

5TH ANNIVERSARY

ACTION
ADVOCACY
CHANGE

Fight C. diff Gala

OCTOBER 23RD, 2015

Innovators Award presented to

Dr. Trevor Lawley

Advocate Award presented to

Rep. Yvette Clarke

Lifetime Achievement Award presented to

Dr. Lawrence J. Brandt



Peggy Lillis Foundation

THE PEGGY LILLIS FOUNDATION IS WORKING TOWARD A WORLD
WHERE C. DIFF INFECTIONS ARE RARE,
TREATABLE AND SURVIVABLE.

Seres Therapeutics is a proud sponsor
of the **Peggy Lillis Foundation** and
salutes the work that they do on a
daily basis on behalf of patients with
***Clostridium difficile* infection.**



SERES
THERAPEUTICS™

PROGRAM

Cocktail Reception

Welcome and Introductions

Christian John Lillis & Liam Lillis

A Year of Successes

Liam Lillis

Building the Movement to Fight *C. diff*

Christian John Lillis

Innovators Award Presented to Trevor Lawley, PhD

Presented by Gerard Honig, PhD

Advocate Award Presented to Rep. Yvette Clarke

Presented by Christain John Lillis and Liam Lillis

Lifetime Achievement Award Presented to Lawrence J. Brandt, MD

Presented by Bruce Hirsch, MD

Dessert & Dancing

Raffle Winners Announced

Welcome

In April, we marked the fifth anniversary of our mother Peggy's death.

It seems impossible to us that we've survived this long without her. It seems equally impossible that in those five years, the Peggy Lillis Foundation (PLF) has grown out of our grief to become the leading national organization fighting *clostridium difficile* infections (CDIs). But both things are true, and both are the direct result of community.

The past five years have brought our family other losses, like Peggy's brother Jim and her brother-in-law Joey. We've also lost Christian's mother- and grandmother-in-law. In every case, we leaned on and into our family and the larger community of friends, colleagues and neighbors surrounding us. Joy was also on hand. Christian and Chris married in May. There has also been joy in watching others wed, welcoming new children, and in seeing our cousins grow into adults.

From the start, community fueled the founding of PLF. At our first fundraiser, Celebrating Peggy's Life, the Brooklyn community where our mother grew up, worked and lived, stepped up to ensure her story saves others from CDIs. In just 5 years, PLF's community has grown from a close knit group of family and friends, to a nationwide network, including thousands of CDI sufferers and caregivers; doctors, nurses and pharmacists; elected officials and public policy makers; companies and philanthropies; and activists working on an array of patient safety issues.

This community has fueled our expanding movement to fight CDIs and our successes this year. We are particularly excited by how many of our accomplishments grew from and strengthened our community. For example:

- ▶ Our new website at peggyfoundation.org is rapidly becoming THE online destination for CDI sufferers and caregivers.
- ▶ Following sustained advocacy by PLF and other patient safety advocates, the Centers for Disease Control & Prevention updated its assessment of the number of people harmed and killed by CDIs each year. This confirmation of the CDI epidemic's breadth is key to engaging the media, prompting government action, and communicating the risk posed to our community health.
- ▶ Peggy's story was featured in Consumer Reports August 2015 cover story, "The Rise of Superbugs," reaching 7 million Americans.
- ▶ Our executive director participated in the White House Forum on Antibiotic Stewardship.

Our biggest achievement was launching PLF's Advocates Council. Comprised of 30 people from across the country who've been impacted by a CDI, directly or through a loved one, the Council exemplifies how we are movement building by investing in community. In August, we welcomed many of these new leaders to our first Summit in New York City. Over two days, 20 experts from medicine, health policy, media, lobbying and grassroots activism, provided

knowledge and skills to our advocates. The Summit also allowed advocates to build community with each other and experts.

