

**Obesity: The Leading Cause of Nonalcoholic Fatty Liver Disease and the
Most Urgent Threat to Public Health Today**

May 15, 2024

8:30 AM to 10:00 AM

U.S. Capitol Building, Room SC-4

Family Perspective: Remarks by David Frank

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Six weeks. That's how quickly Mom went from being diagnosed with nonalcoholic steatohepatitis or NASH* to leaving us forever. Just enough time for the survival instincts to kick in. Enough time for a family not accustomed to failure to execute a plan of attack, to prepare for a transplant, to bring Mom home for a time when we thought a crash diet change and carefully administered medicine would provide a lifeboat to recovery. Just enough time to learn a modest amount about bilirubin levels and cirrhosis and MELD scores and begin to hope that she could beat it.

My name is David Frank, and in October 2014 my mother Geraldine passed away after a very brief and completely unexpected battle with late-stage NASH. She was only 62 years old and had shown no symptoms until just weeks before being diagnosed. Like most people, my family and I had never even heard of the disease that took her from us.

They call NASH the "silent killer" and in Mom's case it was certainly true; she was never diagnosed with any form of liver disease at all before NASH. We had noticed some yellowing of her eyes and convinced her to go to the doctor about a month earlier, but it took time to get an appointment with a specialist, who checked her into a hospital upon the visit. She stayed there for a few days of testing and then was released pending the results of a liver biopsy. My family was concerned but optimistic based on the lack of other symptoms; Mom seemed totally fine. Of course, I now know that simply being overweight is one of the most crucial indicators of NASH.

A few days later I received a frantic call in the early hours of the morning from my dad. Something was wrong with Mom. Luckily, I was only a few blocks away and raced over to find her in a dazed and confused state, aimlessly walking in circles and incoherent, a condition I later learned was due to her liver failing and not being able to cleanse dangerous toxins from her blood. She was rushed to a local hospital, where the initial diagnosis was not good. The liver biopsy returned later that night and confirmed the initial suspicions--Mom had late-stage NASH that had progressed to severe cirrhosis. There was no treatment. She needed a liver transplant to live.

The time frame of my mom's last few weeks really complicated the grieving process for me. It wasn't instant or nearly so, like a massive heart attack or a car accident would be. In those terrible scenarios there is simply no chance to say goodbye, no time for the Kubler-Ross model to kick in, no chance for hope to take root. And yet it was also not as extended and drawn out as someone who is diagnosed with cancer or other deadly diseases that take months or years to steal someone precious from us. No time for it to sink in, to come to terms with it, to be as ready as anyone can be to say farewell.

As a result, when she suddenly took a turn for the worse in her last few days it was like the rug being pulled out from under our feet. We'd had our scare, realized how serious the condition was, and put into motion a plan to get Mom out of it. My sister was ready to donate a portion of her own liver to Mom. It was going to be OK; we had told ourselves. Until it was not.

For a long time afterwards I struggled with grief, guilt, and a complete feeling of helplessness. I'm the kind of person that takes action, fixes things, and always finds a solution. I don't take no for an answer. For really the first time in my adult life, I'd faced a situation where there was absolutely nothing I could do to help Mom.

And so, I started looking for things to do to help others. I researched NASH and other liver diseases and learned as much as I could. I found out that 80-100 million Americans are affected by some form of fatty liver disease* and that about 25% of them may already have progressed to NASH without even knowing it. I realized that NASH has become the number one cause of liver transplantation in the U.S., surpassing Hepatitis C. I discovered that globally nearly a quarter of the entire population of the planet likely has some form of fatty liver disease. These numbers are simply staggering.

Now combine those figures with the one-two punch of NASH diagnoses and remedies; abysmal early detection rates due to a lack of efficient non-invasive diagnostic methods, and very limited treatments for those that are lucky enough to be diagnosed early. Like Mom, when you finally figure out you have late-stage NASH that has progressed to cirrhosis, there is nothing you can do about it except hope to be lucky enough to get a transplant.

I ultimately decided that I couldn't merely read and learn about the disease that took my mom; I had to DO something. I started out volunteering with the great folks at the American Liver Foundation, helped launch their young professional Associate Board, and now serve on the Board of Directors. We've done some great things together and more are sure to come.

Yet I wanted to do more. I'm a big tech geek and waste far too much time online on social media and blogs, and I decided to use some of that energy for good. So, I founded nashaware.com to help raise awareness and educate others. If I can help even a few people it will all be worth it. But we still need to do so much more.

The problem is that liver disease has never been a "sexy" cause. It doesn't get big deals with sports franchises or have A-list celebrities starring in movies about it. And yet unlike some of the more popular or well-known diseases, *every single person* is a potential victim of a disease like NASH. You don't need a genetic predisposition or family history. You don't need to have a "risky" lifestyle. You just need to be overweight for a period of time. It's a preventable health crisis that may soon compete with cancer and heart disease as the leading causes of death for Americans, and yet doesn't get more than a blip in the press.

We've known about the rising rates of obesity in western society for nearly my entire life. The World Health Organization declared an Obesity epidemic in 1997, over twenty years ago. And the numbers continue to grow at disturbing rates. In a 2019 study published in the New England Journal of Medicine, researchers presented staggering projections that nearly half of all Americans will be obese by 2030. These people are all potential ticking time bombs at risk for NASH.

NASH is known as a silent killer because of situations just like my mom's, who was in fact never even diagnosed with NAFLD despite being a high-risk individual for many years. Much of this is because even in the medical community awareness of the severity of NASH is far too low.

A March 2016 Deerfield survey found that almost half of primary care physicians surveyed were unaware of the clinical differences between NAFLD and NASH. An October 2017 survey by the Chronic Liver Disease Foundation found that 58% of medical doctors were unaware of specific NASH trials currently ongoing. Things have improved a bit since then, but we still have a long way to go.

My wife and I found out we were pregnant with our first child while Mom was in the hospital. I didn't tell her until she was already comatose, and we were desperately hoping she would fight through it. My daughter bears my mother's middle name and as she grew up through her toddler years was very curious about her Grammy, whom she sees in all of these pictures, but will never meet. She wears a locket with Grammy's picture in it and helps teach her brother and sister all about her as well.

My sincere hope is that by the time my children are grown, deaths from NASH will be an odd rarity rather than a steeply increasing epidemic, largely due to the efforts of the many medical professionals, researchers, and investors involved in the race for new treatments and diagnostics.

Thank you for coming to this Congressional briefing to learn more about obesity and liver disease, and for listening to my story. I hope that you will spread awareness and continue to help combat the rising incidence of NASH through your work. I can write a bunch of words on the internet, but the actions of people like you will be the ones that save people like my mom in the future.

Thank you.

*The nomenclature for nonalcoholic fatty liver disease (NAFLD) has recently changed to metabolic dysfunction associated steatotic liver disease (MASLD). Nonalcoholic steatohepatitis (NASH) has been renamed to metabolic dysfunction associated steatohepatitis (MASH). Fatty liver disease is now called steatotic liver disease.