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

October 26, 2021

PALs
UNITED
Patient Advocacy Leaders
United for Movement Disorders

A program of

CENTER FOR PATIENT
ADVOCACY LEADERS

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Overview

The **Patient Advocacy Leaders (PALs) United for Movement Disorders: Addressing the Well-Being of Persons Affected by Movement Disorders** event was held on October 26, 2021. This free virtual event convened a select group of over 45 health advocacy and policy leaders to coalesce around common goals to raise the profile of movement disorders, like tardive dyskinesia (TD), and advance patient-centered solutions.

The event broadly addressed the well-being of persons affected with movement disorders through a combination of presentations from key thought leaders and interactive discussions among event participants. Key objectives of the event included:

- Raise awareness and improve understanding of involuntary movement disorders, including TD, in the population of those affected by chronic conditions;
- 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, or lack of employment; and
- 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; and raise awareness about and address issues focused on the well-being of their caregivers.

> “This was a really wonderful, timely event, and I appreciate the focus and the breadth of expertise represented in this meeting.”

Welcoming Remarks

The event began with opening remarks by the event moderator, **Scott Suckow**, Senior Consultant, Perry Communications Group. Mr. Suckow welcomed participants and thanked PALs United for Movement Disorders for their support. He reviewed the agenda (see Appendix 1) and purpose of the event and presented some recommended ways to enhance engagement in the virtual setting. A poll was conducted to learn more about event participants, who were asked to share the roles they play in their organizations, the geographic areas they are from, and their comfort levels in conducting advocacy for addressing movement disorders. (See Appendix 2 for a list of event participants.)

Keynote Address: Overview of the Current Healthcare Landscape Relating to Movement Disorders

Mr. Suckow introduced the keynote speaker, **David Charles, MD**, Professor and Vice Chair, Department of Neurology, Vanderbilt University Medical Center, Medical Director, Vanderbilt Telehealth. Dr. Charles is a neurologist with a subspecialty in movement disorders. Throughout his career he has conducted clinical research for new medications and medical devices for the treatment of movement disorders. Dr. Charles is also a founder of Alliance for Patient Access, a national network of healthcare professionals dedicated to promoting the benefits of patient-centered care. He discussed numerous benefits of patient-centered care including empowering patients to be engaged in shared decision making, not limiting treatment options, advancing policies that support therapeutic access, and strengthening clinician-patient relationships.

Dr. Charles defined the term "movement disorders" as neurological conditions marked by abnormal body movements or slow, reduced movements. These conditions include Parkinson's disease, TD, Huntington's disease, dystonia, essential tremor, Tourette syndrome, ataxia, restless legs syndrome, among others. Millions of Americans are affected by movement disorders. TD impacts up to 30 percent of people who use antipsychotic medications and can significantly affect quality of life for these individuals, especially considering the compounding stigmas of mental illness and movement disorders.

Policy and Advocacy Matters:

1) New medications have been approved for the treatment of movement disorders; however, barriers to access often limit availability of these therapeutics. Dr. Charles outlined numerous challenges to obtaining access to medications and the resulting impact of these challenges.

Challenge	Potential Impact
High co-pays for brand name medications or those that are not preferred by health plan	Increased out-of-pocket costs and possible inability to pay for medications
Specialty tier medications, which require patients to pay a percentage of medication costs	Increased out-of-pocket costs and possible inability to pay for medications
Prior authorization required before medication is covered by health plan	Delay of treatment, during which time the patient's condition may worsen
Step therapy, requiring other treatments be tried before desired medication is covered by health plan	Undermines patient-centered care and interrupts treatment plan
Non-medical switching, whereby health plans change patients to different medications than prescribed to save money	Undermines patient-centered care and interrupts treatment plan
Cost sharing strategies such as co-pay coupons and accumulator programs	Co-pays do not count as deductible expenses; co-pay coupons are not allowed under Medicare
Limited access to specialists (including mental health providers and neurologists specializing in movement disorders), which is especially challenging if health plan requires treatment by specialist before approval	Delay of treatment, during which time the patient's condition may worsen

2) Dr. Charles discussed the increased use of telehealth during the pandemic. Telehealth, he noted, can be used to improve access to care and mitigate barriers such as lack of transportation and scheduling conflicts, especially for patients living in rural areas. Limitations of telehealth include inability to physically examine a patient, difficulty picking up on verbal cues or body language, and limited interaction with family members or other caregivers. Lack of access to broadband and/or poor internet connection can also be a challenge. He offered a resolution as a useful model of care—a combination of telehealth and in-person visits—which policies should support.

Questions and Discussion

After the presentation, participants were given the opportunity to ask questions of Dr. Charles. Following is a summary of this discussion.

Q: Are movement disorders associated with mental illness itself, as well as being associated with antipsychotic medications?

A: Possibly. There are some conditions that cause movements that have no relationship to medications the person is taking. For example, Huntington’s disease is associated with abnormal hyperkinetic, involuntary movement. People with Huntington’s disease can also develop mental health issues, which can grow to become more problematic than the actual movement disorder.

> Barriers to access limit availability to new treatments for movement disorders and may result in increased costs and delay of treatment.

Q: *Can you discuss the “double whammy” of having to repeat step therapy when a patient changes insurance or a specialist?*

A: It is especially challenging when the patient has worked with their clinician to find the right therapy, having gone through prior authorization and step therapy. Changes in insurance should not result in going back to the beginning of the process. If a therapy has been established and has been proven effective, that therapy should be allowed to be continued despite changes in insurance.

Q*: How can we make our advocacy stronger by aligning with other organizations (e.g., law enforcement, housing, employment)?*

A: Any time you can build a coalition of stakeholders, it amplifies your voice. Other stakeholders can look at the problem from different perspectives and provide valuable data. This helps sharpen and improve your message so that policymakers can better understand the story you are telling.

Q: What steps should advocates take to move the needle in improving access to care?

A: Events like this one help us to learn more about the problem, understand the challenges, and become activated. Even one voice can make a difference. Meeting with legislators, policy makers, and staff members can have a huge impact. The effort should include clinicians, patients, payers, caregivers, and others.

Nick Navatta, an artist and illustrator from San Diego, created a graphic recording of the event. Here is Nick's depiction of the keynote session. (See full graphic recording in Appendix 4.)

Panel Presentation: Exploring Best Practices to Raise Awareness, Address Access Barriers, and Reduce Stigma

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

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

Lisa Winstel
Chief Operating Officer
Caregiver Action
Network (CAN)

This panel presentation focused on:

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

Greg Hansch presented several tips for being a partner in TD awareness. He also noted a number of ways to get the message out: toolkits, radio commercials, billboards, social media, and e-newsletters. These ideas can be adapted across any awareness campaign for any movement disorder.

Tip #1: Start with the basics. Since most people don't know anything about TD, it is important to provide information such as prevalence of illness, definition, and available treatments.

Tip #2: Don't reinvent the wheel. Many TD awareness resources have already been developed, so creating new content is not necessary. For example, Neurocrine Biosciences created a TD Awareness Week Toolkit, which includes statistics, templates, infographics and background information.

Tip #3: Identify and engage partners. Expand your reach by identifying other organizations outside of your usual network that might have shared interest. List them as partners/co-hosts of events and have them share information with their partners.

Tip #4: Help people connect with real stories. Put a face to the issue of TD and build an emotional connection and empathy by sharing real stories from individuals who have been personally impacted by TD. Videos and infographics highlighting TD stories are available online.

Tip #5: Harness the power of government. Many states have passed resolutions recognizing TD Awareness Week, thereby increasing understanding and recognition of TD among policy makers.

Tip #6: Facilitate interactivity. People are more responsive and retain information better if they have a role to play. Examples include events, surveys, and Q&A sessions.

