



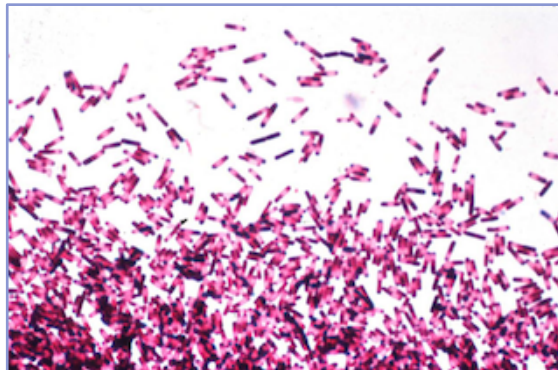
## The Peggy Lillis Memorial Foundation



Igniting **Physician** & **Citizen** Collaboration to Fight *C. diff*

**Gulf Coast *C. diff* Collaborative**

June 2014



# About Peggy



- 56-year-old Kindergarten teacher/  
Part-time waitress
- Former welfare recipient
- 3<sup>rd</sup> of 9 children from Irish-Catholic,  
working class, Brooklyn family
- Single Mother of 2 sons
- Godmother to 12
- Master's degree candidate
- Community Acquired *C. diff*
- Died from *C. diff* in April 2010

# Birth of Peggy Lillis Foundation



# Accomplishments: 2010 - 2013

- **Educating the Public:** First website dedicated to *C. diff* sufferers and their families; First-ever *C. diff* Public Service Announcement with more than 10,000 views; and distributing hundreds of *C. diff* Awareness t-shirts, water bottles and tote bags
- **Raising *C. diff* Awareness in the Media:** Worked with reporters to gather 18 diverse stories from *C. diff* sufferers for *USA Today*'s ground-breaking August 2012 cover story, "Far more could be done to stop the deadly bacteria *C. diff*"; collaborated with reporters at Reuters, The Stockdale Record, and The Associated Press; and placed op-eds in the Baltimore Sun, The Albany Times Union and The New York Times
- **Engaging Federal and Elected Officials:** Built a partnership with the Centers for Disease Control; worked with Congresswoman Louise Slaughter to highlight antibiotic overuse as a key driver of *C. diff*; and shared Peggy's story in Dr. Beth Bell's testimony before the Senate Subcommittee on Health, and in lobbying for budget increase for CDC

## Accomplishments: 2010 – 2013 (Cont.)

- **Emphasizing the “Face of *C. diff*”:** Shared *C. diff* sufferers’ stories through our website and social media and presented the patient perspective to hundreds of healthcare workers at quality improvement meetings in North Carolina, Maryland, Colorado and Ohio
- **Engaging *C. diff* experts within the healthcare industry:** Established relationships with healthcare centers, including Beth Israel Hospital as well as individual physicians and scientists, including Dr. Martin Blaser of NYU Langone Medical Center, Dr. Moshe Rubin of New York Hospital Queens, Dr. Tor Savidge of Baylor, and Garrett Lawlor of Veterans Affairs New York Safe Harbor Hospitals
- **Starting a National Movement:** Grew to 2,000+ supporters nationwide, including *C. diff* sufferers, their families, physicians and corporate leaders; involved experts in medicine, public health, patient safety, and health policy through our National Advisory Council; raised \$200,000 through our annual FIGHT *C. DIFF* Gala to fuel our work; and started partnerships with pharmaceutical, vaccine, diagnostic testing and environmental hygiene companies

# Lessons Learned: 2010 – 2013

Since starting PLMF in June 2010, we have noted several important lessons that can help us chart a path for physician and citizen collaboration.

