**Patient and Family Advisory Board (PFAB) Meeting**

**August 1, 2019**

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| **PFAB Meeting** | |
| **DATE** | October 24, 2019 |
| **FACILITATOR(S)** | Wanda Nichols, RN and Yasmin Garcia |
| **ATTENDEES** | 10 |
| **AGENDA** | 1.Introduction to Patient/Family Advisory Council  2. CF Advisory council- Why we are doing this  3.Collaborate on ideas for the future  4.Logistics-Next Meeting/Feedback  5. Health Literacy-Communication  6. Pt Satisfaction Surveys/ National Conference 7.Future QI programs  8. Other Suggestions/Updates |

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| **AGENDA** | **DISCUSSION/REPORT** | **ACTION PLAN** |
| 1.Introduction to Patient/Family Advisory Council | Exchanged greetings and explained the purpose of the PFAB, particularly at UF Health. | N/A |
| 2. CF Advisory council- Why we are doing this | Spoke with CF patients as to what they would like to get out of CFAB in the future, why they decided to join meeting. | Focus will be more on it being a means for patients and families to share experiences so as to improve experiences and have an overall better level of care, as well as providers and Pts/Families partnering and working together, empowerment and advocacy and providing information to helpful resources. |
| 3.Collaborate on ideas for the future (Mentoring program/pt chats) | Discussed future mentorship program updates and the ideas of future separate pt chats and ideas for/promotion of the 2020 CF conference being held by the center. | Mentioned progress on getting a mentorship program/pt chat program initiated and how we see it being styled to be more for the patients to speak to one another and provide advice and share resources while it’s loosely headed by the members of the team. Will work to have it running by early next year the latest.  Discussed the CF conference and pts/family members sending any ideas/input they have as well as family members attending and we will work to have the event live streamed for CF patients. |
| 4.Logistics-Next Meeting/Feedback | Discussed how frequently to hold PFAB meetings and settled on future meeting date in January 2020. | Meetings will be held on a Thursday of the month as decided at last meeting-*Next Meeting tentatively scheduled: January 9?, 2020 @TBA (does 12pm work again?)*  Pts agreed January would be a good future time to meet and that participants can join meetings periodically when they are available, and that we would try to hold meetings at different times so as to be able to have different participants. Also, discussed making PFAB meetings quarterly. |
| 5. Health Literacy-Communication | Discussed the topics of whether providers are providing clear communication and ways to improve patients’ understanding as well as health literacy.  Touched on how it takes both the patients and the providers having more proactive attitudes and being upfront during communication so as to make certain there is no miscommunication/confusion for both patients and their families at clinic visits. | The participants at the meeting felt that the team members of the CF Clinic do a good job of communicating and getting information across to patients and family members.  Also made sure to reiterate to pts the importance of only calling during emergencies. |
| 6. Pt Satisfaction Surveys/ National Conference | Went over satisfaction survey results with patients and asked members of meeting how they felt about the pt responses and if they felt they agreed with responses and how we can work to incorporate suggestions in the future as well as discussed upcoming national CF conference. | Talks of posting survey results in full in clinic and on website for patients and family members to have access to it.  Participants agreed with suggestions given and stressed the importance of self-advocacy and compliance as well as other activities like going to the gym.  Spoke up utilizing ideas and topics picked up at national CF conference in the clinic and discussing in future meeting, as well. |
| 7. Possible future QI Programs (clinic flow and infection control) | Discussed possible ways to improve aspects of clinic and inpatient admissions, specifically in terms of flow and infection control (issues/ accreditation). | Patients felt that we do a very good job in terms of infection control, especially in comparison to their other past centers.  Some patients felt that our clinic flow and wait times were good in comparison to other centers they’ve visited, and other patients offered suggestions to ways to improve the clinic flow such as having a better communication system between providers or to not leave the paper in the room or have someone go into the room and bring the paper to the next provider so as to minimize downtime, patients aren’t forgotten about, and better use the time available for the visit. |
| 8. Other Suggestions/Updates-  (Nutrition team + Trifakta) | Discussed pts’ past inpatient problems in detail such as issues with the nutrition team in patient not being very efficient at getting supplements to patients. Also discussed important CF news- the FDA approval of the triple combination modulators. | Agreed to look more into this in the coming future to see if there are possible ways of improving inpatient quality of care such as educating inpatient providers.  Also discussed the new push that there will be at clinic by providers to get eligible patients on the new Trifakta triple combo therapy.  **UPDATE:** Looked into issues with inpatient nutrition-patients are advised to contact in-house Nutrition Liaison during hospital stays. Information on liaison will be added to Admissions Guide. |