekend of fun, festive "family tickle fests." It was only after he displayed a newfound distaste for his favorite meal on Valentine's Day that Friday that I called the pediatrician to set up an appointment asking to have him checked for anemia the following Tuesday. With time to kill and the internet handy, that weekend I did the unthinkable – I searched the internet for clues as to my son's condition. And like any good mother with a gut sense that something's not quite right, I scoured the web trying to pair my child's symptoms with reputable online health information sources like those found on the web of NIH or The Cleveland Clinic. Much to my surprise, within minutes, a link to the American Cancer Society's webpage came up linking 4 of the 7 conditions he presented with as childhood blood disorders/diseases, like leukemia. By Monday, my son was pale, lethargic and hardly eating when I had bullied my way into the doctor's office demanding that my child be seen; 4 hours later I had my answer – and it was not good news.

Since then, much of my son's childhood can be chronicled between the bookends of countless tests and treatments at Nationwide Children's Hospital in Columbus, Ohio. We have endured and surpassed the following "typical" treatment plan assigned to a kid diagnosed with standard-risk Pre-B Cell ALL:

- 22 spinal taps and 2 bone marrow tests;
- 115 blood draws (as accessed by a needle inserted into a port stitched into his chest);
- 12 emergency room visits and 45 inpatient admission days (one such stay comprised of a month long sentence in an isolation room after the chicken pox vaccine, given at my child's 12-month 'well baby' check-up, was reactivated as shingles at the height of his most intense chemo stage);
- 60 outpatient appointments (no "clinic visit" is shorter than 6 hours with labs, exam, and Rx);
- 90 IV injections (again through a central line requiring on-site skilled nurse technicians);
- 2,500 chemotherapy pills (plus another 1,650 doses of antibiotics to prevent infections); and
- 215 missed days of school (which is sometimes the hardest part as he's separated from peers).

Fast forward to today – now nearly 3.5 years later. Crosby is soon to celebrate his 8<sup>th</sup> birthday in September but not before he finishes his last round of chemo and gets his port out later this summer. He will take antiviral medication 3 times daily for the next 6-months in hopes to prevent another shingles outbreak (\$621 per 21-day supply). After a few future physical therapy sessions and the replacement of some custom-made orthotics or "night splints" designed to combat a foot deformity common among patients regularly taking Vincristine (a chemotherapy drug), he should be done with corrective bilateral braces.

Likewise, we will still have a year's worth of monthly follow-up visits, followed by another year of quarterly exams and lab work to get through. In the future, statistics suggest that he will likely encounter late affects, secondary diagnoses and other medical problems often plaguing childhood cancer survivors like cognitive delays, cardiac dysfunctions, loss of bone density and possible infertility. Moreover, the minute his treatment ends, relapse rates dramatically increase making it far more likely his cancer may return over the next 2 years than the 'one in a million' odds of originally being diagnosed with childhood leukemia.

**My child's care, like others served by CMH, is complicated, specialized, and expensive – and what's more important – it is not yet complete. There are always more bills to pay and more pills to swallow.** This year, our family of four will pay over \$1,500 per month in premiums for private health insurance through Anthem BCBS (coverage includes medical and dental, not vision). That's nearly \$20,000 in out-of-pocket expenses just to ensure we have primary coverage. At the same time, decreased competition among carriers at the local level have forced many big-named companies such as Aetna and Medical Mutual out of the central Ohio marketplace, leaving only one carrier to provide in-network benefits that includes Nationwide Children's Hospital.

Trust me when I tell you, it's tough enough to fight childhood cancer amid today's vastly changing insurance markets and healthcare landscape – we don't need another coverage issue to contend with. Please do your part in protecting the CMH program from the proposed changes in Governor Kasich's new operating budget. Do not take away the only constant companion many of our Ohio families have been able to rely on in caring for our chronically ill and medically fragile children.

**Protect BCMH as a payor of last resort, helping the most vulnerable citizens of our state – sick kids.**

The outcome of HB49 greatly affects the direction families like ours can take in being able to manage their already complicated lives, doing so much to juggle just getting through another day – at the clinic, at the office, and in the carpool lane at school.

Thank you, Mr. Chairman and members of the HHS Subcommittee. I appreciate being able to share my family's story today and would be happy to take questions or comments.

Sincerely,



Jennifer Fountain

CC: Congressman Steve Stivers – District 15  
Senator Stephanie Kunze – District 16  
Representative Jim Hughes – District 24