- Like many infectious diseases, building a patient/citizen constituency around *C. diff* is challenging
- Inadequate medical education and public awareness among both citizens and physicians delays diagnosis and limits treatment options offered, including FMT
- Shame related to feces inhibits sufferers from seeking care and survivors from discussing their experience
- The people most interested in raising awareness and engaging in advocacy have either lost a loved one to *C. diff* or suffered from multiple recurrences

Still, CDIs are a largely solvable problem

## EDUCATE NATIONALLY. ADVOCATE LOCALLY.

### 2014 – 2016 Strategic Plan

#### Development Process

- Engaged National Executive Services Corps (NESC) in July 2013
- NESC gathered information from PLF and external *C. diff* research
- Interviewed 15 stakeholders and experts in healthcare associated infections and patient advocacy
- Conducted and presented SWOT and Landscape analyses
- Goals and Objectives Developed
- Plan shared with stakeholders for feedback and refinement
- Plan finalized February 2014

#### Select Contributors

- Dr. Martin Blaser, Chief of Medicine, NYU Langone Medical Center
- Dr. Clifford McDonald, Chief, Prevention & Response, Centers for Disease Control
- Julie Reagan, MPH, JD, HAI Focus
- Chris O’Neal, *C. diff* survivor and author, *C. diff: A Patient’s Guide*
- Lisa McGiffert, Consumers Union Safe Patient Project
- Patty Skolnik, Citizens for Patient Safety
- Rosemary Gibson, Author, *The Treatment Trap*



# Strategic Plan Overview



2014

- Recruit founding Board
- Secure \$200,000

2015

- Hire full-time ED
- Refocus Advisory Council
- Secure \$350,000

2016

- Hire additional staff
- Develop next 3-year plan
- Secure \$500,000



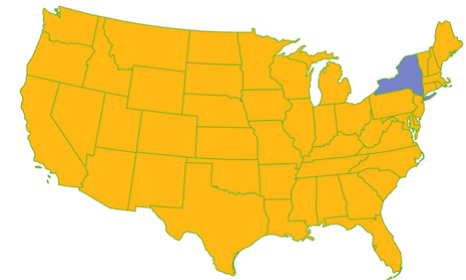
## Educate National Audience: Key Strategies

- Relaunch peggyfoundation.org as a multi-faceted web portal with robust content and tools that support new strategic direction (2014)
- Distribute Public Service Announcements to TV, radio, and healthcare facilities (2014-2015)
- Establish formal *C. diff* Advocates Council of citizens who can powerfully articulate their stories in a variety of venues and media (2015)
- Use traditional news media to create awareness of *C. diff* epidemic by building relationships with sympathetic reporters, trade publications and regularly publishing op-eds (2014-2016)
- Strengthen partnerships with like-minded physicians, activists, companies and organizations by attending key annual conferences, building online provider database and positioning PLF as the leading developer of patient-focused *C. diff* materials (2014-2016)
- Execute phased consumer education programs, including developing and distributing *C. diff* Infographics, video “*C. diff* Story” vignettes, a “*C. diff*: Know The Facts” Consumer Education Course, and the “True Impact of *C. diff*” video series (2014-2016)
- Develop core education toolkit, including fact sheets, prevention tips, informational brochures, discussion guides, waiting room posters, symptoms & prevention wallet cards, and then focused versions for various stakeholders (2014-2016)



## Empower Advocates: Key Strategies

- Develop online interactive US map where visitors can click on each state to find local *C. diff* statistics, state reporting rules, and local physicians and health centers with proven expertise (2014)
- Distribute brochures and fact sheets dealing with various aspects of living with *C. diff* for sufferers and their caregivers (2014)
- Create an online toolkit composed of various support tools and resources that help to foster a sense of community and grassroots activism about *C. diff*, as well as providing opportunities to shape policy (2015)
- Lead two-day convening to train Advocates Council members in sharing their stories one-on-one, with healthcare workers and policymakers, and across the media (2015)
- Conduct a nationwide outreach to organizations that work with immune-suppressed populations for partnership (2015)
- Host survivor and sufferer roundtables, both online and in-person, to provide support and identify potential advocates (2015-2016)
- Train *C. diff* survivors and families to participate in state HAI advisory committees (2015-2016)
- Provide opportunities for advocacy by producing stock letters for citizens to send to local politicians (2015-2016)
- Create “*C. diff* Empowerment” Campaign (2016)