Given that lack of public knowledge, uneven clinical practice, inadequate treatments and unreliable public reporting all contribute to the CDI epidemic, our advocates will have an enormous impact by raising awareness, engaging health care workers, supporting an expanded treatment pipeline and pushing for more transparency. In their communities, advocates are increasing knowledge about CDIs among their friends and colleagues. They are sharing their stories on traditional and social media. Nationwide they form the spine of a growing body of individuals and families demanding increased attention and action from the federal government. At the same time, they are a source of support for other CDI sufferers and their caregivers.

As we look to 2016, your support is more crucial than ever. Next year, we plan a national awareness campaign. We will support advocates working in their communities to effect cultural and policy change. PLF will advance a policy agenda to fight CDIs at the federal and local levels, and work at the state level to mandate public CDI reporting by nursing homes and other health care facilities.

At the heart of each of these is community. It's about helping advocates engage the communities in which they live, work, and socialize. It's about building local alliances between CDI sufferers and doctors, nurses and other health care workers. It's about connecting the ways in which federal laws, regulations, and funding, impact our local communities' ability to respond to CDIs and other dangerous infections. It's about engaging our country in a policy agenda that can radically reduce the death and harm caused by CDIs.

Our mother, Peggy, was a linchpin in our family and all the communities of which she was a part as a sister, teacher, student, waitress and friend. As PLF gradually becomes the linchpin of the CDI community and movement, at the forefront of our work will be the values she instilled in us. These values—compassion, hard work, standing up for the vulnerable, and being a teacher and a learner—bind our community together.

Thank you to everyone who's a part of PLF's community. Your commitment to the fight against *C. diff* is instrumental to our success.

Christian John Lillis
Co-chair

Liam Lillis
Co-chair



Peggy on her back porch in October 2009.

LIFETIME ACHIEVEMENT AWARD RECIPIENT

Lawrence J. Brandt, M.D. earned his bachelor's degree with honors from The College of the City of New York and his medical degree from The State University of New York Downstate



Medical Center. He then did his postgraduate medical education, including a fellowship in Gastroenterology, at The Mount Sinai Hospital in New York, after which he served in the Army as a gastroenterologist in Germany. Dr. Brandt then joined the staff of Montefiore Medical Center in the Bronx, New York, where he currently is the Emeritus Chief of Gastroenterology and Professor of Medicine and Surgery at Albert Einstein College of Medicine.

Among his many contributions to gastroenterology are: the first endoscopic removal of a gastric polyp; the demonstration that in small bowel bacterial overgrowth states, gastrointestinal bacteria produce cobamides from dietary vitamin B12 that may inhibit vitamin B12 absorption; that most cases of newly diagnosed inflammatory bowel disease (IBD) in the elderly are actually ischemic colitis misdiagnosed as ulcerative or Crohn's colitis; the demonstration that metronidazole can heal perineal Crohn's disease; the development of a cytology balloon for the diagnosis of esophagitis in AIDS patients; the classification of ischemic colitis and elucidation that isolated right-sided ischemic colitis has a worse prognosis than ischemic colitis in other locations; and the use of colonoscopic fecal transplantation to treat recurring *C. difficile* colitis.

The author or editor of more than 750 scientific publications and 7 books, Dr. Brandt is one of the three editors of the standard textbook in gastroenterology, and recently completed serving ten years as an Associate Editor for *Gastrointestinal Endoscopy*.

Dr. Brandt is a Master of the American College of Gastroenterology (ACG) and has received many awards, including the Distinguished Educator Award from both the American Gastroenterological Association and the American Society for Gastrointestinal Endoscopy; the Clinical Achievement award of the ACG; and the William Dock M.D. Master Teacher Award in Medicine of SUNY (Downstate).

Dr. Brandt has been Visiting Professor at many institutions, and has given over 500 lectures nationally and internationally. He is an honorary member of the Puerto Rican, Argentine and Dominican Republic's Societies of Gastroenterology. Since 1994, he has been listed every year in Best Doctors in America and since 1998 in Who's Who.

INNOVATOR AWARD RECIPIENT

Trevor Lawley, PhD is a faculty member at the Wellcome Trust Sanger Institute, a world-leading center for health-related genome research in Cambridge UK, where he leads the



HostMicrobiota Interactions Lab. As a postdoctoral fellow, Trevor received the prestigious Royal Society Fellowship to establish a new research program in *C. difficile* epidemiology and pathogenesis at the Sanger Institute.