Mr. Hansch provided the following recommendations:

- Grab attention by portraying stark reality;
- Provide prevalence data to help people connect;
- Present personal stories, as they are the "special sauce;"
- Include healthcare providers' perspectives to bring in trust, science, and credibility;
- Emphasize that help is available and recovery is possible; and
- Include a health equity lens in designing outreach strategies and incorporate data on disparities in prevalence and access.

Robert Davison shared his experience as a healthcare provider with a focus on education for patients, providers, and family members. His key messages were:

- The importance of understanding the patient's perspective;
- Developing a well-working relationship with the patient to freely discuss movement disorders and possible treatments;
- Proactively educating families is also important. Although HIPAA regulations may limit discussions about individual care, they do not prohibit educating families generally about mental illness, medications, and movement disorders; and
- With patient permission, build in a treatment goal to involve family members when indicated.

This work requires time, which can be a barrier, especially in a public system. In these settings, paraprofessionals are often the eyes and ears of the physicians. It is essential that paraprofessionals are well educated about medications and movement disorders through in-person, web-based, and virtual trainings.

> There is no greater advocate or resource for someone with a mental illness or movement disorder than a family member. People are more likely to recover and assume valued roles in the community if families are involved.

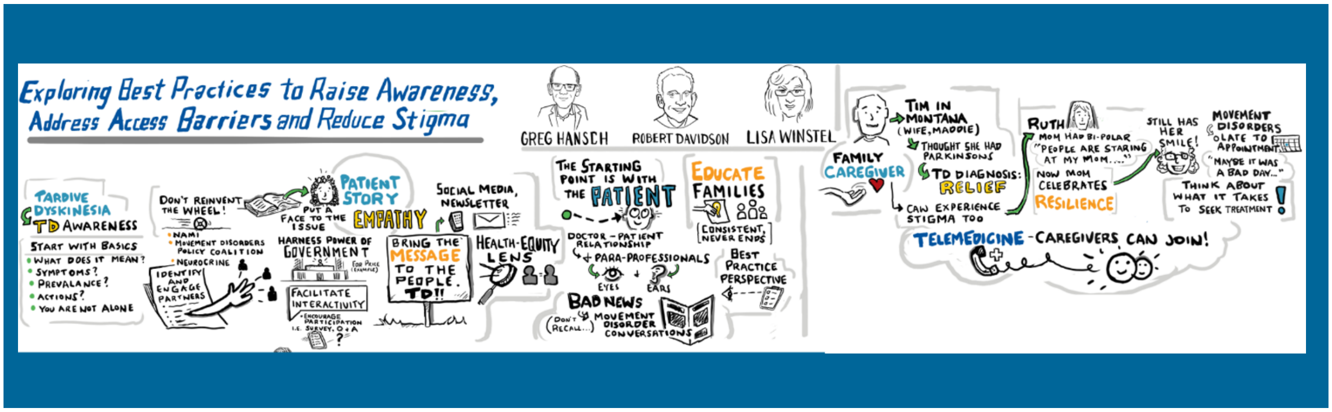
Mr. Davison concluded by pointing out that more work and advocacy are needed to raise awareness about movement disorders among mental health providers at the national level.

Lisa Winstel discussed the perspective of family caregivers. Mental health issues are difficult enough for family caregivers to address, but can be even more complicated when movement disorders are present. She illustrated the importance of TD awareness with a story about Tim, a man from Montana who serves as the caregiver for his wife, affected by schizophrenia and TD, and the struggles they had getting the right diagnosis and treatment.

Another story that focused on stigma involved Ruth, a woman from Massachusetts who cares for her mother, who has lived with bipolar disorder for 15 years and was recently diagnosed with TD. Ruth's mother became withdrawn and uncomfortable in public due to her movement disorder. The stigma involved with TD brought on isolation and depression. Ruth and her mother decided to address these challenges by learning more about TD and practicing activities that promote self-care. This story illustrates how important it is to celebrate learning and building resilience.

Ms. Winstel discussed the importance of healthcare providers understanding the challenges faced by people with movement disorders and their family caregivers. She encouraged healthcare providers to communicate directly with caregivers, who might include parents, spouses, other relatives, neighbors, or friends. She also encouraged family caregivers to join telemedicine calls with patient consent, as their observations can provide useful information regarding the patient's condition.

Ms. Winstel's organization, the Caregiver Action Network, is capturing stories from family caregivers. Family caregivers are encouraged to share their stories to help others achieve accurate diagnosis and treatment and reduce stigma.



Questions and Discussion

After the panel presentation, event participants were given the opportunity to ask questions of the panelists. Following is a summary of this discussion.

Q: Are there key messages that have resonated with patients, providers, and caregivers?

A: Ms. Winstel pointed out the need to encourage caregivers to take care of themselves and to focus on their own goals and needs, as well as those of their loved one. She mentioned that National Caregivers Month is in November, which provides an opportunity for increasing awareness. Caregiver Action Network provides information and builds awareness for caregivers.

Mr. Hansch recommended focusing on the following key messages: 1) provide stark, realistic portrayals of the effects of TD, 2) present data on the prevalence of TD, 3) offer a personal story from someone who has been impacted by TD, 4) mention that treatment and recovery are possible, and 5) provide resources.

Mr. Davison said that there is no greater advocate or resource for someone with a mental illness or movement disorder than a family member. People are generally more likely to recover and assume valued roles in the community if families are involved. He pointed out the importance of healthcare providers working with family members and understanding their challenges and concerns.

Personal stories from individuals with movement disorders and their caregivers can be effective communications and advocacy tools.

Q: Are there video compilations of caregiver stories?

A: Ms. Winstel indicated that the Caregiver Action Network is in the process of compiling videos of caregiver stories. The stories will be presented in a somewhat animated version on the Caregiver Action Network website in February 2022.

Q: Are you familiar with clubhouses and would you describe them as welcoming safe havens for people with movement disorders?

A: Mr. Hansch responded that clubhouses help people feel connected socially and have an atmosphere of acceptance. Clubhouses can be a wonderful resource for people with TD, who are often uncomfortable in social settings. In addition to being accepted socially at clubhouses, these individuals can receive support and assistance in working on their personal goals such as employment.

Ms. Winstel pointed out that clubhouses can be a resource to provide respite for caregivers, although it can be challenging for family caregivers to find clubhouses in their areas.

Q: What are some challenges faced by caregivers of people with movement disorders?

A: Ms. Winstel mentioned that in-home and other respite services are difficult to find for people with movement disorders. She indicated that one reason why individuals with movement disorders are transferred from home to a skilled nursing facility or other congregate setting is because the caregiver is no longer physically capable of moving the person, not necessarily because they can't provide other needed care.

Q: What is your TD elevator pitch?

A: Mr. Hansch responded: TD, or tardive dyskinesia, is a condition of uncontrollable movements affecting the face, torso, or other body parts. TD is associated with taking certain kinds of mental health medicines like antipsychotics, which help control dopamine. The impact of TD, if untreated, can devastate a person's ability to face the world and cause extreme social isolation. Thankfully, treatment is available and people can experience dramatic TD recoveries. People who receive TD treatment may be able to accomplish things that they never thought they would be able to accomplish in their lives.

Mr. Davison added that treatment and recovery are possible for people with movement disorders. He stressed the importance of healthcare providers and patients working together toward improvement.

Successful messaging strategies:

- Provide basic information
- Utilize existing resources
- Expand your network
- Provide real life stories
- Engage policy makers
- Encourage interaction

Ms. Winstel said if you see something, say something. Another participant shared her elevator pitch: It doesn't matter how old you are, if you're on a medication that can cause movement disorders, you need to be aware. The sooner you address movement disorders, the better treatment you can receive.

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Panel Presentation: Finding Common Ground to Collaborate for Collective Impact

Josie Cooper
Executive Director
Alliance for Patient Access
Advocate Advisor,
PALs United for
Movement Disorders

Stephen R. Saklad
Director, Psychiatric Pharmacy &
Clinical Professor
The University of Texas at Austin
College of Pharmacy

Carlos A. Larrauri
Clinician, Speaker,
Advocate

This panel presentation focused on:

- Discussing ways to develop and promote policy to address movement disorders; and
- Key policy matters: how telehealth and 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.