## Shape Policy: Key Strategies

- Advocate for/promote legislation at local and state levels to increase availability of transparent *C. diff* data for long-term care facilities and other non-hospital healthcare facilities (2015-2016)
- Become active in the legislative process developing alliances and building support to mount legislative action (2015-2016)
- Engage existing state-level structures, such as QIOs and healthcare associated infection (HAI) advisory committees, to lift *C. diff* awareness and promote prevention and reduction efforts through advocacy and policy (2015-2016)
- Use conflict constructively in order to elevate attention to *C. diff* and PLF leadership by media and policy-makers (2015-2016)
- Create a basic structure for forming, introducing, lobbying, advancing, and winning a model bill on *C. diff* reporting (2015)
- Gain legislative support for establishing non-hospital-mandated *C. diff* reporting to local and state level regulatory bodies first in New York and then in other states (2015-2016)
- Combine deft, direct lobbying and compelling message-driven grassroots lobbying to maximize pressure for passage of the bill (2016)



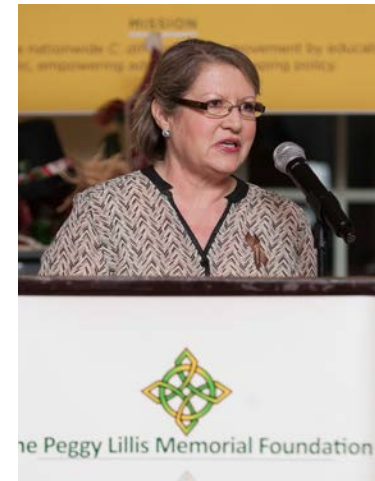
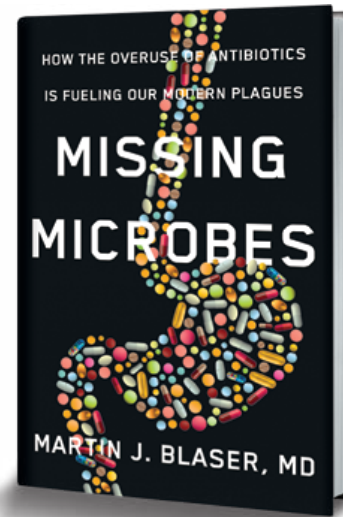
## Build Organizational Capacity: Key Strategies

- Continue to engage and build relationships with leaders in healthcare, public health, pharmaceuticals, testing and sanitation (2014-2016)
- Redefine role and desired membership for National Advisory Council to increase medical and public health knowledge as well as network access (2015)
- Grow revenue year-over-year from \$200,000 to \$500,000 to support hiring of full-time executive director and support staff, who can expand programs and fuel progress (2014-2016)
- Establish founding Board of Directors (2015)
- Incorporate as stand-alone 501(c)3 (2015)
- Diversify fundraising plans to include non-Gala individual giving campaigns and independent foundation grants (2014-2016)



# Engaging physicians & patients to drive change

- ✓ Building a nationwide database of C. diff experts
- ✓ Collaborating on C. diff policy at the state and federal levels (ADAPT Act, CDC)
- ✓ Sharing individual patient stories (70+ to date) and aggregate survey data
- ✓ Serving as patient collaborator for PCORI and other grants
- ✓ How else can we partner?



# Draft: State page on new website

## New York Providers

### **Moshe Rubin, MD**

New York Hospital Queens  
Specialty: Gastroenterology  
Treatments: Antibiotics  
[Contact this physician](#)  
[Rate this physician](#)

### **Jane Doe, MD**

NYU Medical Center  
Specialty: Infectious Diseases  
Treatments: Fecal microbiota  
transplant  
[Contact this physician](#)  
[Rate this physician](#)

### **John Smith, MD**

Private Practice  
Specialty: Gastroenterology  
Treatments: All  
[Contact this physician](#)  
[Rate this physician](#)