Trevor's work has since expanded to focus on developing novel genomic tools to track *C. difficile* persistence and spread in healthcare settings in real time. He has pioneered many aspects of the bacteriotherapy concept, the notion of using health-associated bacteria as medicines to treat disease. This concept offers the potential of novel therapeutic approaches to cure intestinal diseases linked to pathological imbalances in the microbiota, offering new hope for the treatment of *C. difficile* infection and other diseases including some forms of intestinal bowel disease and obesity. Aspects of this research have been highlighted in *The Economist* and the BBC news.

Trevor has always been fascinated by the dynamic and complex relationships between bacteria and their environments. He received his Bachelor's Degree from Acadia University, Canada where he studied pathogenic bacteria affecting the strawberry crops on local farms, and then earned his PhD from the University of Alberta, Canada where he pioneered the use of genomics to study the origins and spread antibiotic resistance in infectious diseases. He received the Canadian Society of Microbiologists Graduate Student of the Year Award for this work. Before moving to the Sanger Institute, Trevor completed a postdoctoral fellowship at Stanford Medical School where he studied how antibiotics can cause infectious disease susceptibility and spread.

Trevor is delighted and deeply honored to be recognized by the Peggy Lillis Foundation, and looks forward to joining this impressive group of allies in the fight against *C. diff*.

2015 Accomplishments

Since our last Gala, PLF has accomplished much in pursuit of our mission to build a nationwide *C. diff* awareness movement as well as building our capacity to fight *C. diff*. We are proud to report significant progress on the following fronts.

Educating National Audiences

Our New Website. In July, we launched our new website to great enthusiasm. The site contains an array of information, tools and sources for people with CDI, their caregivers, healthcare professionals (HCPs), public health officials, policymakers, and CDI advocates. Check it out at www.peggyfoundation.org.

CDI Fact Sheets. PLF created four new fact sheets, available on our website and being distributed at all of our events, including:

- ▶ *C. diff*: Know The Facts
- ▶ Risk Factors & Prevention
- ▶ Treatment Options
- ▶ Caring for Someone with *C. diff*

Raising Awareness through the Press.

- ▶ In February, the Centers for Disease Control and Prevention (CDC) invited PLF to share Peggy's story in a press conference unveiling its updated CDI statistics. We had long advocated for CDC to reassess its count of Americans harmed and killed by CDIs, believing it was too low. This new estimate of 29,000 CDI deaths is more than double previous ones. The news was widely covered with reports including Peggy's story in USA Today, Reuters and the Associated Press.
- ▶ Peggy's story was featured in Consumer Reports' August 2015 cover story "The Rise of Superbugs," reaching 7 million subscribers.
- ▶ PLF wrote a blog post promoting the National Foundation for Infectious Diseases' CDI webinar series.

I just wanted to thank you for inviting me to speak at the summit on Friday. It meant a lot to be a part of such a meaningful event... and [to bear] witness to the beginning of an important healthcare movement."

— Cynthia Bens, Alliance for Aging Research

Empowering Advocates

***C. diff* Advocates Summit.** On August 21 and 22, PLF held our first-ever Summit for 30 CDI advocates. Over two days, 20 experts from medicine, microbiology, health care policy, media relations, lobbying and grassroots activism, provided knowledge and skills to these new leaders. The Summit was an opportunity for advocates to build community with each other and experts. Advocates joined us from Florida, Ohio, Rhode Island, Missouri, California, Indiana, and Maryland.

The critical knowledge and skills advocates learned included:

- ▶ The state of CDI as a disease,
- ▶ Current federal CDI legislative and regulatory framework,
- ▶ How CDIs are tracked and reported in states and how advocacy can increase transparency,

- ▶ How to be effective storytellers that inspire action, and
- ▶ How to educate patients and engage health care workers locally.

