Testimony: Right to Try for Individualized Treatments in Colorado

My name is **Rich DeAugustinis**. I am the vice chair for The Myositis Association and previously served on the board of the Mesothelioma Foundation.

Thank you for allowing me to testify today in support of Colorado House Bill 25-1270 – Patients Right to Try for Individualized Treatments. This is a very important bill.

Given both my personal journey and my nonprofit involvements, I am qualified to speak on this issue.

I am testifying today on behalf of my father Augie and my late wife Tara. One is living with a rare disease, and the other had her life shortened by one.

My father Augie was diagnosed with Inclusion Body Myositis in 2008. IBM, as it's called, is a rare degenerative neuromuscular disease that slowly wastes away all of the muscles in your body. Like ALS, but slower.

My dad is 17 years in, and he is in a wheelchair full time. He can't do much for himself without help. 11 year ago, he participated in a clinical trial of a gene therapy that promised to **rebuild** the muscle tissue in his legs. It was a phase 1 trial, which as you know is focused on safety, not efficacy.

Miraculously, it was successful and built muscle in my father's legs. He was able to walk for a few more years. Unfortunately, the researchers could not find financial support for a phase 2 trial and my father couldn't continue to benefit from the gene therapy.

Had this legislation been law at that time, **it would have cleared a path for my dad to continue utilizing this effective treatment**. It likely would have delayed the further breakdown of his muscles, and extended quality of life for him.

This legislation also could have helped my late wife, Tara. She was diagnosed with mesothelioma in early 2016. Meso is a very rare cancer of the lining of the lung, caused by exposure to asbestos. She fought valiantly but passed in 2017 at the age of 47.

Meso is considered one of the **deadliest** cancers in the world. Generally, if you are diagnosed with meso, it's a death sentence. 95% of meso patients die within 1-2 years. It's not a question of if, but how fast meso will take your life.

Despite that, there are a growing range of experimental, non FDA-approved treatments that are showing promise with mesothelioma. Treatments like CAR-T cell therapy and immunotherapy, among others.

Broader access these treatments and others might just turn mesothelioma into a **chronic disease that can be managed**, rather than a very painful death sentence.

Simply put, this legislation would have given Tara a chance — and just as importantly given her a chance to try some of these experimental treatments.

There are many people in Colorado struggling with rare diseases — very likely in **every single one of your districts**. They need new options to improve their quality of life and to extend their lives. **They need HOPE.**

There are treatments are out there that Colorado residents can't access. ... Effective treatments that are available in other countries or that could be in clinical trials here in the US.

While this bill won't address every single situation, it will open the door to a lot more opportunities for access to care. **It will open the door to HOPE.**

Please support this bill and let's make it law during this legislative session. Do it for Augie and Tara, and countless others in your districts that need it. Thank you.

Rich DeAugustinis
Vice Chair of the Board, The Myositis Association
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404-547-8153

Please vote yes on the important bills.

Thank you,
Barbara Rice
Colorado Springs, CO

Hello,
I am emailing as a Colorado voter who is very concerned about the lack of appropriate environmental regulations and protection of minors in regards to abortion clinics in our state. It is critical that Colorado Health and Human Services supports these new bills to ensure that parents retain their rights to consent to medical procedures for minors and that abortion clinics are held responsible for the environmental damage they may cause by unsafely disposing of dangerous chemicals. It is also critical that Colorado does everything possible to ensure that we have "safe haven" laws so that parents are able to surrender an infant that they are unable to care for. None of these new proposals in bill HB25 should be controversial or partisan. Safe Haven laws, protecting parental rights, and requiring abortion clinics to uphold a basic standard of environmental care is not too much to ask and it is disappointing that these kinds of laws are not already on the books in Colorado. These new bills are a necessary step in making Colorado a cleaner, healthier and safer place for all.

