

SB 1522 ~ CYSTIC FIBROSIS AWARENESS MONTH

TESTIMONY OF LAURA DEMELO
(PARENT OF CHILD WITH CYSTIC FIBROSIS)

Representative Jennifer Williamson, Madam Chair
Erin Seller, Committee Administrator

Representative Phil Barnhart
Representative Vic Gilliam
Representative Val Hoyle
Representative John Huffman
Representative Bill Kennemer
Representative Dan Rayfield
Representative Barbara Smith Warner
Representative Carl Wilson

Thank you Madame Chair and Committee members for letting me submit my written testimony on SB 1522.

My name is Laura Marie DeMelo. I live in Portland with my 16 year old son, Robert Vogel.

Robert has Cystic Fibrosis (CF). He was born with this fatal genetic condition that predominately causes damage to his lungs and pancreas. Robert's disease causes the normal mucus secreted by his organs to be thick and sticky. This leads to breathing and digestion issues. In addition, infections are prevalent with patients like Robert. Because of scarring from infections, Robert will either slowly suffocate leaving his lungs unable to supply enough oxygen to his body or his immune system may simply lose the battle against certain infections.

Unfortunately, as of yet there is no cure for Robert or other Cystic Fibrosis patients like him.

For Robert, this means everyday he takes 37 pills a day, performs 2 hours of lung treatments, and consumes many extra calories. He does this just to stay healthy. Robert starts his day at 5:45am with his first lung treatment so he can make it to class by 7:30 am. He is an active High School Sophomore. He wants to stay that way so he makes the choice to comply with his daily health regimen. I don't know any teenagers that like to get up that early but Robert knows he has to do it.

Robert's commitment to his health is supported by his family. His father and I are there for Robert emotionally and financially, but I won't lie to you; this disease is tough. Beyond the number of yearly doctor visits, medications, and other financial considerations, having a child with Cystic Fibrosis gives me a heavy heart. No one should have to perform chest physical therapy on their 6 month old baby just so mucus doesn't build up in his lungs. No one should ever hear their child ask if he is going to die soon. No one should have to tell their teenager that his disease has likely made him sterile. No one should have to consider that her child will likely die before she does.

Why am I submitting this testimony with my story?

I am here to ask you for your consideration to make the month of May Cystic Fibrosis Awareness Month. I am asking you to be part of the solution. If we have more awareness for Cystic Fibrosis this will help to create more interest and support for finding a cure. Recalling my Marketing classes at U of O and the opera-referenced acronym, A.I.D.A., Awareness leads to Interest which leads to Desire and finally, Action. Help Robert and other Cystic Fibrosis patients by creating more awareness for this rare disease. Do this so they do not feel so alone, and so that ultimately greater steps will be taken toward finding a cure.

Here are some thoughts for you to ponder:

- If your Grandmother was born with Cystic Fibrosis, she would have likely passed away as an infant.
- If your Mother was born with CF, she might have made it to age 5.
- If your Sister was born with CF, she would have started High School but not likely College.
- If your Daughter was born with Cystic Fibrosis, she might be lucky to live 37 years.

All this speaks to the steady advances in medical treatments and therapies which slow the complications of CF resulting in extended lifespan. Yes, we have come far.

However, as patients age with this disease it can become more serious. As time progresses, Cystic Fibrosis can lead to other serious health conditions. As they age, people with CF also have chances of developing diabetes, bone disease, and may require lung or liver transplants.

It is true that people with Cystic Fibrosis are living longer but living longer does not mean living better. There is still much work to do.

I am asking for greater awareness for Cystic Fibrosis. Awareness will stimulate action. CF families like mine need medical advancements. Please be the solution, in part, toward creating more awareness. Link the month of May to Cystic Fibrosis Awareness. Let this be the first step of many resulting in improved quality of life for children and adults with Cystic Fibrosis.

Thank you again for taking the time to read my testimony. I appreciate your consideration.

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