Advocates Council. The Council comprises more than 30 people from across the country who've been devastated by a CDI, directly or through a loved one. Given that the lack of public knowledge, inconsistent clinical practice, limited treatment options and unreliable 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 an expanded treatment pipeline and pushing for more transparency. 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*.

"Amazing experience. My mind is full of information. Very excited to be a part of this." — Meghan Mimnaugh, Advocate who lost her mother to CDI

Tools and Resources for Advocates. In addition to the in-person training that advocates received, the Summit led to a host of enduring tools accessible to current and future Advocates Council members and anyone wishing to take action, including videos of all Summit sessions on PLF's YouTube channel, and tips sheets on federal policy, state advocacy and engaging the media.

Shaping Policy



PLF at the White House

PLF stepped up our efforts to impact federal policy through collaborations and our own campaigns, including:

- ▶ Our executive director participated in the June 2015 White House Forum on Antibiotic Stewardship, one of only three patient representatives invited.
- ▶ Signed on to letters in support of an array of federal legislative proposals, including ADAPT, LPDA and DISARM.
- ▶ Ran online campaigns in support of the Preservation of Antibiotics for Medical Treatment Act and the President's 2016 Budget Proposal which included significant new investments for the surveillance and tracking of CDI and other antibiotic resistant infections.

Increasing Our Capacity

In addition to our work in education, advocacy, and policy, we also increased PLF's capacity and built new partnerships. Examples include:

- ▶ Our executive director is now full-time! In July 2015, Christian left Teach For America to focus on PLF full-time.
- ▶ Welcoming new National Advisory Council members:
 - Dr. Gerard Honig of Symbiotic Health
 - Amy-Elizabeth Hagen of Teach For All
 - Jeff Pollack of Mintz & Gold
 - Lisa Neudecker, *C. diff* survivor and advocate
- ▶ Secured new funding from the Pew Charitable Trusts and Cepheid.

FACES OF C. DIFF

Molly's Story (As told by her mother, Lindsay)

I am a first time mom to a beautiful, five month old baby girl, Molly. At the end of August, she was diagnosed with *C. diff* after a week and a half of constant diarrhea. Her pediatrician told me some babies just have bowel movements after every feeding. My baby was going every hour! I brought a diaper with me to the office, but it was not tested for a possible infection. I was told over and over that it was either a virus or a reaction to her formula. We were advised to change her formula to soy, but the diarrhea continued with the same intensity.



I noticed a gradual decline in Molly's overall demeanor. She was quiet, stopped babbling, didn't smile as often, and was not blowing her silly bubbles. She is a strong girl, so she was not overly fussy and never developed a fever. To others, she may have appeared fine. In my gut I knew something was wrong. Finally my pediatrician suggested we try to see a GI, but I was told that it was not an emergency. I called a GI anyway, and was able to have Molly seen that afternoon. We had the test results back with a positive for *C. diff* the next day.

Molly was treated with Flagyl for ten days. She responded immediately, but two weeks later, the *C. diff* returned. I will never forget that moment. I walked into her nursery in the middle of the night and I could smell it. My heart sank. As a new mom, I had never experienced this type of overwhelming helplessness. Why could I not fix this?

We started the second course of Flagyl the next day. Molly again responded quickly to the antibiotics. She has been off the medication for two weeks. I am constantly sick with worry that it will come back again. I bleach and wash everything she comes into contact with, but it makes me insane that I cannot see the spores. Her GI will not retest her unless she displays symptoms.

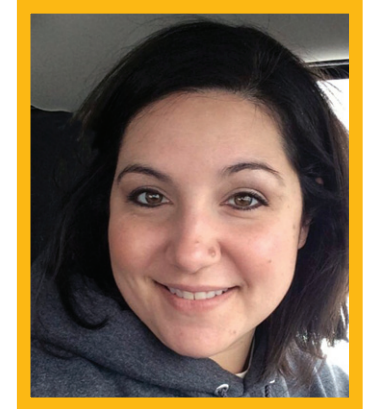
Our new pediatrician feels strongly that Molly developed *C. diff* as a result of Clindamycin transferring through my breast milk. I was prescribed the antibiotic a few days after I delivered her due to an infection. My OBGYN assured me I could continue to nurse and Molly would be fine. Had I known the potential risks of taking an antibiotic while breastfeeding, I would have stopped to protect her.

