

February 28, 2019

Dear Chair Salinas, Vice Chairs Hayden and Nosse, and Members of the Committee,

I live in SE Portland and am writing today to encourage you to support HB 3063 to help kids like my son, Charlie, avoid vaccine-preventable diseases.

Charlie is four years old, and like a lot of four year olds he likes to sing songs, listen to stories, and climb. He was also diagnosed with a relatively rare pediatric brain and spinal cord cancer when he was two.

Charlie's diagnosis and treatment have been terrible. Since he was diagnosed in April 2017, he has been hospitalized eight times, has had five brain and/or spinal cord surgeries, and has had more blood draws and MRIs than I can count. He has seizures, balance problems, and other neurological issues because the cancer interferes with how his brain works. When he catches a cold, he is often so wobbly he can't walk on his own. All of these challenges have significantly delayed his cognitive and developmental growth.

We initially treated Charlie with a chemotherapy drug called temozolomide, which suppressed his immune system. As a result of the chemotherapy, he wasn't able to receive the second dose of the MMR vaccine on schedule to protect him against measles, as well as mumps and rubella. Our oncologist said he needed to wait at least six months after the chemotherapy ended before he could get the vaccine. Charlie's pediatrician said he had some immunity from the vaccine he received when he was younger, but the MMR booster is especially important for measles protection.

Last month, my husband and Charlie were at one of the measles exposure locations the same week as the exposure occurred. As soon as I saw the list of exposure locations, I was immediately worried and checked the calendar. Given how sick Charlie gets when he catches a cold, I know catching the measles would be devastating for his body. Fortunately, Charlie wasn't at the location during the actual exposure window, and we were relieved.

Charlie's cancer continued to grow despite the treatment with temozolomide, and he is now in a clinical trial for an experimental medicine. The new medicine is targeted at a specific mutation in Charlie's cancer, and he is no longer immunosuppressed. Because of the change in treatment, Charlie was able to get the MMR booster a few weeks ago, after the waiting period after the chemo ended. My husband and I are so glad we can

now take Charlie to birthday parties and public places without worrying if someone might be sick with measles or another vaccine-preventable disease.

My experience with Charlie has shown me that there are so many kids who are medically fragile, either because they have cancer or another challenge. Sick kids like Charlie are depending on other parents to vaccinate their healthy children to prevent an outbreak. To me, freedom means that I'm able to take Charlie places and try to make sure he gets to have at least some normal childhood experiences even though he is burdened by the bad luck of his cancer. Freedom shouldn't mean you're free to spread a preventable, highly-contagious illness that could cause serious complications or death for a child with cancer.

My husband and I are on constant high alert about Charlie's symptoms and needs, and it's exhausting. I've learned that this is a common experience among many parents of kids with complex medical needs. Please support HB 3063 to take one concern off the list of these parents of sick kids who are often overwhelmed but doing their best every single day to care for their child.

Thank you for the opportunity to support HB 3063.

Sincerely,

Katie Shriver