FHA PFE Learning Collaborative

*The Advisor Experience*

January 26, 2018
Today’s Agenda

Welcome & Introductions

Elise Bloch
Joe DiMaggio Children’s Hospital

ReadyTalk Overview

Resources on Working with Patient and Family Advisors

Angela Miney
UF College of Medicine

Closing
Two ways to interact with speakers today:

1. Type questions or comments into chat (let us know if you wish to remain anonymous!)

2. Raise hand (*7 to unmute your line when called upon)
Pulling the Curtain Back on the Advisor Experience
Angela Miney
Family Partner
Pediatric Pulmonary Center
University of Florida College of Medicine
I came into the healthcare world ‘kicking and screaming’
Primarily the parent of a young adult who has a chronic, and occasionally serious, illness.

(I have to remind myself that she is not a child anymore 😊)
Maternal and Child Health Bureau Leadership Training Program

Mission of Maternal and Child Health Bureau is to train current and aspiring healthcare providers to be leaders who are, among other things, “patient and family centered.” To this end they encourage the programs they fund to employ family leaders.
It would have been good to know...

- Patience, patience, patience
- Health Center organization and structure
  - Who are the key players?
- The “system” is very complicated
On the other hand...
I had a blank slate and a lot of support from colleagues and the organization
Advice for Other Advisors

• Things happen serendipitously – seize the moment!
• Find your champions
• Don’t take “no” for an answer
• Don’t underestimate your influence
• Take advantage of opportunities to educate yourself about the organization
• Try to see things from the health providers point of view, but maintain your own point of view
Advice for Healthcare Professionals

• Invest in your advisors –
  o Train them to be leaders
  o Help them transition from being engaged in their own care to using their experience to change the system
  o Introduce them to other advisors
  o Facilitate networking and shared learning
  o Tap into their passion but don’t take advantage of it

You don’t have to take everyone – you are looking for people who have a “constellation of personality traits”
Hope for the Future

Developing strong, effective partnerships

- Nothing About Me Without Me
- Family Discipline & Universal Curriculum
- Advisor Network
Most of all, I hope that Catherine will be cured and I can meander gently out of healthcare 😊
Questions?
The Family Advisor Journey

Elise Bloch, Chair - Joe DiMaggio Children’s Hospital –PFAC
Associate Professor, Nova Southeastern University
Overview

- My journey
- Advisory roles
- Advisors 101- tips
- Research
- Where do we go from here?
Numerous iatrogenic effects of treatment continue.

ALL T cell-2002
Relapsed 2004-
bone marrow transplant
Unique Perspective/Lens

- Mom
- Pediatric Occupational Therapist
- Educator
Advisory roles

- Environment and design: Collaboration for new hospital design
- Attend system wide meetings
- Examine hospital policies/ PFCC co-create with hospital staff
- Interview team for new hires
- Educate hospital staff
- **Mentoring families**
- Advocacy
- Health literacy
• Patient and family engagement is a process and journey, always evolving to meet needs of community and best practice.
Advisor Recruitment

**Advisor considerations:**
- Select: are they ready?
- Availability
- Goodness of fit
- Diversity
Advisor tips

- **Education and training of advisors**
  - Roles
  - PFCC 101; Hospital, mentor training
  - Opportunities
  - Support
Advisor tips

• **Infrastructure support from administration**
  - PFCC in mission/vision
  - Stipends for advisors
  - Recognition in system
  - **Education**
Family Faculty

• Family Faculty programs throughout the country are becoming “gold standards” to teach medical and allied health professionals about the experience of care.

• Personal stories of patients and their families move beyond jargon and textbook instruction and goes to the heart of care.

• Listen…. Hear……

• Walk in our shoes……
Tips

• **Education of all hospital employees**
  - Lunch and learns
  - Formal training
  - PR of council news

• **Director of PFCC**
  - support
  - Keep advisors – “in the know”
  - Follow through
Advisors Involvement in PFCC Research:

- Better health outcomes
- Improved health literacy of patient and family
- Decreased litigation
- Improved patient and staff satisfaction

- PFCC Clinical Guidelines for ICU, PICU and NICU *

- (IOM, 2001; Warren, 2012) (Davidson et al, 2017)*
Take home message

• Labor of Love (LOL)- enjoy the journey…..

“empowering patients to do everything they can for themselves and getting better results is the best guarantee of a sustainable healthcare delivery system.”
-Don Berwick, MD (President Emeritus and Senior Fellow, Institute of Healthcare Improvement)
References:

• Davidson et al, (2017). Guidelines for Family-Centered Care in the NICU, Pediatric and Adult ICU. *Critical Care Medicine* 45, (1) pg. 103-128  DOI: 10.1097/CCM.00000000000002169


Questions?

