

Nancy Donley
President, S.T.O.P. - Safe Tables Our Priority
Mother of Alex, 1987-1993

About the Speaker

Nancy Donley has held the volunteer position of President of S.T.O.P. - Safe Tables Our Priority since 1996.

Donley first became involved in food safety after the death of her only child, 6-year-old Alex, from Hemolytic Uremic Syndrome caused by *E. coli* O157:H7-contaminated hamburger. Alex's death occurred in July 1993, six months after the Jack-in-the-Box *E. coli* O157:H7 epidemic that killed an identified four children and sickened 700, catapulting food safety to worldwide attention.

Shortly after her son's death, donley was introduced to S.T.O.P. and became the spokesperson and project leader in working on the development of the Pathogen Reduction/Hazard Analysis and Critical Control Points (PR/HACCP) regulation that was promulgated by USDA. The rulemaking process necessitated two years of traveling to Washington, DC on a nearly bimonthly basis to attend public meetings as the policy was being debated and developed. The outcome, while far from perfect, required for the first time ever, that companies that slaughter meat and poultry to conduct microbial testing and meet microbial performance standards.

Donley was appointed to the National Advisory Committee on Meat and Poultry Inspection by Secretary of Agriculture Daniel Glickman in 1996 and is serving her third appointment. She has won numerous awards for her efforts in developing stronger food safety regulations and for raising public awareness, including the first-ever Golden Carrot Award from Consumer Federation of America given to a non-elected public official, and the Civil Justice Foundation Community Champion Award.

Donley is a licensed real estate broker in Illinois. She has a BS in Marketing from DePaul University.

Slide 1: Welcome and Introduction

Transcripts

MS. DONLEY:

Good morning to all of you. It's -- it's great to see a really large, wide-awake crowd at this time of the morning on Saturday.

We are about to embark on a really truly remarkable and historical event today. And all of us at S.T.O.P are very proud to have been able to facilitate its happening.

This is the first time ever that top medical authorities world-wide on HUS are sharing the latest information available on the sequelae and long-term implications of this disease with both their colleagues and with actual victims and their families.

I would like to add a special thank you to the doctors who have taken their time out of their busy schedules to come here today and, of course, our sponsors.

And I am hopeful that we all walk away with a lot of very good information to take home with us. But I would also like to add a very special thanks to a truly remarkable person, and that is Laurie Girand, this conference's coordinator.

Without Laurie's intense, enormous efforts and sacrifices this event would not be happening today. Would you please join me in a special round of applause for Laurie Girand.

Let me begin by saying that it is not by accident that S.T.O.P chose to host this conference here in Seattle. S.T.O.P's very origin was in the aftermath of the West Coast Jack-in-the-Box E. coli 0157:H7 outbreak that killed four known children and sickened over 700.

S.T.O.P was founded by grieving families and their friends outraged that hamburgers harbored deadly cattle feces and that the government and the meat industry not only knew about it but weren't doing anything about it and that hundreds of illnesses and deaths here in Seattle didn't have to happen because, one, Food Maker, the parent company of Jack-in-the-Box, failed to recall contaminated lots shipped to Seattle and elsewhere. And two, because the lack of public health infrastructure that could have identified and linked the illnesses and death that was occurring in the San Diego area as the first signs of an epidemic here.

Some of you are familiar with S.T.O.P. and have been affiliated with us for a long time. We have here today Donna Rosenbaum, a founder of S.T.O.P. and S.T.O.P.'s first executive director.

We also have Bonnie Rock, also a founder, and S.T.O.P.'s first president. And next to Bonnie is Roni Rudolph-Austin, a founder of S.T.O.P. and the mother of Lauren Beth, whose daughter was the first to die in the Jack-in-the-Box 0157 epidemic.

But some of you are not so familiar with us, and I would like to take a very brief moment to tell you a little bit about us.

At S.T.O.P. we work hard to provide victim assistance, public education on the risks of food borne illness and how best to minimize those risks and on policy advocacy for stronger regulatory programs to make our food supplies safer.

We began by focusing solely on 0157 contamination in meat, but as this pathogen continues to spread its way through our food supply, we have expanded our efforts to include other food industries and other governmental agencies as well.

And we've also needed to expand our efforts to include Salmonella, Listeria, Campylobacter as victims reach out to us and ask for our help.

We've had our successes and we've had our failures. In the meat and poultry industry S.T.O.P. was instrumental in getting a federal regulation passed calling for the pathogen reduction hazard analysis and critical control points.

For the first time ever companies slaughtering meat and poultry must meet microbial performance standards. S.T.O.P. was also instrumental in getting safe food handling labels on raw meat and poultry products and in the USDA's establishment of a zero tolerance standard for E. coli 0157:H7 in ground beef.

S.T.O.P., largely through Laurie Girand's efforts, has forced FDA to promulgate juice safety regulations.

But we have to fight to maintain every step forward because there are constant efforts by some in industry and some in government to roll us back to the way it was.

We invite all of you in this room to join us in our efforts in the strongest and best ways that you can. We appreciate whatever support you can give us, both financially and in personal involvement.

But now back to why we're really here. Every one in this room has experienced the horror, the brutality and the trauma that the bacteria E. coli 0157:H7 can wreak, in some way, shape, or form.

Some of us here barely escaped death as we spiraled down into the hell into Hemolytic Uremic Syndrome. Some of us provided medical treatment to the victims, themselves. Some of us suffered helplessly as we watched our loved ones battling for his or her life, and some of us witnessed the battle lost.

One of the greatest fears in life is that of the unknown. Survivors of HUS and their families live with this fear every single day. I hope that today will provide answers, and perhaps reassurance, and certainly knowledge.

I would like to conclude with the following message to you all, but most especially to the families here today, speaking as a mother who experienced Hemolytic Uremic Syndrome vicariously through her little boy's battle and his ultimate death. I would like to share with you my own personal thoughts, wishes and prayers.

Where there is life, there is hope. Where there is hope, there is a future. And where there is a future, anything is possible. Thank you for being here today.

MS. GIRAND:

Nancy, thank you very much. I'm going to ask you to bear with me while I demonstrate the technological advances of this room. All right. Good, we're off to a good start. Everything's working so far.