Josie Cooper's organization works to advance policy solutions that will improve access to patient-centered care. She also serves as director of the Movement Disorders Policy Coalition (MDPC), which convenes more than 20 advocacy groups representing patients, providers, and caregivers in the movement disorders space. The Coalition is focused on three key areas:

1. Increase awareness to provide accurate information, dispel misinformation, and address stigma. Activities include leadership and messaging for TD Awareness Week;
2. Support innovation to ensure that policies are enacted to explore further treatment options and cures; and
3. Advocate for policy reforms that will increase access to care. Activities include reform of utilization management processes such as prior authorization, step therapy protocols, and other common barriers.

The MDPC provides opportunities to empower stakeholders to engage and educate policy makers in these focus areas. The MDPC produces educational materials, hosts events, and leads direct advocacy efforts designed to impact policy reform and increase access to personalized care. They embrace collaboration and look for opportunities to work collectively with other organizations with similar goals.

Ms. Cooper pointed out that despite having opportunities to advance patient-centered care such as new treatment options and increased utilization of telehealth, policy barriers often limit access. Payers are increasingly determining what treatments patients can access based on cost. Recent advocacy successes include working with pharmacy benefit managers to reconsider and reverse exclusions for movement disorder medications and passage of state legislation that protects patients from step therapy.

Dr. Saklad's work has been primarily focused on conducting research and treating patients, as well as increasing awareness among healthcare providers about best practices. He has advanced numerous interventions related to improving care and monitoring of TD at the University of Texas and San Antonio State Hospital. He reiterated the severe impact and stigma caused by TD and other movement disorders. Although many people do not recognize they have a movement disorder, others are painfully aware of their disorders and may isolate themselves for many years. Dr. Saklad pointed out that more research is needed to study children and adolescents and provide earlier access to treatment and therapy. In addition, more advocacy is needed to reduce barriers to effective treatments.

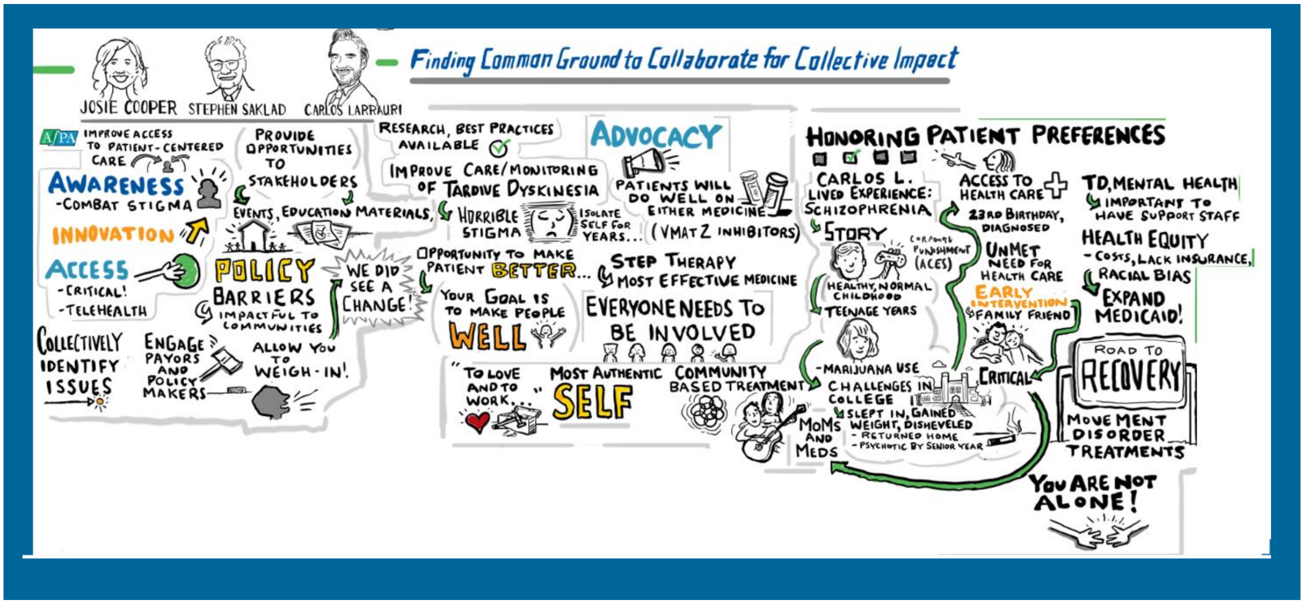
> Advocacy is needed for policies that will address barriers to effective treatment, support integrated care, and reduce stigma for movement disorders.

Mr. Larrauri is a psychiatric nurse practitioner who shared his story of mental illness and hope. Mr. Larrauri began experiencing personality changes as a teenager. He spent six months seeing multiple mental health professionals in a variety of settings and, after a long process was diagnosed with adult-onset schizophrenia at age 22. Despite having health insurance due to the Affordable Care Act (ACA), he experienced barriers to accessing quality care. Having a family member to serve as an advocate, as well as early intervention, were critical assets in obtaining care and treatment and reaching recovery.

Mr. Larrauri pointed out:

- There is a significant need for access to treatment, rehabilitation, and support services within community settings. Examples include diagnosis and medication management, supportive school and work environments, support family and home environments, strong social relationships, volunteer advocacy, psychotherapy, education, support groups, nutrition and lifestyle programs, and peer support;
- Coordinated specialty care is now the gold standard for care for schizophrenia. Other best practice recommendations include clinical assessments for TD at each visit with a structured instrument such as AIMS; for new onset or exacerbation of TD, assessment should be every six months for patients at high risk and every 12 months for other patients; and utilization of in-person assessments, when possible;
- Lack of equity exists for TD treatment. Minority populations face multiple barriers to accessing care and medication adherence due to cost of treatment, lack of health insurance, and implicit racial bias in prescribing practices; and
- Policy advocacy is needed to expand Medicaid, promote the ACA and an essential benefits package, and reduce implicit bias. He discussed the importance of shared decision making and patient-centered care, which help bridge health disparities and can positively impact the quality, cost, and safety of healthcare delivery.

Mr. Larrauri discussed his advocacy work with NAMI, which included a recent trip to Washington DC. He mentioned how advocacy gives him a sense of purpose and provides an opportunity to help others. This work has played an important role in his recovery and he encouraged others with lived experience to share their stories.



Questions and Discussion

After the panel presentation, event participants were given the opportunity to ask questions of the panelists. Following is a summary of this discussion.

A focus on health equity and cultural competency is needed to improve access to care for populations experiencing health disparities.

Q: Access to treatment and employment are important. How do we turn this need into policy to support those who do not have family support?

A: Mr. Larrauri said that people need to be integrated into the community. Family support is critical; without it, individuals may have to rely on public systems for basic needs such as housing, medication, and insurance. Policies could support improvements to the public health system, which is difficult to maneuver with a mental health issue.

Ms. Cooper recommended policy solutions including providing coverage for therapies, medications, and treatments that are not currently covered. She suggested engaging policy makers to support new and innovative policy approaches that may have not yet been tried.

Q: What was the moment you accepted that you had an illness and moved from denial to healing?

A: Mr. Larrauri shared that his psychosis resulted in a lack of self-awareness. Medication made the difference, along with educating himself about his condition, lifestyle choices, and treatment. His mother helped to coordinate his care, as the system is fragmented. Ms. Cooper concurred and encouraged healthcare and other systems to work together to assure that patient care is fully integrated.

Q: As we raise awareness about TD and other movement disorders, how can we be sure this awareness doesn't result in people being reluctant about taking their medications?

