

**Testimony of Jessica Jackson to the Public Health Committee regarding *House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants***

February 6, 2009

Senator Harris, Representative Ritter, members of the Public Health Committee: Thank you for giving me the opportunity to speak to you today about *House Bill 6263, An Act Requiring The Administration Of A Screening Test For Cystic Fibrosis To Newborn Infants*.

My name is Jessica Jackson. When I was pregnant I was tested to see if I was a carrier for CF. My doctor told me I was not a carrier because, an employee at my doctors office wrote negative in my chart, which my results were positive. So my boyfriend was never tested to see if he was a carrier of CF. I went to get an ultrasound when I was 40 weeks pregnant and my doctors saw that my daughter's intestines was enlarged. So I had to go to JDH and get a level 2 ultrasound and the Doctor at JDH said she thought everything looked fine. However, she wanted us to deliver at JDH because my boyfriend, my doctor and I were concerned. So I went to JDH on 12/6/07. Our daughter Kayanna Maryella Hine was born on 12/7/07. The best day of our life but at the same time is was the scariest day of our life. I had to have her by c-section, because her heart rate keep dropping after I received my epidural. We are glad I had her by c-section because her stomach was 36cm round when she was delivered. She had a malrotation which is twisting of the intestines (or bowel). She had her first surgery 6 hrs after she was born that lasted 6 hrs longs. They removed 20% of her intestines and she had to have an ileostomy for almost two months.

The doctors asked if we would allow them to test Kayanna for CF. We allowed them to. We found out that she has CF 4 days after she was born and that's the reason why her intestine was twisted. If we did not allow them to test her for CF we would have know not as soon as we did. On 1/31/08 she had her second surgery to reconnect her intestines. We went home on 2/8/08, but ended back at the hospital on 2/9/08 because she stopped eating and was throwing up. On 2/13/08 she had her third surgery because they found 12 adhesions and her intestines was twisted again. We finally left the hospital on 2/25/08. The surgeon put a liner in her intestines to try to stop her intestines from forming more adhesions. However, there is always a possibility of her getting adhesions. On 3/6/08 we were back in the hospital because she had blood in her stool, they found out she has Clostridium difficile so she was in the hospital till 3/8/08. She does have to take Creon 5 every time she eats for the rest of her life for her Cystic Fibrosis. We have to give her vitamins twice a day and add salt to her food. We also have to give her albuteral treatments twice a day and four times when she is sick. We have to do chest PT also after each treatment. In July her CF doctors did yearly labs. So we went to her monthly doctor's appointment on August 5, 2008 and we found out that Kayanna has Primary Biliary Cirrhosis. They tested Kayanna's blood 3 times after we found out. Every 3 weeks to check the level of enzymes in her liver and the enzymes count are extremely high but they went down each time but not by a lot. Her liver Doctor doesn't understand

how she is functioning normal, because levels that high she should be sick. She is a fighter. She has to take actigul everyday for the rest of her life also.

Look my situation, I got tested when I was pregnant and was told I was not a carrier. However, my daughter still has CF. If our daughter was born normal with nothing wrong with her intestines, like some kids are. We would have not known that she had Cystic Fibrosis as soon as we did. The sooner a person finds out that they have Cystic Fibrosis, the easier it to get under control. It took a while for my daughters CF to get under control but it has been. Thank God!

Thank you for time to listen to my story why I think that every infant born should be tested for Cystic Fibrosis.