

DEPARTMENTAL PFACs

Patient and Family Advisory Council of the Johns Hopkins Memory and Alzheimer's Treatment Center– (MATC-PFAC)

Chair: Andrea Nelson, RN MSN

Established in 2008, the MATC-PFAC works in an active and mutually beneficial partnership with patients, family members and providers of the Memory Center. The MATC-PFAC incorporates the patient and family perspective and obtains council members' input throughout the development of Memory Center programs and practices, providing a forum of exchange of interests, concerns and proposals between the council members and the Memory Center.

Current Active Membership:

16 Patient and Family Advisors

6 Staff members

FY 19-20 Highlights

- 8 PFAC members reviewed the 6th edition and provided feedback for the upcoming 7th edition of "The 36-Hour Day", written by JHU emeritus professor Dr. Peter V. Rabins.
- The PFAC provided support and volunteers for the Family Resource Center (FRC), an on-site resource for families visiting the Memory Center, until temporary closure of the FRC during covid-19 in March 2020.
- PFAC members participated in the planning of the 12th Annual Journey to Hope Conference for Caregivers on Nov 9, 2019. They also served as hosts, Masters of Ceremony and on-site resources for families the day of the event.
- PFAC members continue to support Club Memory, a monthly social engagement group for dementia patients and their caregivers. In April 2020, Club Memory went virtual. PFAC members continue to participate and volunteer.
- Council members collaborated with Jane Marks RN, MSN and the GWEP (Geriatric Workforce Enhancement Program), to plan the second annual conference targeting the challenging issues facing caregivers, entitled "Roadmap for Caregivers: Navigating the Nuts and Bolts of Dementia Care". This event was canceled due to covid-19 and rescheduled for June 2021
- 3 PFAC family members attended the annual dinner of the Memory and Aging Community Advisory Board (MACAB) of Greater Baltimore on 10/22/19 to learn more about dementia-related needs in the local African-American and Latino communities.
- 3 PFAC family members attended a quarterly meeting of the MACAB on 11/12/19 to gain insight and advice regarding diversifying council membership.
- PFAC membership increased by 4 family members in 2019-20. 3 of the 4 new members are African American. One staff member retired.
- The council met with MATC staff to discuss beautification efforts and expenses to enhance the appearance of the Memory Center. This included purchase of 2 new/updated exam tables and new artwork in the exam rooms.

- One PFAC family member and two PFAC staff members were invited and traveled to the Abramson Center in Philadelphia to discuss the role of a PFAC, key steps in development of a new PFAC and the services PFACs provide for patients and families
- Two PFAC members met with, trained and advised a JHSPH intern for her practicum in the Family Resource Center from December 2019 to April 2020. The final result was presentation of an FRC operations analysis since its inception in 2017, reorganization and addition to current resources and an updated and streamlined data collection flow sheet.

FY 21 Goals

- The 13th Annual Journey to Hope conference for dementia caregivers will take place virtually on Saturday Nov 14, 2020. The PFAC is actively participating in the planning of the event, including designing the agenda, as well as to advise the event planner and digital/audio production company. Several PFAC members will serve as panelists.
- The PFAC will be launching a blog on the Memory Center website in fall 2020.
- PFAC members will collaborate with Jane Marks RN and the GWEP to present the second annual “Roadmap for Caregivers: Navigating the Nuts and Bolts of Dementia Care” conference in June 2021. This event will include a virtual component for caregivers unable to attend in person.
- The council has committed to increasing membership by 10% (i.e. adding 2 new members) in FY 20-21.