A: Mr. Larrauri suggested educating both patients and healthcare providers about treatments for movement disorders, as well as reducing barriers to accessing medications. Peer-to-peer education is also helpful in creating hope for recovery.

Q: How can we increase training and education for healthcare providers for the purpose of improving health equity?

A: Ms. Cooper pointed out that shared decision making is crucial. People need to feel heard and that their preferences are being acknowledged. She discussed barriers to care such as prior authorization, which can deter continued care and medication adherence. Mr. Larrauri suggested requiring medical training to include healthcare providers to meet directly with people with lived experience and caregivers from various cultures. It is also important to train more healthcare providers from underrepresented populations with a focus on race/ethnicity and gender.

Advocacy can provide individuals with movement disorders a sense of purpose and the opportunity to help others.

Closing thoughts included encouraging patients and providers to get involved in advocacy. Mr. Larrauri expressed his appreciation for providing the space and opportunity to have these conversations with cross-sector partners.

Making it Happen – What Now?

The event's final session focused on learning 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 TD. Mr. Suckow facilitated this group conversation along with Mike Cohen, Associate Director of CPALs.

Mr. Suckow asked what we need to do as a community to best support people with movement disorders and whether there should be an organization completely dedicated to movement disorders.

Ms. Cooper mentioned that MDPC is a policy coalition that focuses on a range of movement disorders. Event participant Kathleen Shea mentioned that she started the National Organization for Tardive Dyskinesia in 2019. This organization is dedicated to raising awareness, conducting advocacy, and providing education to patients with TD. Resources are available on the organization's website.

Mr. Suckow asked how we can build a network of motivated health advocates to collectively address both policy and education around movement disorders that captures the needs of a diverse population including communities of color. He pointed out that PALs is an experienced convener of subject matter experts and thought leaders who address a variety of health issues and that they could provide leadership around the issue of movement disorders.

One participant mentioned that membership and advocacy organizations should integrate TD and movement disorder awareness into their regular education efforts as a way to normalize the conversation. Mr. Cohen mentioned that the educational resources presented previously will be available on their website. He highlighted the following key takeaways:

- Barriers to access to care should be recognized and addressed;
- Advocates should work at the state level to assure that public and private health insurance covers the best treatments available for persons with serious mental illness and/or movement disorders;
- When possible, telemedicine should be used as one effective treatment option;
- The voice of persons with lived experience—including patients and caregivers—should be included at all levels, both in conversations with providers and in advocacy; and
- Health equity is vital and should be considered by healthcare providers.

Mr. Cohen discussed the challenges in working collaboratively with others outside of our own silos. CPALs will share a list of event participants and Mr. Cohen encouraged everyone to reach out to others to build their networks across systems and organizations to continue moving the effort forward. He asked if there is continued interest in this topic and if PALs United for Movement Disorders can play a coordinating role and participants responded affirmatively.

Anne Easter, Director of CPALs, and Mr. Cohen expressed their appreciation to the speakers, to Mr. Suckow for moderating the event, and to the event participants. They indicated that further efforts are needed and that PALs United for Movement Disorders will convene stakeholders and accelerate the dialogue around education and policy advocacy.

Mr. Suckow reminded participants to complete the evaluation of the event. CPALs is committed to continuous quality improvement and uses data from evaluations to improve upon future events. He concluded by affirming that we are stronger when we come together and encouraged participants to reach out to Ms. Easter at CPALs if they would like to become more engaged with PALs United for Movement Disorders.

Event Evaluation

The event evaluation revealed high levels of satisfaction and the intention of participants to use information shared in future activities (see full evaluation results in Appendix 5). Findings include:

- Overall, 94% of respondents rated the event as "Excellent" (75%) or "Very Good" (19%). The keynote and panel presentations received very favorable feedback as well.
- In total, 88% of respondents indicated attendance at the event will be useful in their work.
- Participants were asked what specific actions they or their organizations plan to take as a result of attending the event. Responses included:
    - "There were a number of practical ideas that can be used, especially related to education and awareness."
    - "This information will help in our next steps…it will help a lot."
    - "I will discuss the ideas presented to see how we can implement them in our community outreach and advocacy work."
    - "We will be more involved in advocating for equitable health care."

The PALs United for Movement Disorders event site (https://www.taicfcp.org/PALsUnitedforMovementDisorders#) will remain available to attendees who may be interested in resources from the event related to movement disorders. CPALs will be adding additional information to this site as it becomes available. (See links to slides and additional resources in Appendix 6.)

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DBSA
Depression and Bipolar Support Alliance

Neurocrine BIOSCIENCES

AfPA Alliance for Patient Access

CTD Coalition of Texans with Disabilities

Thank You Attendees & Partners !

NAMI
National Alliance on Mental Illness

TD National Organization for Tardive Dyskinesia

CALIFORNIA Chronic Care Coalition
We're About People. We're About Health

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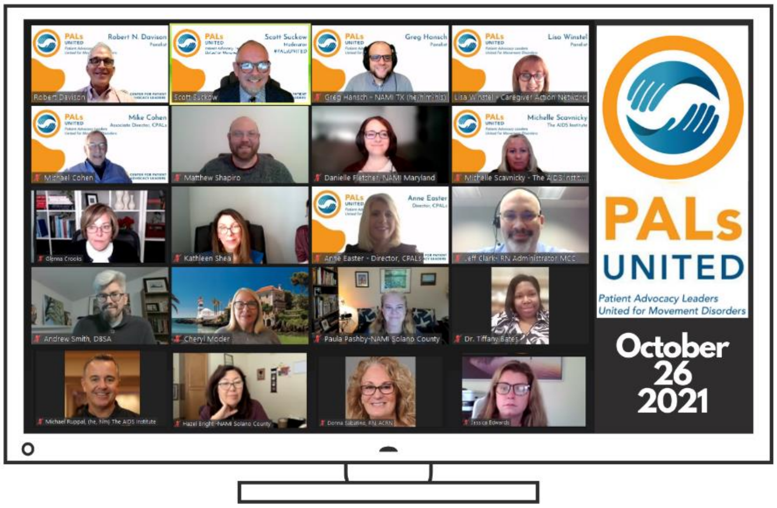
THE AIDS INSTITUTE



CPALs
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By Advocates, For Advocates

The ***Center for Patient Advocacy Leaders*** *is an evolution of a program called PALS that was developed in 2002. Since 2016 CPALs has been housed within* ***The AIDS Institute****. Work continues to be across disease states and populations, and driven by an advocate-centered model,* ***By Advocates, For Advocates****. For more information, please visit the CPALs website at https://www.centerforpatientadvocacyleaders.org/.*

Appendices

Appendix 1: Event agenda

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

*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

- Raise awareness and improve understanding of involuntary movement disorders, including tardive dyskinesia, in the population of those also affected by chronic conditions.
- 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.
- 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.

12:30 pm – 12:35 pm	***Opening/Welcoming Remarks*** ***Moderator:*** ***Scott Suckow – Affiliated Partner, VPI Strategies***
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.

<u>Panelists:</u>

- ***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***

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.

<u>Panelists:</u>

- ***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

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.

