Patient Advocacy:
What It Means for Our Community and Those We Serve

Patience Leino, American Board of Pediatrics, UNC PICU Parent Advisor

Tricia Lawrenson, CF Patient, Cancer Survivor, Special Needs Parent, Advocate

September 2017
Objectives

• Define patient-/family-centered care
• Understand the role patient advocacy has within quality improvement and the Member Board community
• Examples of patient advocacy from the ABP
• Examples of successful partnership from UNC Medical Center
• Lessons from Tricia Lawrenson: Patient, Parent, Advocate
• Explore ways to integrate patient advocacy into your Portfolio
Isaac Jordan Leino

- Diagnosed with Hypoplastic Left Heart Syndrome at 20 weeks gestation
- Born February 25, 2005, at North Carolina Children’s Hospital / UNC Medical Center
- Multiple other anomalies discovered after birth
- 5 surgeries in first 10 weeks of life, including open-heart surgery at 3 days old.
- 3 separate DNR discussions
- Initial PICU admission – 110 days
- Trach/ventilator/feeding pump dependent
- Discharged home with 24 hour in-home nursing
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• Died on August 5, 2005. He was 24 weeks old.
Bedside Partnership Led To Healthcare Contributions

• Became a Family Advisor to UNC’s PICU in 2009
• Member of PICU’s multidisciplinary Partners in Improving Quality and Measuring for Excellence
• Six Sigma Green Belt project on communication between clinicians and families on the PICU
• Published by the American Academy of Pediatrics
• Presenter at the 5th International Institute for Patient- and Family- Centered Care Conference in Washington, D.C.
• Senior Advisor to Project T.I.C.K.E.R.
• Faculty of UNC’s Institute for Healthcare Quality Improvement, training residents effective communication during difficult diagnoses/outcomes and partnership in care and QI
• Founding Co-Chair of the North Carolina Children’s Hospital Family Advisory Board
• Published in the American Journal of Medical Quality
• ABP Senior Administrator of MOC External Activities
Collaboration Begets Significance
Patient-And Family- Centered Care

Innovative Approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families*, and providers that recognizes the importance of the family in the patient’s life.

*Families is broadly defined.
Evidence Based and Essential

“The most direct route to the Triple Aim is through Patient- and Family- Centered Care in its fullest form.”

Outcomes of Patient- and Family- Centered Care

• Improve patient and family outcomes, experience and satisfaction
• Build on child and family strengths
• Provides crucial element of purpose and influence to patients
• Equip clinical staff with critical communication and collaboration skills
• Increase staff satisfaction and reduces burnout
• Decrease health care costs
• More effective use of healthcare resources and innovative future design
Leading By Example

- Currently the ABP has a patient and/or family advisor on every leadership committee.
- Family Leadership Advisory Counsel established in 2016
- 2016 Annual Report focused on partnerships.
- Parents integral to design of MyCertifiedPediatrician.org, a website for parents on the meaning and significance of board certification in pediatrics.
“These parent advisors have a strong understanding of board certification and, in particular, quality improvement activities. Through their experience caring for a child with a chronic condition—with so much of their lives entwined with the health care community—they help us stay focused on our mission to set standards of excellence for pediatricians.”

- David Nichols, M.D., President and CEO of the ABP
“Parents bring a new level of energy to the committees on which they serve and have provided the ABP with closer links to the powerful work being done by collaborative networks. The addition of parents is one of the most important things that has happened at the ABP. Their stories inspire and focus us. Patients and parents provide valuable feedback to the Board about what outcomes matter to them and help to focus work around communication, quality and safety.”

- Christopher Cunha, M.D., 2016 Chair of the ABP Board Of Directors
While multiple approaches to QI exist, all follow the same basic principles.

Traditionally, if at all, patients and families voices are brought into a project during the Verify phase. This results in:

- Missed gaps in quality and care
- Missed innovation
- Missed opportunities for growth
- Missed increase in key stakeholder buy-in
Examples of Successful Partnership at UNCMC

• **PIQME: Partners for Improving Quality and Measuring for Excellence**

• A multidisciplinary team that meets quarterly to review team progress, address issues impeding progress, and share lessons learned.

• Measures related to goals of eliminating hospital-acquired infections and implementing patient- and family-centered care are posted on the PICU dashboard.

• [https://www.med.unc.edu/cce/programs/picu/dashboard](https://www.med.unc.edu/cce/programs/picu/dashboard)
Why Is Communication So Difficult?

- Demonstrates lack of clear pathways and expectations for communicating with families.
- Patient/Family caught in the middle of a web of communication.
- Surveys indicated this resulted in frustration for clinical staff and distrust on the part of families.
Statistically Significant Improvement

By implementing Lean Six Sigma methodology, a multi-disciplinary project team increased daily documented communication between clinicians and families on the PICU went from a mean of 0.14 to 0.66.


https://doi.org/10.1177/1062860615600858

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Ways To Integrate Patient/Families Into QI

• INTEGRATE the patient/family voice into ALL levels of your Portfolio Program

• TAP IN to your organization’s family advisory boards.

• Utilize NURSING STAFF to identify potential patient/family partners.

• Create and refine projects from those DIRECTLY IMPACTED by the gap.

• Involve the patient/family voice at a project’s GENESIS.

• LISTEN to your clinical staff. How have they personally been impacted by the gap in their patients’ lives?

• STORIES always trump sheer data. Share your Portfolio’s stories – clinicians and patients.
Tricia Lawrenson
Cystic Fibrosis Patient, Cancer Survivor, Special Needs Parent, Advocate
May 13, 1982
My Parents: Don & Agnes
Tammy: Foster sister who passed away from cystic fibrosis at 12 years of age who lived with us. Here she is 10, I am under 1.

Doing treatments and my sister giving me percussion.
Dr. Gray, CF & Transplant Pulmonologist
A Day In The Life: Meds Edition
CF Gene Mutations:

Mutations in the *CFTR* gene disrupt the function of the chloride channels, preventing them from regulating the flow of chloride ions and water across cell membranes. As a result, cells that line the passageways of the lungs, pancreas, and other organs produce mucus that is unusually thick and sticky. This mucus *clogs the airways* and various ducts, causing the characteristic signs and symptoms of cystic fibrosis.

Other genetic and environmental factors likely influence the severity of the condition. For example, mutations in genes other than *CFTR* might help explain why some people with cystic fibrosis are more severely affected than others. Most of these genetic changes have not been identified, however.
Duke University Medical Center
Liberty University & Wedding 2004
Found out I was pregnant Sept. 2008
Gwyneth Rose – “Blessed Rose”
Gwyneth’s Early Days
The first time I saw Gwyn
First Touch
Waiting for transplant in Duke
Post lung transplant
Diagnosis of Lymphoma – June ‘08
PTLD / Chemo / Sadness
Evaluation PDA, CP, HA
Spring 2013
Expect Miracles Inside this room
Day before my transplant: 31st birthday
Worth The Investment

Integrating patient advocacy into QI efforts benefits your Portfolio, community, and healthcare organization. It improves job satisfaction for providers, reducing burnout, and honors families who have walked the difficult road of needing care for their children in the hospital.

We are always better TOGETHER!
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