



FIGHT C. DIFF 2015

Remarks by Executive Director Christian John Lillis

So we've done a lot in the past 5 years! Since losing Mom, the biggest lesson for is the value of community. Though our last name is Lillis, Liam and I were really born into the large, working-class, Irish-Catholic, multi-generational Daly clan. With 9 children, my grandparents virtually birthed their own community. Having me at just 19 years old and Liam three years later, Mom relied a lot on her family, particularly after she left our father. (Actually, she threw him out since she didn't want to care for three helpless babies.) The blessing and curse of growing up in the Daly family is that we were literally surrounded by community.

The blessings include free childcare from a grandparent, sibling, cousin, niece or nephew. This was essential for a young, single-mother working AND going to college. Liam and I had lots of aunts and uncles close in age to play with and who babysat for us. We also had a seemingly endless parade of cousins. Really we had this vast community of people taking care of us. Our uncles and their friends taught us to play sports. Or, rather, they taught Liam. Our aunts took us shopping for records and cool clothes. They took us to the park, the Irish Fair, and Coney Island. They even helped us with our homework. This community exposed us to rock music and disco, totally age-INAPPROPRIATE movies like *The Exorcist* and *The Warriors*, and beach days at Bay 14. When I was 15, my uncle Robby and aunt Mary took me to my first concert: Fleetwood Mac at Jones Beach. Our community also offered protection. You didn't mess with a Daly in Bergen Beach. For a little Christian who wanted to be Wonder Woman when we played superheroes being a Daly saved my ass more than once.

The curse of such a tight-knit community is that we didn't get away with anything. Everyone knew everyone. So if we got in trouble at school, it wasn't just with our teacher. Depending on the grade, our teacher could also be the mother of one of our uncles' best friends. More than once, we'd be sneaking beers with friends at Utica Park and end up dragged home by an aunt, uncle or one of their buddies. Despite this occasional public humiliation, the positives outweighed the negatives.

Struggling to come out at 16 was another "curse" of growing up "small-town" Brooklyn. In the dark days before Internet, and 25 years gay marriage would be legalized, gay people had to seek out community in person. For me, and other LGBT people in the boroughs, that meant going The Village. I won't bore you with tales of 16-year-old Christian's first furtive attempts to find a boyfriend. What matters is that I came out in 1989, at the height of the AIDS crisis. Though my mother accepted me wholeheartedly, HIV terrified her. Because of how Mom raised us, I quickly got active in LGBT rights and HIV/AIDS activism. I participated in a pretty famous ACT-UP protest that shut down the Brooklyn Bridge before my freshman year of college.

Those brave people protesting the government's inaction and the media's callous disregard for people with AIDS, showed me how a community can be galvanized into a movement. 26 years later, the world is a very different place. Though AIDS remains a terrible epidemic, the efforts of those early

activists as well as the scientists, doctors, nurses, elected officials and other brave souls, have made important strides and saved countless lives. Out of what seemed like an infectious disease apocalypse, grew a powerful movement for equality and dignity that has transformed our laws, our culture and our institutions.

While we have long thought grassroots advocacy is vital to reach a time when C. diff infections are rare and always survivable, four recent events made it clear to me that building community around this disease is step one.

The first was getting married. Despite my youthful appearance, I've already given away that I'm old enough to remember when marriage equality seemed, if not impossible, than highly unlikely. Our wedding reminded me of those we've lost, and how important it is to keep the people you love close.

The second was being on our honeymoon in Ireland when gay marriage was legalized by popular vote. Ireland, an officially Catholic country, was the first ever to vote in favor of marriage equality. Both research and anecdotes tell us that knowing someone who is gay is the primary reason people support our rights. In other words, seeing queer people as part of your community equals wanting us to be safe and treated as full citizens.

There were two events in August. The first was our Advocates Summit, which Liam has already spoken about. It was truly incredible. Much like the first time I walked into the LGBT community center, being with our new advocates and the amazing presenters, I knew these people were part of my tribe.

Finally, I'm a Zumba enthusiast. Dancing is my favorite form of cardio and I've met a lot of people through Zumba. The day after the Summit, two of my Zumba instructors held a fundraiser our friend whose daughter was battling leukemia. It was a Sunday afternoon in August but the place was packed. I'm happy to say that we raised a lot of money and Mahlina has a great prognosis. However, my friend did call me a few weeks ago because Mahlina had C. diff. Thankfully, it was a mild case. But if not for our Zumba-based friendship, odds are Felicia would never have heard of C. diff.

In fact, a recent Harris poll conducted for the Sepsis Alliance revealed only about 30% of Americans have even heard of C. diff. That same poll showed that 98% have heard of Ebola. Last year, Ebola killed one person in the United States. C. diff killed about 30,000. If you watched the news last October, you might have felt that at any moment you were going to be stricken with Ebola. In response to the media hysteria and resulting public outcry, Congress appropriated hundreds of millions of dollars to combat Ebola. To be clear, Ebola is a terrible disease the causes untold suffering. I'm absolutely for our government helping to arrest the epidemic in West Africa. However, your chance of dying from C. diff is magnitudes greater than Ebola. Despite that, when the president asked for \$1.2 billion to combat C. diff and antibiotic resistant infections, it barely made the news here. And both the House and the Senate budgets offered only a fraction of what was requested. The issue isn't that Ebola got too much money. It's that C. diff hardly got any. That must change.

There was a time when HIV/AIDS wasn't covered or funded as it is today. It took a powerful movement rooted in community to demand that the media and the government pay attention and respond. We're at the beginning of that journey for C. diff now. We need everyone in this room and people all across this country to stand with us.

Next year, we plan a national awareness campaign. We will advance a policy agenda to fight CDIs at the federal and local levels. We will support 30 advocates working in their communities to raise awareness and change policy. We will work at the state level to mandate public CDI reporting by nursing homes, starting right here in New York.

We will do this by growing and inspiring an ever-larger C. diff community unwavering in its belief that we can and must do better. A community that says loudly that losing 29,000 Americans to a preventable disease is unacceptable. We will do this by supporting advocates as they engage the communities in which they live, work, and socialize; by building local alliances between CDI patients and caregivers with their doctors, nurses and other health care workers.

We will do this by calling attention to the ways in which federal laws, regulations, and funding, impact our local communities capacity to respond to C. diff and other dangerous infections. Collectively, we will do this by investing our country in a policy agenda to profoundly reduce the death and harm caused by CDIs.

We will do this together – as a community – as a movement – until we reach there day when C. diff is rare treatable and survivable.