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Patient Advocacy Leaders
United for Movement Disorders

***Patient Advocacy Leaders United for Movement Disorders:
Showcasing TD Awareness Week Best Practices to Ignite a Movement***
A program of the Center for Patient Advocacy Leaders (CPALs)

***1:30 - 3:00 pm EDT
May 12, 2022
A Virtual Event***

This Patient Advocacy Leaders United (PALs United) event promotes the mission of the Center for Patient Advocacy Leaders (CPALs): To improve the lives of those affected by disease and chronic health conditions by educating and mobilizing health advocacy leaders to work collaboratively in developing impactful policy and advocacy solutions. Our advocate-centered model, “By Advocates, For Advocates”, focuses on the needs of patients and caregivers, patient advocacy leaders, their organizations, and the diverse communities they serve.

OBJECTIVES

- 🕒 Showcase educational and awareness activities conducted during TD Awareness Week.
- 🕒 Highlight best practices from TD Awareness Week to improve understanding of how to more effectively address TD/Movement Disorders.
- 🕒 Continue to unite and strengthen the network of TD advocates to raise awareness and address issues impacting the well-being of persons and caregivers affected by TD.

1:30 pm – 1:45 pm *Opening/Welcoming Remarks*

Moderator:

Scott Suckow – Senior Consultant, Perry Communications Group

***Josie Cooper – Executive Director, Alliance for Patient Access (AfPA)/
Movement Disorders Policy Coalition (MDPC)***

1:45 pm – 2:30 pm *TD Awareness Week Best Practice Showcase Examples*

This session will illustrate the practices used by different advocacy groups to improve the awareness and education of diverse audiences as it relates to access and treatment quality issues associated with TD. The focus of these practices is on



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improving public understanding, or educating policy makers, addressing stigma or health equity. Each example will be followed by time for moderated Q&A.

- 🕒 ***Alliance for Patient Access (AfPA)/Movement Disorders Policy Coalition (MDPC)***
Josie Cooper, Executive Director
Lauren Carter-Early, Associate
AfPA/MDPC will highlight their collaborative TDAW efforts including a number of virtual events aimed at policymakers; a co-hosted Twitter chat with MHA and CAN, sharing of their online TDAW toolkit, and a sign-on campaign relating to state recognition of the awareness event.

- 🕒 ***National Organization for Tardive Dyskinesia (NOTD)***
Kathleen Shea, Founder & President
William Cote, Senior Director
NOTD will share learnings from their federal level Hill Day educating and advocating lawmakers, held in Washington, DC on May 4th.

- 🕒 ***National Alliance on Mental Illness-New York State (NAMI-NYS)***
Matthew Shapiro, Director of Public Affairs
NAMI-NYS will relay information on state-level awareness building activities via social media, direct email alerts and “TD-blue” lighting of NY landmarks. Also highlighted will be ideas for integrating TD awareness information into several large-scale events.

2:30 pm – 3:00 pm **Building on TDAW Efforts, Amplifying TD/MD Collective Voice, Next Steps**

This session builds on the presentations to help participants identify the common elements of effective awareness programs and what works best with different audiences. The discussion will focus on how these elements can be used in future TD awareness and education programs, how these elements can be applied to other advocacy activities and what it takes to sustain such work. Focus will also be on where time and resources should be spent to assure that persons with TD get the right care, at the right time, in the right setting, delivered by the right person.

3:00 pm **Event Concludes**



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A special thank you to all of our Advocate Advisors for their valuable input and contributions to this event and the PALs United for Movement Disorders initiative!

- 🕒 **Rhonda Blandford**
Public Relations & Technology Coordinator,
National Alliance on Mental Illness (NAMI) Louisville
- 🕒 **Dennis Borel**
Executive Director, Coalition for Texans with Disabilities
- 🕒 **Josie Cooper**
Executive Director, Alliance for Patient Access
- 🕒 **William Cote**
Senior Director, National Organization for Tardive Dyskinesia
- 🕒 **Phyllis Foxworth**
Advocacy Vice President, Depression & Bipolar Support Alliance
- 🕒 **Greg Hansch, LMSW**
Executive Director, National Alliance on Mental Illness (NAMI) Texas
- 🕒 **Liz Helms**
President & CEO, California Chronic Care Coalition
- 🕒 **Elizabeth Marconi**
Manager, Corporate Relations, National Alliance on Mental Illness (NAMI) National
- 🕒 **Ray Merenstein**
Executive Director, National Alliance on Mental Illness (NAMI) Colorado
- 🕒 **Matthew Shapiro**
Director, Public Affairs, National Alliance on Mental Illness-New York State (NAMI-NYS)



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