## New York Advocates

### **Christian John Lillis**

Christian lost his mother to *C. diff*  
in April 2010  
*Areas: Public speaking, lobbying,  
print, audio and video media*  
**Contact Christian**

### **Gina Del Re**

Mother of a two-year old son  
who survived *C. diff*  
*Areas: Lobbying, print, audio and  
video media*  
**Read Gina's Story**  
**Contact Gina**



## State Laws & Regulations

- Public Reporting
- Treatment
- Et cetera

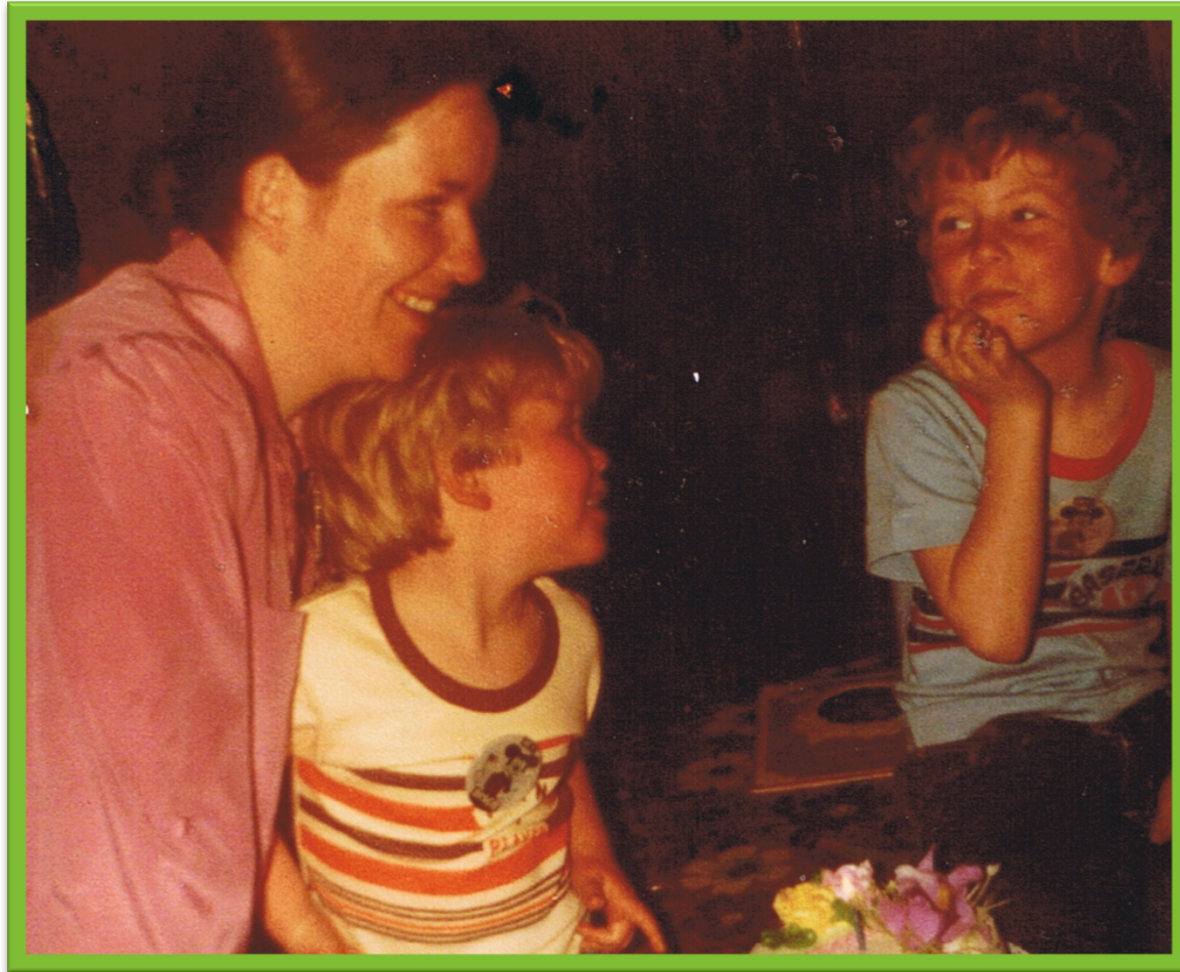
## Take Action in New York

[Sign our petition to  
mandate HAI reporting by  
nursing homes](#)

