

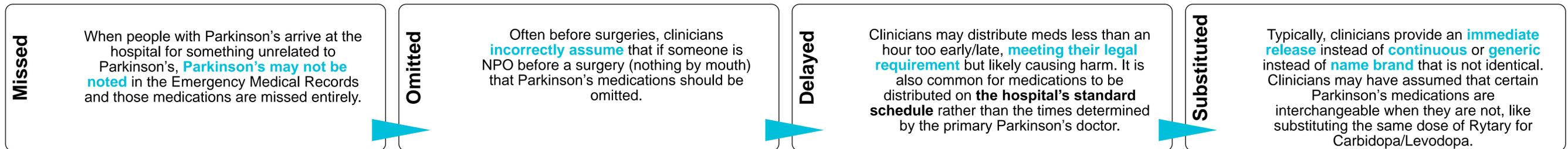
## Introduction

The objective is to share the discussion of the December 6, 2019 Parkinson's Hospitalization Convening. The Parkinson's Foundation (PF) assembled thought leaders in hospitalization and Parkinson's disease (PD) to understand hospital care needs for people with PD, models of success and best practices that can enable that care, and common barriers, drivers, and strategies for adoption. Estimated annual costs of hospital inpatient services for PD is \$7.19 billion, 28.4% of the total direct medical cost of the disease. This cost is due in part to improper medication management for almost 75% of people with PD who are hospitalized, over 50% of whom have complications that could be avoided. Despite significant impact on healthcare quality and cost, hospital care for people with PD varies widely and no nationally recognized standard of care exists.

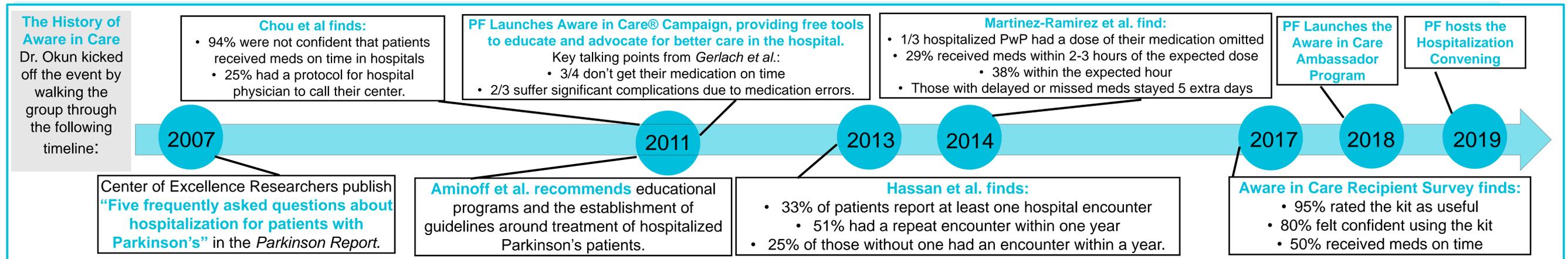
## The Event

The convening gathered leaders in PD care from PF (staff, advisory committee/board members, and the National Medical Director, Michael Okun) and representatives from Hackensack University, Kansas Rehabilitation Hospital, University of Rochester, the Joint Commission and the Edmond J Safra Foundation.

Attendees presented progress made in their institutions, challenges and best practices focused particularly on the prescription of contraindicated medications or mistakes in how Parkinson's medications are distributed when the hospital staff either Missed, Omitted, Delayed or Substituted Parkinson's medications, from which an acronym is used, MODS.



## The Event




**Hooman Azmi, MD, FAANS** outlined the work that has been done at Hackensack University Medical Center by utilizing the Joint Commission Parkinson's disease specific Certification.

*"We are aligning the protocol with the Joint Commission platform which is a very, very effective platform for identifying the measures that are meaningful and then following those measures and making sure there is a plan to improve."*

**Key first steps to implementing Parkinson's Specific Protocols in an acute care hospital:**

- Establish a way to identify all Parkinson's patients within the chart and train staff to understand what it means when a patient is flagged for Parkinson's
- Address the availability of medications on formulary with pharmacy
- Utilize the Electronic Hospital Record (EPIC in their case) to allow for the custom input of each Parkinson's medication
- Conduct widespread and ongoing education around the critical importance of medication timing for Parkinson's patients



**Christian Benedict, DPT** outlined the approach that Rehabilitation Hospitals should take based on his experience at Kansas Rehabilitation Hospital.

*"Every Rehab Hospital should understand the importance of timing of delivery of PD medications, but that one-hour window that our initial Joint Commission surveyor told us was acceptable for most places shouldn't be good enough."*

**Key Elements to Parkinson's care in a Rehabilitation hospital include:**

- PD Specific evaluations is completed by a Physical Therapist, Occupational Therapist, and if indicated, Speech Language Pathologist and Nutritionist/dietitian.
  - Monthly interdisciplinary team meetings
- Patient education that measures whether they are able to teach back information on Parkinson's and on community referrals



**Katherine Amodeo, MD & Amy Chesire, LCSW-R, MSG** shared their two-pronged approach to improving hospitalization outcome through community conversations and hospital engagement at the University of Rochester.

One care partner from their community roundtables shared:  
*"I felt like I knew so much more about my husband's PD and it was hard to advocate for his medication needs, in particular, I knew what medications he should not take and yet they wanted to prescribe it and didn't necessarily want to listen to me. I felt very angry and frustrated."*

**Key Strategies in their Approach:**

- Ongoing conversations with the Parkinson's community regarding their lived experiences in specific community hospitals
- Addressing issues with what medications are not on formulary
- Tracking the prescription of Haldol for a month showed hospital leaders that the warnings were necessary
- Hospital team education through the Parkinson's Foundation Allied Team Training for Parkinson's™

## Conclusion

Based on the convening, PF was able to establish clarity of the issues regarding inadequate hospital care for people with PD including key care domains. There was an established consensus on a draft set of core hospital care guidelines, that recognize global guidelines but are unique to the US care system, to be finalized by the Advisory Committee, for all hospitals treating people with Parkinson's disease and for use by Aware in Care Ambassadors in their local hospital outreach.

The Parkinson's experts in attendance agreed that there is a need for the refinement of the long-term vision for the PF Aware in Care program and its ability to drive nationwide changes in the delivery of hospital care for people with PD. Attendees agreed to work towards establishing standards within four areas: PD Medication Management/Avoiding Missed, Omitted, Delayed and Substituted Medications (MODS); Special Considerations for Medications; Potentially Inappropriate Medications/Contraindicated Medications; and Fall Risk and Ambulation. It also includes checklists to be used in the following settings:

1. Emergency Department Checklist
2. Admission Checklist
3. Perioperative Checklist
4. Discharge Checklist

## Acknowledgements

Parkinson's Foundation would like to thank the Parkinson's experts who volunteered their time to join us to discuss hospitalization and Parkinson's and how to improve the hospital experience for people with Parkinson's disease and the Edmond J. Safra Foundation for their continuous support of the Aware in Care campaign.