

**UNITED STATES DISTRICT COURT
FOR THE SOUTHERN DISTRICT OF OHIO
WESTERN DIVISION**

PRETERM-CLEVELAND, et al.)	
)	
Plaintiffs,)	
)	
v.)	Case No. 1:18-cv-109
)	Judge Timothy S. Black
LANCE HIMES, DIRECTOR, et al.)	
)	
Defendants.)	
)	

DECLARATION OF EMILY CHESNUT

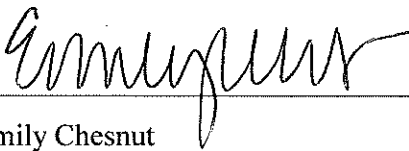
I, Emily Chesnut, pursuant to 28 U.S.C. §1746, declare under penalty of perjury that the following is true and correct:

1. My name is Emily Chesnut, and I reside with my husband and our four children in the Cincinnati area.
2. One of our children, our 7-year old daughter Nora, has Down syndrome.
3. I submit this Declaration because I want to speak on behalf of my family and many friends who also love someone with Down syndrome.
4. I believe that, in passing and signing Ohio House Bill 214, Governor Kasich and state legislators used *our child* as a political tool to promote their own agenda of restricting access to abortion. They do not care about Nora. If they did, they would devote their efforts to making sure that children born with Down syndrome have what they need to live a healthy, full life.

5. Children with Down syndrome need affordable health insurance coverage to pay for the medical treatments and therapy that many require.
6. Half of all individuals with Down syndrome have congenital heart defects – including Nora who had open heart surgery at seven months old.
7. Individuals with Down syndrome are more likely to have issues with their eyes; Nora has had eye surgery.
8. Individuals with Down syndrome are also more likely to have gastro intestinal issues, respiratory issues, thyroid issues, and hearing issues/hearing loss. And the list goes on.
9. These medical issues are treatable and can have positive outcomes. Individuals with Down syndrome thrive when given supports such as occupational therapy, speech therapy, glasses, hearing aids, walkers, and many more tools. If politicians were concerned with people with Down syndrome, they would be working to assure that families had adequate health care coverage, to access these treatments and therapies.
10. If Ohio lawmakers wanted to make Nora's life better, they would also increase funding for developmental disability services. To access these services, one needs a "waiver" (because, by accepting services from my county Board of Developmental Disabilities, I am waiving Nora's place in an institution). When Nora was born, I was told to call and get her on the waiver waiting list so that – someday – I could hope to get a waiver.
11. The length of the waiting list varies by county, but the median waiting time in Ohio is more than 9 years, according to a report by the Ohio Colleges of Medicine Government Resource Center for the Ohio Developmental Disabilities Council,
http://www.fixthelist.info/uploads/8/3/7/2/83720792/dd_council_report.pdf.

12. My family needs the waiver to obtain services for Nora to try to meet our long-term goal for her to be an active, independent member of the community. She is currently in first grade, so such services would now focus on her academic, speech and occupational therapy needs. When she graduates, waiver funding would help Nora with transportation to/from a job, on-site job coaching to be successful, and support so that she could live in an apartment on her own.
13. The current waiver system is very broken, in addition to the nine-plus year waiting times. Families (including mine) are confused by the bureaucratic complexity and the inability to know when one's turn will come up. If my law makers cared about Nora and her peers with Down syndrome as much as they are claiming, they would fund Developmental Disability waivers and support County Boards with additional funding.
14. My lawmakers would also be working to address other legislative needs, such as the need for inclusion in schools, employment opportunities and independent living.
15. Having a child with Down syndrome has been life-changing for me and for my family. It has given me new paths in life that I never would have found before Nora. Now I am an advocate on Down syndrome issues so that future families can see more positives than negatives, so that inclusion is the norm, and so that a diagnosis of Down syndrome isn't as scary.
16. No parent should have to embark on this journey uninformed. A pregnant woman should be able to have a frank, honest conversation with her doctor about what it will mean to have a child with Down syndrome. She should have all the information she wants, and be encouraged to ask more questions, so she can make this very personal decision freely and knowledgeably.

17. H.B. 214 does the opposite, however. This bill makes it dangerous – impossible – for a pregnant woman to have an honest conversation with her doctor. A woman will know that, if the doctor learns that she is worrying about a fetal Down syndrome diagnosis, she will not be able to make the decision on her own whether to have the baby, and will instead be coerced by the state to carry the pregnancy to term.
18. I understand that talking about Down syndrome tugs at heartstrings. I understand the fierce pride and protectiveness that parents of children with Down syndrome feel. I feel it, and my husband does too.
19. But this bill is not about helping people with Down syndrome or their families. It is not about protecting Nora – or any child with Down syndrome – or about making their lives better. This bill is about putting another hurdle in front of women who have a constitutional right to make their own decisions about their bodies and their futures.
20. The politicians who enacted H.B. 214 are using my daughter and her peers as a pawn in a political effort that is only going to harm women and make it harder for them to make the right decision for themselves – and their families.



Emily Chesnut

3/8/18

Date signed