• Contact info: ebloch@nova.edu
Questions?
Resources on Working with Patient and Family Advisors
PFA’s, Staff, Clinicians, and Leaders: Prepared for Success*

Beverley H. Johnson
IPFCC President/CEO
First Annual Patient and Family Engagement Summit — FHA HIIN
Orlando, FL — July 21, 2017

*Excerpt from breakout session: The Role of PFAs: Be Bold, Be Clear, Be Brave
Building the Infrastructure to Support Effective Partnerships
Best practice is to have a “staff liaison” with the skills and attitudes to successfully facilitate, coordinate, and sustain the work with PFAs and PFACs.
Best practice is to have a variety of ways that patient and family advisors are involved and to show the impact of this collaboration.
Orienting Patient and Family Advisors

- Mission, values, and priorities of the organization.
- PFCC and PFE concepts and strategies.
- Speaking the language – Medical and QI Jargon 101.
- Who’s who in the organization and on committees.
- Day in the life of a physician, nurse, and/or therapist.
- Provide a tour of the organization
- Meeting attendance expectations.
- Logistical details:
  - What to wear.
  - Where to find food and location of bathrooms.
  - Child care, transportation and parking.
  - Stipends/reimbursement of expenses.
Orienting Patient and Family Advisors (cont’d)

- Roles and responsibilities.
  - Confidentiality and privacy — Privacy training.
- PFAC staff members’ roles and responsibilities.
- How to be an effective advisor.
  - How to ask questions.
  - What to do when there is disagreement.
  - Listening to and learning from others’ viewpoints.
  - Thinking beyond your own experience.
  - Sharing a story and how to tell a “negative” story.
  - The impact of anger.
Fostering a Successful Beginning:
Orienting Staff, Clinicians, and Leaders

- Explain how staff, clinicians, and organizational leaders should be involved.
  - The importance of listening.
  - Effective approaches to meeting facilitation.
  - Act on advisors’ observations and recommendations when appropriate and provide information when not implemented.
- Be open to questions and challenges.
- Try not to be defensive.
  - Respond/explain without being defensive.
  - Defensiveness usually has a negative effect.
Resources for Advisors and Hospitals

• Agency for Healthcare Research and Quality (AHRQ): Working with Patients and Families as Advisors Implementation Handbook

• AHRQ Health Care Innovations Exchange Patient-and Family-Centered Care Learning Community: Patient and Family Advisor Orientation: Helpful Resources for Hospitals

• American Hospital Association (AHA): Partnering to Improve Quality and Safety: A Framework for Working with Patient and Family Advisors

• Institute for Patient- and Family-Centered Care (IPFCC): Better Together Toolkit

• Joan’s Family Bill of Rights: Starting and Sustaining Patient & Family Advisory Councils: From Leadership Assessment to Success Metrics

Have something that you would like to share? Please email allisons@fha.org
Closing
Save the Date

In partnership with the FHA We Have Your Back (WHYB) Worker Safety Collaborative: Planning for Workplace Violence with Patients and Families

February 8, 2018
12:00pm to 1:00pm, ET
Registration
Cultivating Hospital Advocates and Champions

Webinar #2: Cultivating and Motivating Caregiver Advocates
Featuring: Baptist Health Jacksonville
January 26, 11:30 a.m. - 12:30 p.m. EST

During this webinar, FHA staff and representatives from Baptist Health Jacksonville will walk through how to consistently engage and inspire caregivers in the advocacy process, with a Q&A segment to follow.

Webinar #3: Engaging Community Partners
Featuring: Martin Health System
February 2, 2:30 p.m. - 3:30 p.m. EST

During this webinar, FHA staff will illustrate the importance of engaging community partners in advocacy. Representatives from Martin Health will share examples and best practices of successful outreach, with a Q&A segment to follow.

Webinar #4: Grassroots Advocacy for Rural Hospitals
Featuring: Jackson Hospital (Marianna)
February 7, 2:30 p.m. - 3:30 p.m. EST

During this webinar, FHA staff will share advocacy tools and resources available through the Association. Representatives from Jackson Hospital (Marianna) will share how they accomplish their advocacy goals with limited resources, with a Q&A segment to follow.

Register Online
Caregivers at the Capitol

The event will provide an opportunity for patients and caregivers to advocate on behalf of patients by sharing their knowledge and patient care experiences with policy makers.

February 21-22, 2018

Learn more and reserve your spot today!
Upcoming Virtual Events

- Jan. 30 – SCRIPT UP: Optimizing Patient Medications, Minimizing Adverse Events
- Feb. 2 – Readmissions Stakeholder Quarterly Virtual Meeting #1
- Feb. 8 – PFE Learning Collaborative & FHA WHYB Worker Safety Joint Webinar
- Feb. 13 – Chasing Zero Infections Coaching Call: CAUTI: Catheter Utilization
- Feb. 14 – TCAB Cohort 2 Collaborative Webinar #3
- Feb. 26 – Children’s Hospitals: Reducing Readmissions
- Mar. 1 – IVAC Bi-Monthly Webinar #1: IVAC and the GET UP Campaign

Check your weekly Mission to Care Newsletter for details and registration
Let’s get social!

@FLHopsitalAssn
Webinar Evaluation Survey & Continuing Nursing Education

- Eligibility for Nursing CEU requires submission of an evaluation survey for each participant requesting continuing education: https://www.surveymonkey.com/r/PFELC012618
- Share this link with all of your participants if viewing today’s webinar as a group
- Be sure to include your contact information and Florida nursing license number
- FHA will report 1.0 credit hour to CE Broker and a certificate will be sent via e-mail
- We would appreciate your feedback even if you are not applying for CEUs!!
- Web participants can stay logged in as the webinar closes to be redirected to the online survey (the link will also be provided in a follow up email)
That's all Folks!