

## **Sarah Moynihan, member of Safe Tables Our Priority**

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### **We're counting on you**

My name is Sarah Moynihan and I am from Somers, CT. My 12 year old sister Lizzy was diagnosed with E. coli O157:h7, and subsequently HUS (Hemolytic Uremic Syndrome) in May of 2002 from eating a hamburg. Like most people, we had never heard of HUS - never mind understood what it was.

When I was hit with the news that my sister was suffering a deadly food borne illness, I went completely numb. Something terrible just happened to an innocent beautiful child right before my very eyes. This "something" was invisible, it had no smell, no taste, no sound, and we didn't see it coming.

My older sister Amy & I are both members of a volunteer Fire Department and Ambulance Division. We are BOTH medically trained to help people in the event of an emergency. It is our DUTY to help the sick, the injured, and those that need immediate medical attention in our community. **With all of our years of volunteering on the Fire Department, all the car accidents, structure fires, sick people, and traumatic injuries we've seen, we both agreed this illness was by far the worst thing we have EVER witnessed - it was happening to OUR little sister, and there was NOTHING we could do to help her.**

We learned quickly all about HUS. It is a brutal attack on your body. **It is relentless.** We learned that you will lose blood out of every possible orifice on your body. You cannot eat. You cannot drink. When your blood count gets too low - they give you more **in hopes** it will keep you alive. **And worst of all, we learned there is no cure.**

Lizzy was hospitalized for 17 days. She missed the entire last month of 7th grade. She received not one, but two, PICC lines which are like I.V.s except they are threaded through the veins in your arm right up to your heart. She received three blood transfusions and morphine for pain, as there is no medicine to cure this illness. She vomited uncontrollably every 10 minutes throughout her stay until finally, part of her stomach lining came up.

Lizzy suffered physically in many ways, and we all suffered financially and emotionally. Amy and I took turns staying with Lizzy at night so that mom could get some sleep and still work at her children's clothing and toy boutique during the day. For the most part - there was a sign on the door that read "closed due to a family emergency". I particularly remember the night when I stayed up watching Lizzy's blood pressure drop to dangerously low levels while counting the black and blue marks that were popping up all over her body. I cried in between counting them, and reporting my findings to the nurse

every 15 minutes. By morning, I was tired and worn from lack of sleep and tears but went to work anyway. On my drive home that day, I fell asleep at the wheel and thankfully hit a metal sign - which woke me up just in time to avoid hitting a telephone pole. There was damage to my car but I had it fixed immediately so my mother wouldn't see it, as I didn't want her to worry about anything else.

Although Lizzy is now past the acute stages of her E.Coli / HUS infection, she is still on medication because she has permanent kidney damage. As a result, she receives regular checkups for protein in her urine. Lizzy attempts to live the life of a normal teenager. She is trying to run an 8-minute mile. But she can't. She gets winded quickly and easily. She gets pains in her back - where her kidneys are located. She takes pills every day that make her sick, but are supposed to be helping her. Statistics say that over the first 10 years a relapse is possible, especially during her reproductive years. During childbirth, her kidneys could fail and she would need dialysis, or possibly a kidney transplant.

Lizzy doesn't ever talk about her illness, but I asked her how she is doing and what concerns her the most about it. She told me she fears going to the Hospital because she is afraid she will never come home. If she breaks a bone, at least then she knows what she's going in for. A broken bone is something she can see, and it can be fixed.

We are so very thankful that Lizzy is still here with us today. She is still smart and beautiful. Still an honor student. She can still play the piano like a little Mozart and used her babysitting money to buy a guitar and has learned how to play it this year. However, unlike Lizzy, many children don't survive this illness. I found this unacceptable, and so I continued to research the problem.

Unfortunately, the more I researched, I found that we were not alone. Lizzy was not the only case of food borne illness that year. **In fact there are an estimated 76 million food borne illnesses each year in the US with 325,000 of them, like Lizzy, requiring hospitalization.** Also, **5000 people died that year**, and every year, from food borne illness. This country has gone to war when we lost half that number on 9/11. We are vulnerable today to bioterrorism and our food supply is at risk.

Since Sept. 11th it's become very clear that government is well aware that bio-terrorism is a reality that needs to be addressed at every level, including the food supply, and they are taking baby steps to prepare for it. But, it's not enough. What we need is more proactive measures to ensure the safety of the public and the food supply, and we need it now.