Molly had one suspected recurrence since then, but has been symptom-free since October 2014.

FACES OF C. DIFF

Sarah's Story

In February 2010, I was treated in the Emergency Room for a panic attack. I believe this is where I picked up *C. diff*. After being asked to provide a urine sample, I used the rest room after a lady who had several bouts of diarrhea. Of course I washed my hands, but after opening the rest room door, I only used alcohol-based hand sanitizer after getting back to my triage room.



Three days later, I was having excruciating abdominal pain. It felt like a combination of being stabbed and a burning sensation of being eaten alive from the inside out. This went on for ten days before I was diagnosed with a CDI. My primary doctor thought anxiety was causing my gastrointestinal upset. After a week of unrelenting symptoms, she decided to do a stool culture. Three days later, I had an answer... *Clostridium difficile*. I took the standard ten days of Flagyl, but my symptoms persisted. My doctor refused to test me again. She said that I took the course of the medicine, and I was "cured." I knew my body, and I knew something wasn't right.

I felt like I had a "brain fog", so I visited an ENT doctor. The ENT believed that I was still dealing with *C. diff* and referred me to a gastroenterologist. I then had my first colonoscopy to assess any damage that *C. diff* had caused. I was lucky. Though the colonoscopy revealed I still had *C. diff*, my intestines were pretty much unscathed. My GI treated me for eight months. At that point, I began testing negative and went on to have another beautiful baby.

The antibiotics given during my C-section allowed my dormant *C. diff* spores to become active again. My symptoms didn't begin until three months post-partum. I was fortunate that I wasn't having several bouts of diarrhea a day and lengthy ER stays, but I was plagued by severe stomach pain and abnormal bowel movements. My GI told me that I was "an interesting case."

After almost four years of dealing with *C. diff* and trying all of the recommended antibiotics without success, I received a Fecal Microbiota Transplant (FMT). It wasn't instant relief. For a while afterwards, I felt like I still had CDI.

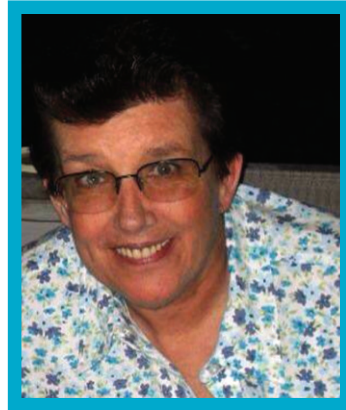
C. diff isn't just a physical battle; it is also a mental and emotional battle. Before *C. diff*, I was a 27-year-old healthy mother and wife. I wasn't a stereotypical patient, but learned the hard way that *C. diff* doesn't discriminate.

FACES OF C. DIFF

Gail's Story (as told by her daughter, Meghan)

My mom was 64 years young when she died from *C. diff* colitis. My mom had long suffered from chronic obstructive pulmonary disease (COPD) and bouts of pneumonia. She hid her health problems from my brother and me as much as she could. She wanted to protect us; she never wanted to "worry" us.

On August 4, 2012 I received a phone call from my mom's nursing home concerning a "stomach bug." She was to be taken to Rhode Island Hospital that day. I was told that I shouldn't be alarmed. I still went to the emergency room. Mom was her usual social self. They eventually decided to admit her as a precaution. The following morning, I received a phone call from a surgeon requesting that my brother and I get down to the hospital as soon as we could to have a conversation about my mom's condition. When I arrived at the hospital, a nurse informed me that I should wear gloves, a gown, and a mask to go in and see my mom. Wait, what?



Seven hours ago she was fine. Now they are diagnosing her with *C. diff*. What? I Googled it. We met with the doctor and surgeon who explained our options. Surgery, which she was not strong enough for and most certainly wouldn't survive, or strong doses of antibiotics. My mom was involved in the discussion. She refused any mention of surgery. She said, "Maybe tomorrow we can talk about it." So we went with the antibiotics. She wanted to take a nap... "Good night Mom... I love you..."

