



**PALs  
UNITED**

Patient Advocacy Leaders  
United for Movement Disorders

## ***Patient Advocacy Leaders United for Movement Disorders: Addressing the Well-Being of Persons Affected by Movement Disorders***

*A program of the Center for Patient Advocacy Leaders (CPALs)*

***12:30 pm – 4:00 pm EDT  
October 26, 2021  
A Virtual Event***

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*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**

- ④ Raise awareness and improve understanding of involuntary movement disorders, including tardive dyskinesia, in the population of those also affected by chronic conditions.
- ④ Explore the current educational and awareness work being conducted by patient advocates which addresses the personal disruptions due to the symptoms of movement disorders, along with the corresponding actions taken to address the condition including the secondary impacts of stigma and discrimination, depression, social isolation and or lack of employment.
- ④ Connect and unite participants to: identify potential policy and advocacy strategies and tactics that address movement disorders; engage and mobilize other stakeholders; collaborate to ensure policies are inclusive, patient-centered and can lead to improved health outcomes for those affected by these conditions; raise awareness and address issues focused on the well-being of their caregivers.

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CENTER FOR PATIENT  
ADVOCACY LEADERS  
*By Advocates, For Advocates*



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Addressing the Well-Being of Persons Affected by Movement Disorders***

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12:30 pm – 12:35 pm ***Opening/Welcoming Remarks***

***Moderator:***

***Scott Suckow – Senior Consultant, Perry Communications Group***

12:35 pm – 1:05 pm **Overview of the Current Healthcare Landscape Relating to Movement Disorders**

***David Charles, MD***

***Professor and Vice Chair, Department of Neurology***

***Vanderbilt University Medical Center***

***Medical Director, Vanderbilt Telehealth***

1:05 pm – 1:20 pm **Moderator Facilitated Q&A**  
***Submitted via chat***

1:20 pm – 2:05 pm **Exploring Best Practices to Raise Awareness, Address Access Barriers, Reduce Stigma**

This session will focus on:

- 🕒 Illustrating public engagement and education to address movement disorders, how these actions fit within their overall advocacy for chronic illness and how they illustrate the necessity for collaboration with other community organizations;
- 🕒 Identifying the effective messages for public understanding of these conditions and for reducing stigma associated with them;
- 🕒 How highlighted activities illustrate a focus on health equity to assure better access to education and awareness for all;
- 🕒 Identifying common messages and effective strategies and tactics that can be used by others to build larger coordinated education and awareness campaigns.

**Panelists:**

🕒 ***Greg Hansch – Executive Director, NAMI – Texas  
PALs United for Movement Disorders Advocate Advisor***

🕒 ***Robert N. Davison – Chief Executive Officer,  
Mental Health Association of Essex and Morris County (New Jersey)***

🕒 ***Lisa Winstel – Chief Operating Officer, Caregiver Action Network***



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2:05 pm – 2:20 pm **Moderator Facilitated Q&A**  
*Submitted via chat*

2:20 pm – 2:30 pm **Break**

2:30 pm – 3:15 pm **Finding Common Ground to Collaborate for Collective Impact**

This session will focus on:

- 🕒 Discussing ways to develop and promote policy to address movement disorders;
- 🕒 Key policy matters: how telehealth/face to face visits can be useful for patient and provider, how access to treatments (getting the right treatment at the right time) can be achieved, how effective policy can offer hope to patients and their support network, how policy addresses diversity and inclusion.

**Panelists:**

- 🕒 *Josie Cooper – Executive Director, Alliance for Patient Access  
PALs United for Movement Disorders Advocate Advisor*
- 🕒 *Stephen R. Saklad – Director, Psychiatric Pharmacy  
& Clinical Professor, The University of Texas at Austin College of  
Pharmacy*
- 🕒 *Carlos A. Larrauri – Clinician | Speaker | Advocate*

3:15 pm – 3:30 pm **Moderator Facilitated Q&A**  
*Submitted via chat*

3:30 pm – 4:00 pm **Making it Happen – What Now?**

This session will focus on:

What more is needed by participants to build a policy campaign or support an already existing campaign to better meet the treatment and supports needed for overcoming movement disorders, including tardive dyskinesia.

- 🕒 Is there will/motivation and leadership to build a policy campaign?
- 🕒 If so, is there energy and resources to move forward?
- 🕒 Where should this campaign be focused - on the national and/or state level of government; in regulatory agencies and/or public or private insurance entities?

4:00 pm **Event Concludes**



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