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, are 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**

Appendix 2: Event participants

Name	Title	Organization
Frankie Berger	Director, State Public Policy	Neurocrine Biosciences
Todd Bledsoe	Executive Director, Patient Engagement & Advocacy	Neurocrine Biosciences
Linda Brown	Outreach	NAMI GH
Jacki Brown	Retired	Retired
Lauren Carter-Early	Associate	Movement Disorders Policy Coalition
Michael Cohen	Dir. for Cross-Sector Alliances and Policy	Center for Patient Advocacy Leaders (CPALs)
Josie Cooper	Executive Director	Alliance for Patient Access
William Cote	Vice President	National Organization for Tardive Dyskinesia
Glenna Crooks	Co-Founder	CogentSage Group
Anne Easter	Director	Center for Patient Advocacy Leaders (CPALs)
Jessica Edwards	Director, External Relations	NAMI
Tatiana Gonzalez Quiroga	Advocacy and State Program Director	NAMI Louisiana
April Grant	Director	Supported by NAMI Alaska
Gail Green	NA	NA
Jerry Hall	Training Manager	Teva
Neil Hamilton	LOSS Coordinator	NAMI Lorain County
Greg Hansch	Executive Director	NAMI Texas
Chuck Harman	Director of Patient Advocacy and Engagement	Neurocrine Biosciences
Mejken Hernandez	Outreach Director	Alsana
Frank Hood	Manager, Hepatitis Advocacy	The AIDS Institute
Wendy Jensen	Self employed	Wendy Jensen
Sandi Jones	Partner	MHSA
Zena Kelley	Retired	NAMI South Bay

Sean McIntosh	Research Coordinator	The AIDS Institute
Irene McThomas	LPS Conservator	Family Member
Ray Merenstein	Executive Director	NAMI Colorado
Kathyleen Mesa	Intermediate Typist Clerk	County Of Los Angeles
Cheryl Moder	Vice President	Moder Research & Communications
Valarie Molaison	Director Government Affairs	Neurocrine Biosciences
Kim Molnar	Director, Center for Convening and Planning	The AIDS Institute
Mike Morris	Advocate Advisor	Center for Patient Advocacy Leaders (CPALs)
Judy Riley	Nurse Administrator	CMHCM
Elaine Rohr	NAMI Board Member	NAMI San Gabriel Valley
Luke Russell	Deputy Director	NAMI Ohio
Michelle Scavnicky	Associate Executive Director	The AIDS Institute
Kathl Shea	President	National Organization for Tardive Dyskinesia
Frida Shemesh	NA	NA
Steve Silvestri	Director, Government Affairs	Neurocrine Biosciences
Sally Skidgel	Wellness Coordinator	DOT
Andrew Smith	Community Engagement Program Manager	Depression and Bipolar Support Alliance
Julia Spiess	Senior Vice President	Perry Communications Group
Christina Taliaferro	Founder and CEO	East Texas Human Needs Network
Jodie Tierney	Director State Government Affairs	Neurocrine Biosciences
Jennifer Toon	Mental Health Peer Policy Fellow	Coalition of Texans with Disabilities
Thad Watanabe	Facilitator	NAMI San Fernando Valley
Dr. Kathleen Weisel-Plumb, PSYD	Doctor of Psychology MN CCNS Psychiatry	Executive Stress Consultants

Appendix 3: Speaker biographies

David Charles, MD
Professor and Vice Chair, Department of Neurology, Vanderbilt University Medical Center
Medical Director, Vanderbilt Telehealth

Dr. Charles is Professor and Vice-Chair of Neurology and Medical Director, Vanderbilt Telehealth. His research interests include the treatment of spasticity and cervical dystonia and he is currently leading the only clinical trial approved by the United States Food and Drug Administration to test deep brain stimulation in people with early stage Parkinson's disease.

Dr. Charles is a member of the American Neurological Association, Fellow of the American Academy of Neurology, and Chair of the Alliance for Patient Access. He is a member of Alpha Omega Alpha honor medical society and in 2007 received the CANDLE Award. Recipients are chosen based upon their positive impact on the lives of physicians-in-training and are recognized by their students as examples of excellence in medical education. From 1997-98, Dr. Charles served as a Health Policy Fellow in the United States Senate on the staff of the Labor Subcommittee for Public Health and Safety. In 1998 he studied deep brain stimulation for the treatment of movement disorders as a Fulbright Senior Scholar at the Universitaire de Grenoble in Grenoble, France. In 2000 Dr. Charles was a nominee for the United States House of Representatives from Tennessee’s Sixth Congressional District.

Dr. Charles graduated from Vanderbilt University School of Engineering in 1986 with a B.S. cum laude in Computer Science and Mathematics and earned his medical degree from Vanderbilt University School of Medicine in 1990. He did his internship in the department of Medicine and his residency in the department of Neurology at Vanderbilt. From 1993-94 he was Chief Resident in Neurology, and from 1994-95 he was a Fellow in Movement Disorders and Clinical Neurophysiology at Vanderbilt. In 1996, he completed a Health Care Management course at Vanderbilt’s Owen Graduate School of Management, and in 1997 he completed the Harvard Macy Institute Program for Physician Educators at Harvard Medical School.

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

Greg Hansch serves as the Executive Director of NAMI Texas. He joined NAMI Texas in 2012 and he has served in the roles of Public Policy Director and Policy Coordinator. In his current role, he is responsible for providing direction and leadership toward the achievement of NAMI Texas’ mission. He is a Licensed Masters-Level Social Worker and a family member of a person with serious mental illness. He received a Master’s degree in Social Work with a concentration in Nonprofit and Public Management from Rutgers University and a Bachelor of Arts degree in Government and Politics from the University of Maryland. Greg is a NAMI SMARTS for Advocacy State Trainer. He is an alumni of the Policy Academy of the Hogg Foundation for Mental Health at UT Austin. In his spare time, he enjoys helping people register to vote, being active outdoors, watching the Dallas Cowboys, and listening to podcasts.

Robert Davison
Chief Executive Officer
Mental Health Association of Essex and Morris County (New Jersey)

Robert N. Davison, Chief Executive Officer of the North Jersey based Mental Health Association of Essex and Morris, Inc. (MHAEM), is an accomplished professional who has been serving the mental health needs of communities throughout New Jersey for more than 35 years.

In his role as MHAEM's Chief Executive Officer, Mr. Davison manages the overall operations of a comprehensive community mental health facility that each day serves the needs of more than 1800 individuals and their families who are confronted with mental illnesses or emotional disturbances. A staunch advocate for humane, compassionate, and ethical treatment of individuals who suffer from mental illness, Mr. Davison has helped to establish the Mental Health Association of Essex and Morris as one of the state's premiere service providers, with services in Essex, Morris, Passaic and Sussex Counties.

In addition to his professional service, Davison maintains his interest in community issues in a variety of other ways. He was a founding Board member of the Newark-based Partnership for Children of Essex County Inc., a child-welfare agency, and is also was a founding member and past president of Advance Housing Inc., a community-based organization whose mission is to provide independent, normalized living arrangements for individuals with mental illnesses. A former three-term councilman in Caldwell, he also served as a legislative aide to Assemblyman John F. McKeon. He is also a former member of the Board of Directors of The Bridge, Inc., a non-profit family service agency based in West Caldwell.

In November 2004, Mr. Davison's commitment to public service was recognized when he was called upon to serve as Chairman of New Jersey Governor Richard J. Codey's Task Force on Mental Health. Over a period of fourteen months, the task force addressed key issues such as housing, community-based services, insurance parity, and conditions in state and county psychiatric hospitals. Their work and the Task Force's Final Report provided a blueprint for overhauling and comprehensively reforming New Jersey's mental health system

In 2006, Mr. Davison served on Governor Jon Corzine's Transition Team for Human Services and on Governor Corzine's Policy Advisory Council on Human Services Restructuring. In 2007, Mr. Davison was appointed to the Governor's Campus Security Task Force. Mr. Davison served on the New Jersey Attorney General's Less-lethal Advisory Committee. In November 2008, Mr. Davison was appointed to the Governor's Task Force on Police Suicide. In 2009, Mr. Davison was elected to the Board of Directors of Active Minds, Inc. a national organization focusing on college and university mental health, located in Washington, DC. In 2014 he was appointed by the Chief Justice of the New Jersey State Supreme Court to the Judiciary's Mental Health Implementation Committee. Mr. Davison was elected to the Board of Directors of the National Council for Behavioral Health, beginning his term on July 1, 2015, and re-elected for a new term starting on July 1, 2018. He was appointed to the Judiciary Mental Health Review Committee by the Chief Justice in 2020.

A 1984 graduate of Seton Hall University, Davison received his Master's Degree in Counseling from Montclair State University in 1990. In addition to his academic credentials, Davison is a Licensed Professional Counselor (L.P.C.).