-Sincerely,
Colleen Longua, Colorado citizen

Please pass these Bills to provide a safe environment for the most vulnerable.
Thank you!
Ellen Bonner
Sent from my iPhone

House Health & Human Services

03/05/2025 01:30 PM

HB25-1270 Patients' Right to Try Individualized Treatments

Typed Text of Testimony Submitted

Name, Position, Representing	**Typed Text of Testimony**
LyleJen Reinhardt For themself	Hello Lawmakers, We appreciate your interest in, and concern, for those living with rare medical conditions. Our daughter, Jennifer Reinhardt, shared details of the on-going fight to save our granddaughter’s life (Maya). We pray that the journey to save Maya will give others hope and encouragement. It is for this reason that we join our daughter in advocating for Right to Try legislation in Colorado. We believe terminally ill patients should have access to drugs, alternative drug treatments like bio-phages and devices that have not yet been approved by the U.S. Food and Drug Administration. Why? It is because our daughter’s efforts to research and procure potentially life-saving medication for Maya were extremely difficult. Maya’s medical crises were numerous and on-going. When the “approved” drugs did not treat Maya’s infections, we were at a loss. The approval process on any new drug that could potentially help, could take up to a decade before receiving approval. Thus, Maya was left hanging on.

We understand that there are concerns. An article published in the Stateman's Journal on February 4, 2015 said, "....patients might be taken advantage of, that the unapproved therapies would be unsafe, that patients would be siphoned out of the clinical trial system and that attempting experimental drugs would make patients ineligible for hospice care." However, it is also true that patients need to be vigilant when doctors prescribe medicines that are FDA approved. Adverse effects for these drugs are numerous and some side effects are deadly. (article attached as pdf)

While these are concerns, our focus was on saving Maya. Our daughter Jennifer

researched options and chose a successful alternative path for our granddaughter

Maya. Jennifer took sole responsibility for the outcome. It should be her right to try to save her daughter's life. Jennifer administered the bio-phage treatment (used

successfully in other countries for decades) and was successful in keeping Maya's lung function from deteriorating.

What is often overlooked or not talked about is the fact that patients need hope and encouragement. Yes, we did experience miracles in many forms on Maya's behalf. We know, that God wants us to do what we can to encourage others and miracles are just that – acts of God in His timing and wisdom.

Simply put, we are asking for legislation that would allow those with rare medical conditions in Colorado to have the Right to Try potential life-saving drugs, drug

alternatives like bio-phages and devices that are not yet FDA approved.

Sincerely, Maya’s Grandparents – Lyle and Connie Reinhardt

Letter from daughter:

Hello Committee,

Thank you for considering running the Right to Try bill. I am blessed to be able to talk to you and have a happy ending to my story. I went to Oregon from Colorado in 2017 to get a treatment for my terminally ill daughter, because they were one of a few states that were allowed to do international medicine through the Right to Try bill. It would be amazing if we could have that law here in Colorado and Maya’s story could help someone else, like the people who came before us in Oregon helped her. The Right to Try bill in Oregon helped save Maya’s life. I am happy to testify, or meet with you, or anyone to help give someone else the opportunity Maya was given.

Here is our story.

My daughter, Maya was born in Colorado in 2001 with a heart defect as a blue baby. She had to have open heart surgery at 3 days old after being on a ventilator. After surgery, she got sepsis and was not growing. She almost died. At this point, her newborn screen came back positive for cystic fibrosis. After a series of miracles and a few months of hospitalizations, Maya was stabilized, and we were then dealing with the cystic fibrosis. CF does not have a cure.

Cystic Fibrosis is a life threatening genetic rare disease. Maya's body could not fight common bacteria that caused infections, and she could not digest her food. Eventually, we were told she would be diabetic, and she may have liver issues as her disease progressed. The median age for someone with cystic fibrosis when Maya was born was around 30, however together with her heart issue no one knew how long she would live. The surgery to save her heart was new and so there were no old people with her shunt. The CF gene is recessive. My uncle died of CF when he was 2, which made Maya's diagnosis particularly terrifying for my mom's side of the family. My grandma cried and cried. I didn't know that Maya was sick until she was born, as they didn't do gene screening for mothers in 2001. My ultrasounds were normal, and the baby's heart valves don't open until birth so Maya grew ok until she was born.

