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
- 3rd 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
- Lisa McGiffert, Consumers Union Safe Patient Project
- Patty Skolnik, Citizens for Patient Safety
- Rosemary Gibson, Author, *The Treatment Trap*
Strategic Plan Overview

Educate National Audience
- Website re-launch
- National distribution of updated PSA
- Core public education toolkit deployed
- Phased consumer education programs executed

Empower Advocates
- Train *C. diff* sufferers to be powerful advocates
- Map state regulations, physicians, organizations
- Engage immuno-suppressed populations
- Catalyze local and national campaigns

Shape Policy
- Position citizen advocates on state HAI advisory committees
- Push legislation for HAI reporting by long-term care facilities
- Coordinate statewide lobbying efforts

Build Organizational Capacity To Fulfill Mission

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)
- 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)
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 debt, 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...

Cycle of Blame

- Patients
- Doctors
- Administration
- Janitorial
- Nurses
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.