Lisa Winstel
Chief Operating Officer
Caregiver Action Network (CAN)

Lisa Winstel has served as the Chief Operating Officer of Caregiver Action Network (CAN) for the past 11 years and represents CAN and caregiver issues as an advisor, advocate and speaker. Currently, Lisa serves as the Chair of the Advisory Board for the Patient Experience Policy Forum, as a strategic advisor to the Embracing Carers initiative, and a Board member of the CARIN Alliance, focusing on consumer directed exchange of healthcare data. This past year, Lisa has written about caregiving during the pandemic, penning essays on caregiver grief, caregivers' role in telehealth appointments, pandemic risk management, and how the pandemic may impact caregivers' view of long-term care moving forward. Lisa served on the Curriculum Development Advisory Committee for the Alzheimer's Journey Coordinator certificate program with Rowan University, Camden County College and the Rutgers-Camden Board of Governors. She represented CAN on LEAD (Leaders Engaged in Alzheimer's disease), the Global Council on Alzheimer's disease (GCAD) and represented caregivers for 2 years on the Post-Acute Care /Long-Term Care workgroup of the National Quality Forum's Measure Applications Partnership.

Some of Lisa's accomplishments with CAN have included building a robust Corporate Leadership Council, spearheading annual caregiving inserts in USA Today and securing caregiving PSA's in Times Square. Lisa was the team lead in developing a partnership with Sam's Club to support caregivers and on the launch of a website for family caregivers of loved ones with rare diseases, RareCaregivers.org. Other projects include developing caregiver content for the Veterans Administration's Caregiver Support Program at caregiver.va.gov, fielding multiple caregiver surveys, developing national public relations campaigns around caregiving and representing caregivers on multiple PCORI initiatives.

Lisa has more than twenty-five years' experience as a non-profit executive having served as the chief executive for five different non-profits throughout her career. She has managed four leadership transitions including three founder transitions. She received her master's degree from The Heinz School (then the School of Urban and Public Affairs) at Carnegie Mellon University, where she also earned her BFA. Lisa brings her personal experiences as a sandwich generation caregiver to her role at CAN, having been her mother's caregiver during a battle with a rare cancer and providing hospice care at home for her father during the pandemic.

Josie Cooper
Executive Director, Alliance for Patient Access
PALs United for Movement Disorders Advocate Advisor

Josie Cooper serves as executive director of the Alliance for Patient Access. At AfPA, Ms. Cooper has worked in stakeholder and clinician mobilization, developing policy and educational strategies to improve patient access to care.Ms. Cooper has a background in communications, research, grassroots organization and campaign politics. Ms. Cooper has worked at the state and national level advising political campaigns and public affairs clients on supporter and stakeholder mobilization. She has worked on major races across the country, from presidential campaigns to Senate and congressional races. Prior to joining AfPA, Ms. Cooper worked for a DC-based consulting firm and for a trade association representing biotechnology companies.

Stephen Saklad
Director, Psychiatric Pharmacy & Clinical Professor
The University of Texas at Austin College of Pharmacy

Dr. Saklad was born in Los Angeles, California in 1953, and graduated from Pacific Palisades High School in 1970. He received his baccalaureate degree cum laude in Bacteriology from the University of California, Los Angeles in 1974. His Doctor of Pharmacy degree was earned at the University of Southern California in 1978. He had a National Institute of Mental Health training fellowship in Psychiatric Pharmacy supervised by Jim Wilson, Pharm.D., BCPP at the Nebraska Psychiatric Institute of the University of Nebraska Medical Center at Omaha in 1978-9. He then joined the faculty of The University of Texas at Austin College of Pharmacy and the clinical staff at San Antonio State Hospital (SASH) in 1979. He was the first clinical pharmacist employed by the Texas Department of Mental Health and Mental Retardation (now Texas Health and Human Services) when he began as Clinical Coordinator at SASH. He has lived in San Antonio, Texas since 1979. He is married and the father of triplet sons.

During his 38 years career, Dr. Saklad has provided clinical care, education, and research in a variety of settings and treatment roles at SASH. He team teaches didactic courses for second and third professional year pharmacy students. He is the course director for Advanced Pharmacotherapy Laboratory, a third professional year opportunity for students to develop their clinical presentation skills that is given across four campuses. He precepts and mentors third and fourth professional year pharmacy students (P3’s & P4’s) at SASH. He received the UT Austin College of Pharmacy’s Teaching Award from the Class of 2014. He authored and successfully discussed with members of the Texas Legislature the creation of a clinical research unit at SASH that was funded by the Texas Legislature and jointly governed by the UT Austin College of Pharmacy, UT Health Science Center San Antonio Department of Psychiatry and SASH.

Dr. Saklad initiated and developed the first websites for the UT Austin College of Pharmacy in 1994, the College of Psychiatric and Neurologic Pharmacists (CPNP) in 1997, and the CPNP Foundation in 2015. He helped to design, organize and was a founding member of CPNP when it incorporated in 1998 as well as the CPNP Foundation in 2012. In 2003, he was elected to the Board of Directors of the CPNP for a two-year term. He has served as a member or officer of the CPNP Communications Committee since the creation of CPNP from 1995 to 2011 and was the Founding Senior Editor of the Mental Health Clinician, CPNP’s Open Access journal, from 2011-13. Currently, Dr. Saklad is Treasurer of the CPNP Foundation a member of the CPNP Business Development Committee. He was on the task force that developed The Mental Health Pharmacy Directory to improve patient access. He is the Director of The University of Texas Psychiatric Pharmacy Program. In 1988, he helped to create and has chaired The University of Texas at Austin College of Pharmacy’s Psychiatric Pharmacotherapy Update since 2007.

Dr. Saklad publishes articles and presents to many groups around the country on a variety of pharmacy and mental health-related topics. He edited Psychopharmacology Update newsletter from 1998-2002 and edited two editions of a compendium based upon this newsletter, Psychopharmacology Desktop Reference, published by Manisses Communications Group in 1999 and 2002. He provides updates on his Twitter feed on a variety of topics @pharmacopsych.

Dr. Saklad is a principal or co-investigator for several studies of the efficacy and adverse effects of Phase II, III, and IV psychotropic agents in schizophrenia, mood disorders, depression, and other serious and persistent mental illness, as well as their pharmacokinetics and interactions. He was the Director of UT

Health Science Center San Antonio's Advanced Pharmacotherapy Research with research facilities located at Laurel Ridge Treatment Center and President of Alamo Superior Research, LLC. He has been affiliated with the Behavioral Wellness ("Be Well") Center, Department of Psychiatry, UT Health San Antonio since 2009.

Carlos Larrauri
Clinician | Speaker | Advocate

Carlos A. Larrauri serves on the Board of Directors for the National Alliance on Mental Illness. Diagnosed with schizophrenia at 23 years of age, access to affordable health care, community-based treatments, and early intervention afforded him the best opportunity for recovery. Mr. Larrauri is board certified as a Family Nurse Practitioner and Psychiatric Mental Health Nurse Practitioner and formerly lectured at the University of Miami and Miami Dade College.