My Uncle and Aunt went to see her. She woke up; she was thirsty, she had errands to do, when was she going home? She wanted to take a "short" nap after my aunt and uncle left. She thanked me; she loved me.

She never woke up.

I knew something was wrong. She didn't look right, her urine bag was empty, yet she was being pumped with fluids. She said that she was tired, and drifted back off to sleep. The doctors told me to go home. I came back after a half hour and just knew. There was nothing they could do but make her comfortable. Time stood still. This disease killed her as fast as a bullet.

I felt guilty. I felt alone. Who can I blame? The doctors, the cleaning staff, the nurses, the hospital, the nursing home, myself? Why didn't I know this disease? Why couldn't anyone do something?



SYNTHETIC

B I O L O G I C S

Developing therapeutics to protect the microbiome while targeting pathogen-specific diseases.

Lead candidate in Phase 2 development is **SYN-004**, designed to protect the gut microbiome from the effects of certain commonly used IV antibiotics for the prevention of *C. difficile* infection and antibiotic-associated diarrhea.

Learn more at www.syntheticbiologics.com

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Van West Media is proud to support the Peggy Lillis Foundation and its dedicated work on fighting *C. diff* over the last five years.



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Rebiotix is excited to partner with the Peggy Lillis Foundation to fight *C. diff*!

We are a clinical stage biotechnology company focused on a treatment for recurrent *C. diff* infection as many patients fail standard therapies with nowhere else to turn. To achieve the goal of curing recurrent *C. diff* infection, Rebiotix works closely with the leading physicians in infectious diseases and gastroenterology, as well as scientists involved in research for this disease. Advocacy partners like PLF are critical to help bring awareness and voice of the patient and caregivers to this growing epidemic. Rebiotix is thrilled to be a sponsor and help raise awareness of *C. diff* and help patients afflicted with this disease.



The United Federation of Teachers

salutes the

Peggy Lillis Foundation

for leading the fight against *C. diff* in the name of Peggy Lillis, who was a paraprofessional and kindergarten teacher in Brooklyn public schools



Photo of Peggy, Melissa, and Liam

"Miss you and think of you every day.

Love always,"

– Liam & Melissa

"I think we're here for each other." – Carol Burnett



Photo of Peggy and Chris

"Our mother was always there for anyone in need.

*Peggy Lillis Foundation will always be here for *C. diff* sufferers and caregivers.*

All our love forever and ever." – Christian, Chris, & April



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VISION

We envision a world where *C. diff* is rare, treatable and survivable

MISSION

We are building a nationwide *Clostridium difficile* awareness movement by educating the public, empowering advocates, and shaping policy.

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GRATITUDE

We are deeply grateful to everyone who has joined us on the first 5 1/2 years of this journey. Though losing our mother was the initial motivation for starting the Peggy Lillis Foundation, the steadfast support of our most loyal friends and donors, as well as the growing number of individuals, families, doctors, healthcare workers, elected officials, and policymakers who have joined us along the way keep us going. Since not every gift can be quantified, we want to thank the following people and organizations for their unique contributions that have had an incredible impact on our work.

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SPECIAL THANKS

To the **Pew Charitable Trusts, Seres Therapeutics** and **Synthetic Biologics** for supporting our first Advocates Summit.

To all **Advocates Summit speakers and presenters**, for sharing your knowledge and expertise with these incredible new leaders.

To **Laurel Ahnsbrak** and **Katie Curl** for all of your hard work this year. We could not have done it without you.

To **Van West Media** for being an amazing partner in helping us develop THE best website for *C. diff* sufferers, caregivers and other stakeholders.

To **John Chan** for being our constant and stunningly awesome pro-bono photographer for the past 6 years. John was also Christian and Chris' wedding photographer!

To **Phyllis McEwan** for 6 years of the most fabulous centerpieces! You make every Gala more beautiful and special than the previous one.

To this year's **Gala Committee**, for all of your help in making this evening a success.

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