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

Patient Perspective: Remarks by Susan Avallone, RN Advocacy Ambassador, American Liver Foundation, and NASH patient My name is Susan Avallone from Gardner, MA and I am an American Liver Foundation (ALF) Advocacy Ambassador and patient living with nonalcoholic steatohepatitis (NASH)*.

Today, I stand in front of you to talk about the shocking correlation between the rising obesity epidemic and the increased prevalence of liver disease nationwide. As a retired school nurse, I have seen first-hand the perils of not educating people about proper diet, nutrition and exercise and unless we find a way to change that, the rise in obesity and other comorbidities, such as obesity, type-2 diabetes and liver disease will skyrocket and continue to plague future generations.

You may think that as a practicing registered nurse, I would have known about fatty liver disease and been aware of its risks, however the truth is, there is a severe lack of education about liver health from both the public and medical perspectives. I have had NASH and type-2 diabetes for 21 years and when I was first diagnosed in 2003, I had stage 2 liver fibrosis. I was told that if I kept my diabetes under control my liver should be OK and maybe liver cirrhosis might be found on autopsy after natural death. My younger brother died of cancer and six months later my father suddenly died. I thought I was depressed when I began to feel weak and lethargic. Symptoms progressed to joint pain, leg pain, chest pain and shortness of breath when I walked more than 10 feet. When I sought medical help, not only was my blood glucose high, but all of my liver function tests were extremely high, including high cholesterol and lipids. Once my lab numbers normalized, I had a liver biopsy, which showed fatty liver with inflammation and some fibrosis. I carefully followed my treatment plan, and in 2017 my endocrinologist encouraged me to seek a follow up liver biopsy. I was shocked to find out that I had progressed to stage 4 NASH or cirrhosis. At that time, I learned how damage to the liver often occurs in silence until severe damage shows symptoms.

My family history does not have anyone with liver disease; however, my siblings and parents have or had autoimmune diseases, diabetes, heart disease and cancer. I had gestational diabetes and knew I was at high risk for diabetes but had no concern about my liver. Initially when I was diagnosed with cirrhosis, all I could think about were the patients I cared for who had end stage liver disease. I felt angry that I should have this disease. I was a single parent, and I did it all: maintained a home, worked full time, was involved in my children's activities and schools and was a community volunteer in many areas. Fast food and prepared processed foods were a large part of our nutrition. I was always tired, burning the candle at both ends. I decided I was going to do everything I could to fight to prevent my disease progression and adopted a "Look Good. Feel Good "mindset, followed a Mediterranean-type diet and lost 35 pounds, pursued regular exercise and found a balance of life to try to keep stress levels under control. I am thankful for each day. I am fortunate for my excellent medical team and being close enough to Boston medical facilities. Unfortunately, many of my fellow patients with NASH who are with me in ALF support groups, share that they are hundreds of miles from knowledgeable gastroenterologists and hepatologists. Many of them ask questions about the disease process, which should have been explained to them.

With early diagnosis and treatment, fatty liver disease can actually be reversed, and many Americans have already achieved remission by following an approved diet and exercise plan. Unfortunately, my liver damage is so severe that there is no hope of reversing it, however, I strive to slow the disease progression by remaining as healthy and active as possible in hopes of avoiding the need for a lifesaving liver transplant – in fact, NASH has become the number one cause of liver transplantation in the U.S.

As an ALF Advocacy Ambassador, I work to educate and raise awareness about fatty liver disease nationwide, but also locally by participating in health fairs, meeting with my elected officials, and sharing information about this deadly disease. Liver disease can affect anyone. It affects all ages, races and genders through three different factors: genetics, lifestyle or environmental toxins. Many of the foods we eat today are highly processed and full of preservatives; combine that with a busy work and school schedule and lack of activity and you have a recipe for the potential for fatty liver disease. My daughters have made changes in their lifestyles, especially with nutrition and exercise. My grandson is three and my daughter closely monitors his nutrition avoiding foods with preservatives, large amounts of added sugars and frequent snacks.

Teaching proper nutrition, portion control and simple exercises for today's busy American population is key, but creating a nationwide plan for addressing fatty liver disease is critical. Together, we can confront this public health threat affecting nearly 100 million Americans head on.

I asked my hepatologist how I should describe my current disease status. Her response was that I am one of the lucky ones with slowed progression of my disease. I remain at high risk for liver cancer and have scans and lab work every 6 months. Thankfully, I am able to share my story in the hopes of raising awareness and education.

Thank you for listening.

^{*}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.