It was a full-time job raising Maya, and so instead of going to graduate school for social work, I got into real estate so I could make a living working part time and have flexible hours. I was only 23. I researched all the alternative medicines, and which doctors in which states had higher life expectancies. We flew to Minnesota to meet with Dr Warwick, a pioneer in cystic fibrosis. Maya got on inhaled NAC, because in Minnesota the median life expectancy was 16 years higher than Denver and that is what they did there. Through a private dietitian, we got Maya on an anti-inflammatory diet. The hospital was giving her Ensure (a mix of corn syrup and canola oil through their contract with Nestle) to gain weight. Once she was off of that, she started to get less sick. I reached out to a man in his 50s in California with CF who was also a doctor. 50 is old for CF. He said that she had to run, that the pounding in her chest and coughing would help dislodge her mucus. So, I sent Maya to taekwondo, crying. For years. She would spar and cry as her Cuban teacher told her that "crying don't fix nothing". The running made her tough and even though she hated it, we were trying to buy time until a treatment for CF came out. The doctors in Denver thought it would be 10 years, for a gene therapy. Dr Accurso at Children's hospital oversaw CF gene therapy research, and he was Maya's doctor. One day it would be like asthma instead of a death sentence, he said. So we kept fighting. I think with a dying child, without hope, you can't keep moving. As long as I had something to fight for, I kept going.

Her daily schedule all her childhood was to wake up, do a nose wash, get hooked up to a vest that shook her for 30 minutes with a nebulizer, and go to school with another nebulizer in the car on the way to downtown. She needed pills to digest her food, and was on a schedule of a month on, a month off, of strong antibiotics to keep her infections at bay. They made her nauseous, so she had a room to lay down in the nurse office and a private bathroom. Although I lived by the airport, I drove her downtown to a charter school as she needed a special school and had an IEP. The schools by us were very poorly rated and I didn't have a lot of extra money to go to private school. I am grateful there was a charter option to drive to. After school, Maya did more treatments at night. Maya jokes she spent her life plugged into a wall until she got better. The nebulizer and vest had to be plugged in, so she couldn't move around. She got good at art and writing because she could do that while plugged in and worked around the vest shaking her little body.

Maya was hospitalized several times, and we did several clinical trials. One trial called the Inspire Tiger trail, they had to hold her down and put IVs in her body while she yelled. She was around 7. It was very hard. And it didn't work. We kept going, because there was no other option.

Dr Accurso at Children's Hospital Denver warned us that once Maya got a bacteria called pseudomonas, that she would decline rapidly as the antibiotics would not work. It is found in standing water, and hard to not get as there is water everywhere outside. I washed our clothes in borax, put our toothbrushes through the dishwasher, and changed our shower heads to prevent getting it. I kept researching how to keep it away. Eventually, she still got it, at around 13 years old. For 3 years, we were controlling it with essential oil washes and special herbs from the naturopaths. I took Maya to special doctors in the mountains and Boulder. Then, when she was 16, nothing worked. Her infection was raging despite 2 months of cipro antibiotics. Her sinuses were full of mucus, and she was dizzy, along with being sick from being on antibiotics for 2 months. The hospital offered to do sinus surgery to get rid of some of the mucus, but I chose not to since the mucus was full of super bacteria, and I didn’t want it in her blood stream again. I was afraid of sepsis. The antibiotics did not work against her bacteria, because the bacteria protected itself with a bubble called a biofilm. The medicine didn’t touch the bacteria, so Maya kept getting sicker.

I think this part is important, because if she had not gotten this sick, or if there was a treatment that worked in Colorado, we would not have gone to extreme measures to try to save her. I knew that people with cf with these bacteria could die in their teens.

My mom is a nurse, and she sent me an article from Prevention Magazine, on how there was a treatment for antibiotic resistant infections in Tbilisi, Georgia. The Georgia by Russia, not the Atlanta kind of Georgia. Here is the article she sent me.

https://www.prevention.com/health/a20447787/the-cure-for-antibiotic-resistance/

The problem of antibiotic resistance isn’t just for people with cystic fibrosis. Because of antibiotic overuse in the United States, especially for meat production, a lot of bacteria don’t respond to antibiotics. 35,000 people in the US die every year, according to the CDC.