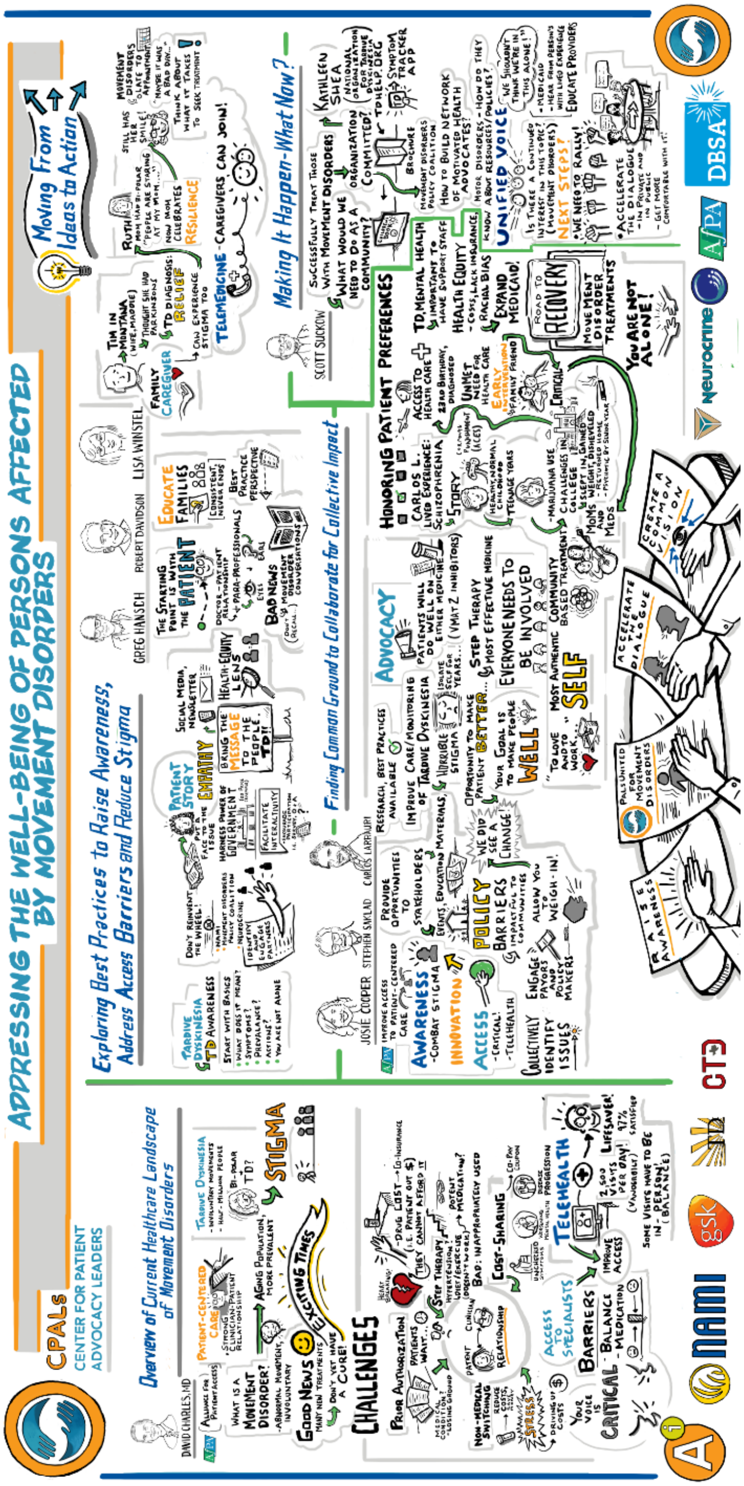
Mr. Larrauri is currently pursuing a law degree and concurrent master in public administration at the University of Michigan Law School and the Harvard Kennedy School as a Zuckerman Fellow. He aspires to interface clinical practice, health policy, and research to reduce health inequities for people living with mental illness. To learn more about Carlos and his work, visit https://www.carloslarrauri.com/ or visit his LinkedIn.

Scott Suckow
Senior Consultant
Perry Communications Group

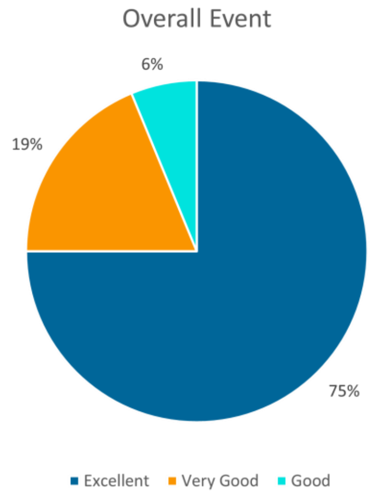
Scott has a long history of involvement in the non-profit community, particularly around improving healthcare access and standards of care. At Perry Communications Group (www.perrycom.com), he uses this experience to build relationships with our alliance partners to identify shared goals with our clients. He has held leadership positions throughout the country with some of the nation's leading voluntary health organizations, including: American Diabetes Association, American Liver Foundation, Huntington's Disease Society of America, International Bipolar Foundation, Mental Health America, and Muscular Dystrophy Association.

Over the course of his career, Scott has provided testimony at the local, state, and federal levels of government and helped draft state legislation. He has served on numerous national, state, and local boards of directors. He was the appointee on three county government level commissions, focused on HIV/AIDS, health & human services, and poverty. Scott was named one of San Diego Magazine's "50 People to Watch," is a LEAD San Diego graduate, received an Outstanding Community Partner Award from Community Health Improvement Partners, and is a Star of Advocacy recipient by California Chronic Care Coalition.

Appendix 4: Graphic recording

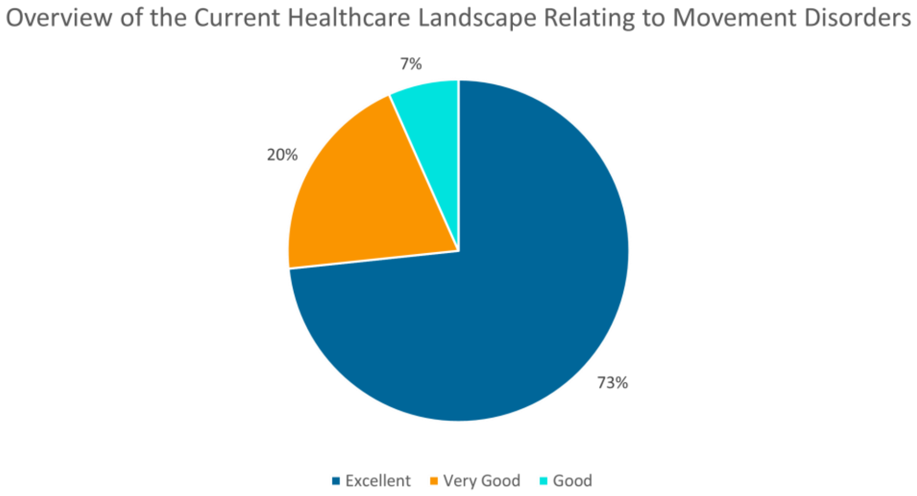


Appendix 5: Event evaluation results


Overall Event

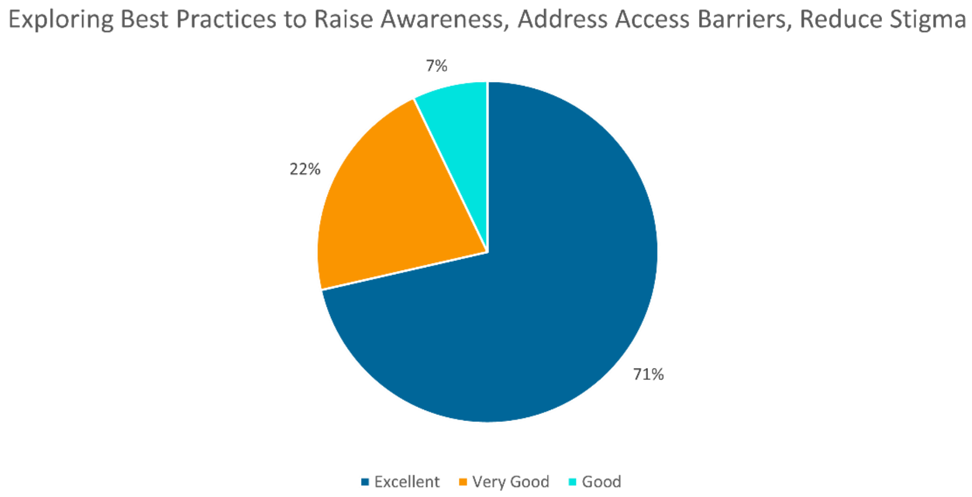
Comments:

- I thought this was a really wonderful, timely event and I appreciate the focus and breadth of expertise represented in this meeting.
- This web meeting brought together dedicated advocates and presenters to address a very important topic. I appreciate all the investment in learning and advocacy ideas.


