



Peggy Lillis Foundation

Fighting C. diff through Education and Advocacy

FIGHT C. DIFF 2015

Remarks by Co-founder Liam Lillis

This past April was 5 years since we lost Mom. I still miss her every day. I know many of you do, too. To be honest, while I miss her a little more when life is hard - like when we lost our uncle, Mom's brother, Jim last fall, I really miss her the most when things are great. That pain doesn't fade.

Since our last Gala, we've had some great personal and family times and I wished constantly that she were here with us to celebrate them. Christian and Chris finally got married. And me and Melissa are working on it. I also got promoted at work, and Christian left his job at Teach For America to run the Peggy Foundation full time. I told him if it doesn't work out, he and Chris could live in our basement.

The weirdest thing about how the Peggy Lillis Foundation has grown is that with each success we have, I want to call Mom and tell her. But the whole reason we're doing THIS is because I can't call her; because she's not here. Still, we've accomplished so much more than we ever imagined 5 years ago. I want to share the things that we're most proud of so far.

First, we've educated a LOT of people about C. diff in the past 5 years. Through our public service announcement, at this Gala, and in newspaper and magazines, literally millions of people have learned about C. diff through Mom's story. Just this summer, Consumer Reports featured Mom in its cover story, "The Rise of Superbugs." They sent a photographer to take our picture, and included a blurb about the foundation in it. It's crazy to think about it but Mom's story has also been in USA Today and the New York Times. She's kind of famous now.

You may have seen that we launched a new website this summer. It is without a doubt, the best place online for patients and families dealing with C. diff to find information and resources. In creating the site, we strived to build what we wished we had when Mom was in the hospital. The site also contains a lot of info about why and how to advocate for the regulations and policies we need to save lives. You can also download our new brochure and fact sheets, which you'll find in the PLF mugs at your tables. Please take them with you tonight. The knowledge in them can save lives.

Second, our advocacy work really started to show some results this year. In February, the Centers for Disease Control & Prevention released updated estimates on the number of people who suffer with and die from C. diff infections every year. Along with other groups, we had been pushing for CDC to reassess its number because we knew they were too low. The CDC now says that nearly 30,000 Americans die from C. diff each year. And another half a million are harmed. Ultimately, we're working toward a day when no other family will have to like ours. And knowing just how terrible this epidemic is will help us to focus more attention on it.

We also lent our support to several federal legislative proposals, most importantly, the president's plan to combat antibiotic resistant bacteria. In fact, the Peggy Lillis Foundation was one of three patient-focused organizations invited to participate in the White House Forum on Antibiotic Stewardship in June. I really wanted to go hang out with Michelle and Barry but, unfortunately, only one person from each group could go. At least that's what Christian said when he left me in Brooklyn.

Lastly, we had a really great event back in August. Since we lost Mom, we have gained a lot of new friends - members of the Peggy Lillis Foundation's extended family. Last year, we honored the Dexter family with our first Advocates Award for all the awareness and fundraising they've done in memory of Judy Dexter. Mom believed deeply in helping other people. And in the importance of every day people working side-by-side as we and the Dexters have.

So on August 21 and 22, PLF held the first-ever Summit for C. diff advocates. We invited over 25 people from all across the country who've been personally impacted by C. diff, either directly or through a loved one. None of them are professional activists. Rather, they included a hair stylist, a medical biller, an office manager, a social worker, and others. Over those two days, more than 20 presenters and trainers with a wide range of expertise in medicine, microbiology, federal and state health care policy, media relations, lobbying and grassroots activism, provided vital knowledge and skills to these new volunteer leaders.

The Summit highlighted PLF's focus on the second plank of strategic plan, Empowering Advocates, and the public launch of our new Advocates Council. In addition to those mentioned, another 25 people have joined the Council. These advocates will serve as leaders in their communities and, collectively, nationwide. Given that lack of public knowledge, inconsistent clinical practice, limited treatment options and varying degrees of public reporting all contribute to the CDI epidemic, our Advocates are poised to have an enormous impact by raising awareness, engaging health care workers, supporting efforts to expand the treatment pipeline and pushing for great transparency. We are happy to have several of them here with us tonight. I'm going to ask them to stand so we can acknowledge their commitment to fighting C. diff.

The Summit was also a rare opportunity for C. diff advocates to meet in-person and build community with each other and the experts present. Advocates joined us from Florida, Ohio, Rhode Island, Missouri, California, Indiana, and Maryland. The critical knowledge and skills advocates learned included:

- The state of Clostridium difficile infections as a disease,
- How C. diff is tracked and reported in the states and where advocacy can increase transparency,
- The way the C. diff epidemic intersects with others issues, including aging, antibiotic overuse and misuse, infection control, and the larger movement to end medical harm,
- How to tell their stories effectively to raise awareness and inspire action by policymakers, health care workers, and the general public,
- How advocates can work in their local communities to educate patients, raise money and engage health care workers, and
- Effective ways to leverage social media for advocacy and C. diff awareness, and

Both our Advocates and presenters have been unanimous in their praise for the Summit, and in the need to build a nationwide movement to fight C. diff. Our Advocates Council are going to be the leading edge of that movement.

Now, Christian is going to share with you what we've learned in the past year and what we plan to do in the coming year.