Through my research I learned that it is hard to patent something that is alive, like the phage who eat bacteria in nature. If pharma doesn’t see money in it, they don’t bring it to the United States. Phage Therapy has been around for a century in Tbilisi, it isn’t new, and it isn’t expensive. One treatment at the time cost around $60. You just couldn’t legally get it in Colorado, and the doctors at Children’s hospital would not help me because it was not FDA approved. To get a treatment through the FDA, it takes around 10 years and 1.3 Billion dollars. Sadly, I did not have 10 years and a billion dollars.

One thing about me is that I am a fighter too. I raised Maya and my little son as a full-time sole parent. The only way I could do this was because I work in real estate and have flexible hours (and enough money) to travel all over and time to research and connect to other people doing the same thing which is trying to save themselves and their families.

I pulled all the research papers on the bio phage and cystic fibrosis through the health journals. One of my client’s cousins was head of the NIH. My friend from church’s husband was a pulmonary surgeon. I asked them if this was a good idea. They both said that it was a real medicine, but just international and couldn’t be used here. Well, if there was a treatment, I was going to try to get it for my child. That wasn’t ok, that she would just die because of geography.

The next steps were to find someone who used it. I looked online, and through all the CF message boards. I found a guy that had used it in Oregon. He connected me with a doctor in Oregon. The doctor was busy for a few months. I kept calling, and calling. Finally I got an appointment. Part of the law was that she had to see us in person. This was difficult. My son was little and in school. I was single and working. My family couldn't help me in Colorado with the timing of the appointment. So I reached out to my cousins in Seattle. I had to

	fly to Seattle with my kids, Maya really sick. I left my son in Seattle and rented a car and drove Maya to see Dr Ambrose in Oregon. Dr Ambrose could now get Maya the treatment, but it had to be ordered from Tblisi. It has to go through the FDA and Federal right to try laws and clear customs in Detroit. It is not easy, even with the laws, to get the medicine. Because Maya was so sick, Dr Ambrose figured out how to get us one box of medicine while the other ones were on order. Maya nebulized the phage and also we put it in her nose, for her sinus infection. The infection finally drained and she got better. Now this wasn't a cure. I learned to facetime the doctors in Tbilisi, and how to get Maya better. Each time Maya got an infection that didn't respond to antibiotics, we had to do this. When her window leaked and the water from the leaves got into her space, she was sick. It was a constant struggle to keep her healthy. She was sick over and over again. The phage also didn't not help her organs impacted by cystic fibrosis other than her lungs. But the lung failure is what will kill you. Maya's lungs healed with the phage and her lung function got back up into the 100s. She has 100% lung function of a healthy person, sometimes 125% lung function of a healthy person (PFTs or pulmonary function test). People with CF lose lung function as they age until they die. I was able to keep Maya's lungs undamaged until a better treatment came out. The cystic fibrosis foundation was working on a medicine. I was watching it in the pipeline.

Then in December 2019 Trikafta came out, and since then she has not had a lung infection. She could stop taking her insulin. Her lung function is 115-125% of a healthy person.

Trikafta is a drug that corrects the CFTR defects in her cells, and it is super effective. It gives her close to a normal life expectancy if taken daily. Since Trikafta, she hasn’t had to take the phage because she hasn’t gotten that sick.

Without the bio-phage, I don’t know if we would have made it to 2019. I don’t know how bad the infection would have gotten and if she would have come back from it. Once the lungs are damaged, you can’t fix them. Also she was starting to have to take insulin in 2019. It felt crushing, the amount of work needed to keep her alive. As a single parent I was starting to break down.

That is why I got involved with the PDAB last year in Colorado, and started getting more involved in the law making process. That is how I got connected to you all. I am not a rare disease advocate by trade, I am a real estate broker. I got involved because we don’t want to go back to Maya being sick, it would take over our lives. Maya will die if she loses access to Trikafta.

I think everyone should have the right to try medicines if they have a life threatening disease. It doesn’t hurt anyone else, and a lot of the medicines are not expensive. Most importantly, you need hope. Without hope, there is no reason to keep going. I needed to keep going for myself and my son even if the worst had happened. I don’t know why Maya was saved and so many people die of rare diseases. But I can use my voice and say, let other people have the right to try different medicines, so they have hope until their miracle drug comes out too.

