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2023 Patient Advisor Retreat

Patient Engaged Research Center

10-26-2023

Our Contributions to the Hermelin Brain Tumor Center (HBTC)

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Recommended Citation

Sauer, Megan; Betman, Marc; Leach, Ron; Coughlin, Mike; Barry, Jeni; Mackowski, Dominik; Scarpace, Lisa; and Gay, Nestelynn, "Our Contributions to the Hermelin Brain Tumor Center (HBTC)" (2023). *2023 Patient Advisor Retreat*. 3.

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Placement Scope

The Hermelin Brain Tumor Center Patient and Family Advisory Council is comprised of patients and care partners who have generously agreed to come together to share their experiences and ideas.

Placement Goals

Mission Statement:

Our goal is to drive patient and caregiver education, innovation, research, and success to continue to be a center of excellence. We aim to amplify the strengths of the Hermelin Brain Tumor Center by sharing our combined experience as patients, caregivers, and clinicians to its continual improvement and development.

Photos



Figure 2



Figure 3



Figure 4

Figure 1. Megan Langford, PFAC member who we sadly lost at the beginning of 2023.

Figure 2. HBTC Patient and Family Advisory Council

Figure 3. Roundtable meeting with Dr. Mark Rosenblum, Chair Emeritus-Henry Ford Health Department of Neurosurgery.

Figure 4: Game on Cancer event at Ford Field

Past & Current Projects

- Complete Abstract detailing the process of developing a comprehensive patient handbook. The aim is to use this to develop an article to be submitted for publication in a journal.
- Focus on recruitment and continue to develop a retention plan.

Accomplishments

- Created List of Activities for Caregivers/Friends to support a Patient.
- Published patient handbook update. Volume 3!
- Developed handout to be distributed in clinic that details the MRI process for patients.
- Provided feedback that addresses the day and time for the brain tumor support group with the aim to increase attendance. These suggestions led to both a day and time change that is anticipated to better serve the HBTC patient population
- Developed magnet so patient could readily access important phone numbers within reach.
- Hosted a roundtable meeting with Nurse Navigators and chemotherapy nurses to discuss clinic patient experience.
- Hosted a meeting with Dr. Mark Rosenblum, Chair Emeritus-Henry Ford Department of Neurosurgery to discuss the history and goals of the Hermelin Brain Tumor Center.
- Advised in the development of the surgical "pre-hab" module and new patient clinic handout.

Challenges

- Scheduling conflicts preventing advisor attendance.
- Inability to finish publication (although that is actively being remedied.)
- Identifying new projects to take on.
- Difficulty for virtual participants to be fully engaged in the meetings as they are not in the room.

Acknowledgements

Special Thanks to:

Patient Advisor Liaisons:

Lisa Scarpace

Nestelynn Gay

HFH Partners:

Tobias Walbert, MD

Ian Lee, MD

James Snyder, DO

Adam Robin, MD

Lisa Rogers, DO

Conclusions/References