INTRODUCTION: In 2010, The Michael J. Fox Foundation launched the Parkinson’s Progression Markers Initiative (PPMI) to study how Parkinson’s disease (PD) starts and changes over time. Volunteers participate in clinical, online, or both. PPMI is now prioritizing recruitment of individuals with possible or probable REM sleep behavior disorder (RBD) without a PD diagnosis (goal of 500 in clinic). As 30% of people with RBD and smell loss receive a PD diagnosis within four years, RBD may provide a model to understand the evolution of the prodromal phase of PD. This presentation will describe diverse recruitment strategies utilized since 2020 to enroll individuals with RBD, to inform best practices for engaging this population in research.

METHODS: A key strategy for identifying individuals with possible RBD was the dissemination of educational content on the disorder and its connection to PD. Materials emphasized that not everyone with RBD develops PD but that, in some people, RBD is an early symptom of the disease. Educational materials and messages (with associated calls to actions) were shared via webinars, print, and online publications, emails, animated videos, radio, TV, and paid social media ads. Materials included scientific, participant and influencer spokespeople and were targeted to both individuals with RBD and bed partners. PPMI study sites sought referrals from sleep physicians.

RESULTS: More than 535 individuals with a self-reported diagnosis of RBD (without PD) have enrolled in the online PPMI platform (59.4% male, 68.1% aged ≥60). Nearly 185 have been screened for site enrollment; 111 are contributing data at a study site. Foundation-led emails (16.1%) and paid social media ads (9.3%) were highest drivers to online enrollments. The most common referral sources to a PPMI RBD information and screening phone line were email (38%), social media (19%), and family/friend referral (19%). Approximately one-fourth of clinic enrollments were from physician referrals.

CONCLUSION: Multi-modal recruitment strategies, linked to tailored educational content, are critical for enrollment of individuals with RBD in clinical research studies including, but not limited to, those investigating and aiming to prevent other neurologic disorders.

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