Thank you for listening to my story.

Here is a movie on a family’s journey who's story is similar to ours. They had to jump through so many hurdles in the United States to get the medicine, whereas I went directly to the Tbilisi clinic’s supply to save Maya. But the movie is like watching my own experience with Maya. It is very well done. Please watch it if you have time. 10% of people with CF still do not have a treatment like Trikafta, as it is based on genotype. The rare disease community matters and has a voice.

Salt In My Soul. https://www.youtube.com/watch?v=aGxCjASgMB8

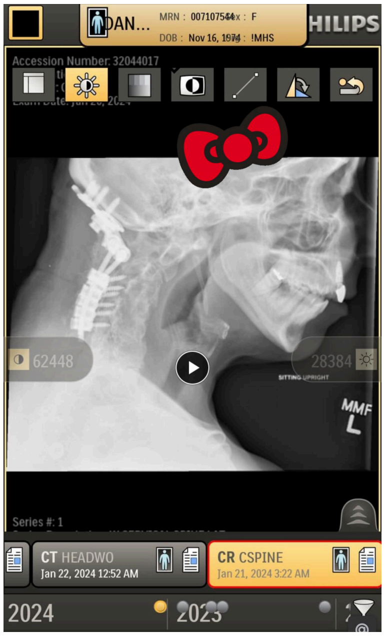
We want people to make it and have hope. Please cut the red tape out of Colorado, as so many people don’t have the resources or experience to navigate the complex bureaucratic systems. Especially if they are sick. In 2017 I didn’t know about the “Right to Try” law in Oregon. I was so blessed there were others that thought about it before me and paved a road for me to travel on.

Jennifer Reinhardt 303-514-8491

Honorable Representatives,

Today, I’m urging your support for the Right to Try bill, HB25-1270. I have multiple illnesses, but one of the most pathological is Ehlers-Danlos Syndrome. As I’ve gotten older, this generic rare disease has dissolved and ruptured nearly all my tendons and ligaments - and I do mean nearly all. I’ve lost the use of my hands, elbows, shoulders, knees, ankles, and feet. Several of my muscles are free hanging, and I can move my ribs around like I’m playing a game of Jenga. The worst is my spine that is no longer held together and decided to identify as a slinky.

Last January, I needed a life-saving cervical spine surgery because my head was literally hanging off my neck compressing my brain stem and spinal cord. My bones decided to fuse naturally from C3-C7, but that pesky occipital joint just wouldn’t stay still. Had this not been fixed, I would have stopped breathing within 3 months. My body clearly likes to live on the wild side. See the photo below of my fancy new neck hardware. Bow added to make it snazzy.



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There is no treatment for my illness. I’m only 50 and it’s like the entire car just broke at once. Soon, all of my organs are going to start to break down. Ehlers-Danlos Syndrome (EDS) means my body makes some forms of collagen in a faulty manner. Collagen is in every organ and at some point my arteries and veins will start breaking, my heart will stop functioning right, and you don’t even want to know what will happen to my digestive system. Think amoeba. Or Jello. Or maybe that ooze you made in 3rd grade science class. Fun, right?

So what does this have to do with the bill? Well, research on my disease is becoming trendy finally. Hopefully, new therapies will be developed and stay clinical trials in the future. I’m no longer a spring chicken, but I would jump at the chance to try a new therapy, even if it doesn’t work. Not just to try and stop my body from eating itself, but it could also help science so those coming after me don’t ever become like this. You see, my children and grandchildren all have EDS. Theirs isn’t terribly pathological now, but may become so as they age. I’d also like to see them grow up, graduate, and even have families of their own. However, right now my time is extremely limited. I want the right to be able to try new things, even if experimental.

Please, please, pass HB25-1270 so anyone and everyone in my situation has the option to at least try. Cancer patients, sickle cell, spinal muscle atrophy, alternating hemiplegia of childhood, and all those rare disease patients deserve the choice. Thank you for supporting this bill.

Bridget Dandaraw-Seritt
Colorado Springs
Founder, Advocates for Compassionate Therapy Now