[Contact Your Local  
Legislators](#)

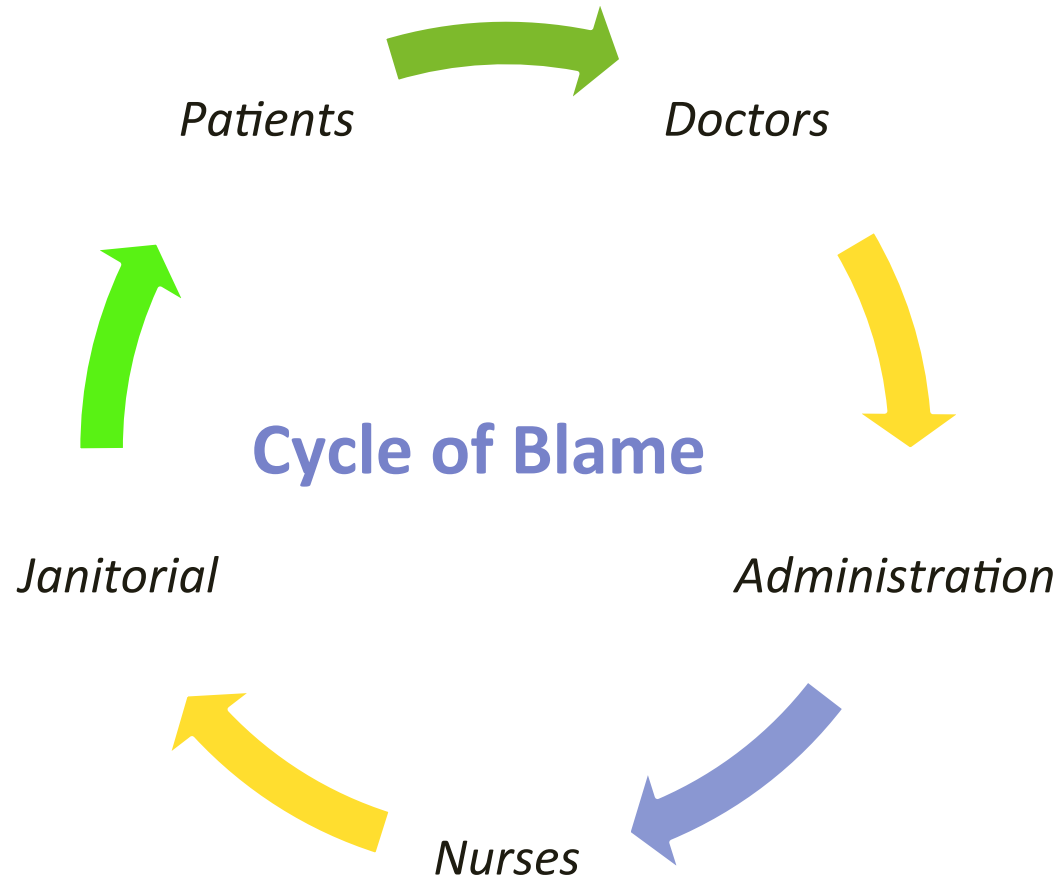


**“All you have in this world is each other”**





# Moving Past Blame...



## Areas for Collaboration

- ✓ Research for prevention (CDC) and treatment (*Cdiffense*)
- ✓ Raising awareness of underutilized treatments (FMT and Fidaxomicin)
- ✓ Increasing transparency (public reporting of LTC facilities HAI rates)
- ✓ Advocating for increased public and private funding
- ✓ Patient education (particularly around antimicrobials)
- ✓ Other areas for collaboration?

# Peggy's Vision

A World Where *C. diff* is  
Rare, Treatable and  
Survivable.