How can the greatest country in the world knowingly allow unsafe food to be shipped to grocery stores so that innocent people can get sick and even die? Why aren't there stricter regulations put on industry to test the food and get the results **before they allow it to leave their plants?** This is unacceptable - and yet our government and industry allow it to happen. There are certainly methods to prevent this - but why haven't they been implemented?

I'm sure you all remember the feeling on Sept. 11th wondering - who did this to us? Who would harm these innocent people? We were suddenly at war - and we don't even know whom with? Well, that is the same feeling you get when you watch your little sister lying in the hospital bed. You get that helpless feeling, not knowing what's happening or who did this to an innocent child?

It is immoral and completely negligent if government continues to ignore the cracks that exist in our food supply today. The system is broken and must be fixed. Traceback from the table to the farm does not exist. Voluntary recalls are too slow, and people become ill and die before recalls are even issued. There is no system in place to quickly and efficiently find the source of contamination, prevent it from spreading, and more horrifying than that - there is no cure once you become ill. We must protect the people most susceptible to food borne illness, specifically our children, our elderly, and those with compromised immune deficiencies.

I am the author and editor of the 9-1-1 Newsletter that is published and sent to 5 towns in North Central CT. We advise people, on behalf of our Fire Dept and ambulance, about swimming pool safety in the summer so that we can reduce the number of annual drownings - mostly children. We also encourage people to teach their children not to use matches or lighters, and to make a fire escape route with their families at home in the event of a fire. Each year our firefighters go to the schools to teach the kids about stop drop and roll to try and prevent the annual deaths - mostly children who hide under a bed or in a closet because they are scared during a fire. I'm sure you're all aware of the things you can do to protect children from drowning or from fires. But do you know what to do to keep them safe from the food they eat? Did you even know it was a danger?

According to the CDC, there are approximately **3300 drownings** in the United States each year, and approximately **3300 deaths from fires** each year. Yet, **there are over 5000 deaths each year due to food borne illness**. That's almost as much as those two combined. And, while I've dedicated newsletters to the public in my area about the food recalls, safe handling and cooking of food to the recommended temperatures, I am appalled that I have to tell them this. Why is our food being shipped with E. Coli and other deadly pathogens in the first place? And why aren't we doing more to prevent it at the source, instead of putting the responsibility on the consumer?

One last point I want to make involves the lack of public health response once you get a food borne illness. We had a receipt, and proof of purchase for the hamburger we thought made Lizzy sick. We thought that was enough. Then, there was a very large recall of beef issued - months after Lizzy first became ill. When I called the store they told me to "just return the beef for a full refund". Well, it was a little late for that. When I told the store my little sister nearly died from eating the hamburger, they changed their story to "Well, we didn't actually get any of the contaminated beef, we are just doing a voluntary recall to make the consumers feel safe in case they want to return the product". I was then told the only way to prove the link was not the receipt - but a genetic match was needed. The State of CT Health Department refused to give us that information or even speak to my mother about Lizzy citing "patient confidentiality". The Dr's told us not to worry, because

in most cases, people never find the cause of E-Coli so don't waste your time. Everywhere we turned for help, the door was being shut in our face. No one wanted to help us. Not the Public Agencies, and Certainly not the private companies who are protected by law from sharing information with the general public.

It took me over two years of phone calls, letters and emails to the Attorney General's office, the Health Dept and to my State Representative who was concerned enough and kind enough to set up a meeting at the State Capitol. Finally, one day, her PFGE Isolate suddenly "appeared" at her Dr's office. Two years, just to get one piece of information that may or may not help us. This is simply unacceptable and we need to have a system in place that HELPS track down the source of food borne illness - and prevents new cases immediately - not years later - when most people will have long given up.

I was even asked by someone at the State level "**your sister is alive, isn't that enough?**" In other words - why was I still fighting to find out the cause? I will tell you why - it is unimaginable to me that 325,000 children every year have to suffer like Lizzy did in a hospital for something that could have been prevented in the first place. I thank God every day she is still alive, but no - it's not enough. I want to know that I have done everything I can to help prevent another child from suffering from food poisoning or worse, dying from it.

IF there was only one thing that I could say to you - and one thing you would take away from listening to me today it's this: **Our food supply is NOT safe enough. There is more that government and industry can do to make it safer. You have the reach and the resources to enact measures to better prevent the tragedy of food borne illness. You can, and must, help to stop it.** We are counting on you!

Thank you.