Overview of the Current Healthcare Landscape Relating to Movement Disorders

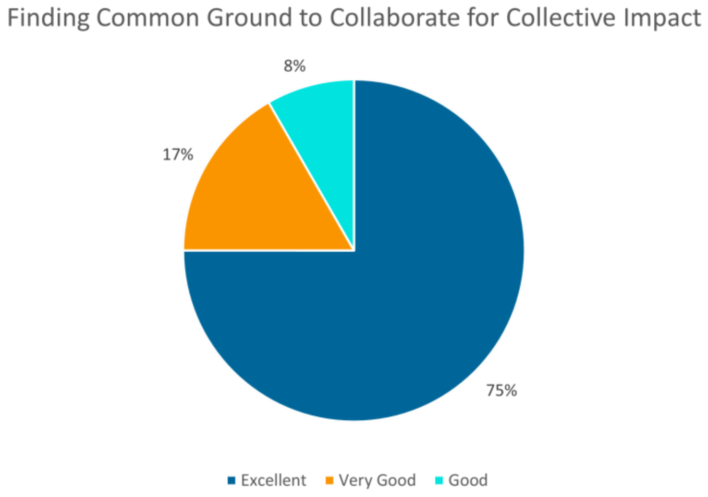
Comments:

- Very good, clear presentation.



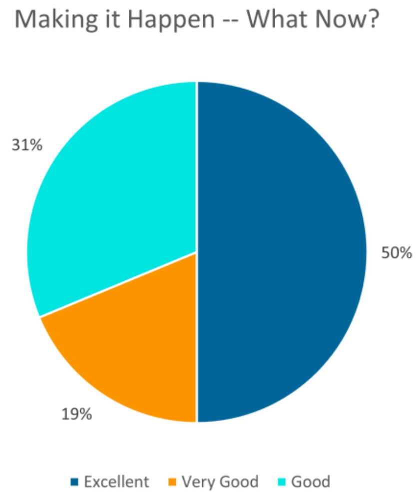
Comments:

- Thank you for valuable information and resources.
- Lisa’s insight was much appreciated.
- Especially liked the resources, examples and discussion about caregivers.
- Good discussion and ideas for educating patients and public.



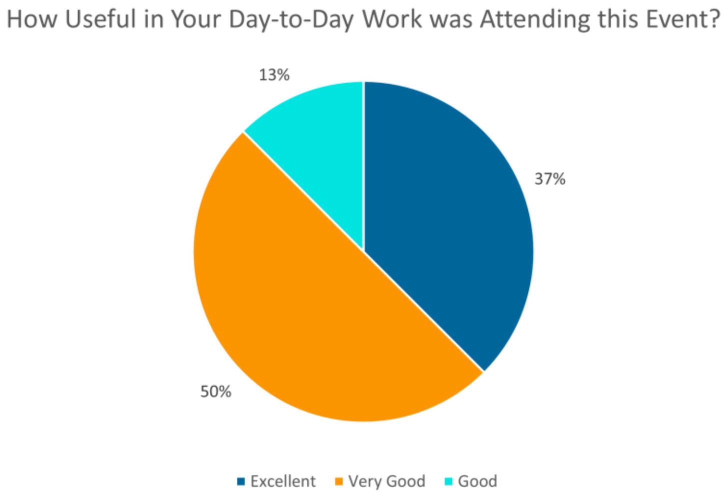
Comments:

- Very valuable to hear from Carlos with his lived experience. Thank you so much!
- Carlos was an engaging speaker and gave a good presentation, but because to my understanding he does not have TD, his presentation didn’t resonate with me.
- This session needed more policy ideas. Carlos Larrauri presented some that could have been expanded upon, especially in next session.



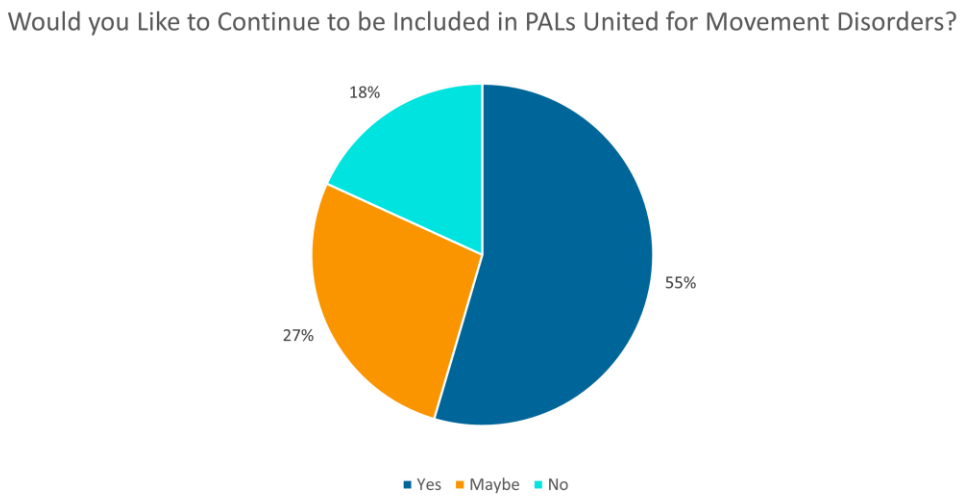
Comments:

- Thank you for bringing all the speakers together in this presentation. Well done.
- Hard to do on Zoom.
- I was hoping there would be more buy-in to move forward. But as moderator noted, looks like more work needs to be done to coalesce an advocacy group together. Many advocates already have full plates and it's hard to take new things on.



Comments:

- There were a number of practical ideas, especially related to education and awareness, that can be used. Policy ideas are much harder to implement and will take more time—but I won't give up.



Comments:

- Thank you for valuable information and resources.
- Lisa’s insight was much appreciated.
- Especially liked the resources, examples and discussion about caregivers.
- Good discussion and ideas for educating patients and public.

Please list specific action(s) you or your organization plan to take as a result of attending this event.

- Our organization is already very actively engaged and will continue to ensure we are able to raise awareness and support for individuals with movement disorders.
- Discuss all the ideas presented to our group and see how we can implement these ideas in our outreach and advocacy work in our community.
- Continue to raise TD and movement disorder awareness. The state resolution idea was also very beneficial and something we will pursue.
- Will incorporate into our work for the future.
- This will help in our next steps - it will help a lot.
- Am contacting some of the presenters with information that might be helpful for them. Have updated some of our information.
- We will be more involved in a advocating for equitable health care.

Please list the best thing about this PALs United event and a suggestion for improvement.

- Seeing all the other NAMI people there and learning the different ways people engage, including the continued barriers to care, was really eye-opening.
- Diversity of speakers and patient stories. Well balanced!
- Always appreciate bringing more diverse perspectives to the conversation - something to aim for
- next time! Really good program.
- The music was a great addition to a Zoom! I enjoyed hearing from colleagues. And I can't wait to meet in person once again.
- Great meeting moderation!
- The presentation on the different barriers to accessing prescription medicine.
- Best speakers were Dr. Charles and Josie Cooper. While it’s difficult to find a patient who is an experienced speaker, that would have been an asset.

Appendix 6: Resources

Overview of the Current Healthcare Landscape Relating to Movement Disorders

- Slides shared by David Charles, MD

Exploring Best Practices to Raise Awareness, Address Access Barriers, and Reduce Stigma

- Slides shared by Greg Hansch

Supplemental materials:

- Caregiver Action Network
- Information about the Mental Health Parity Awareness designation in TX (Link shared by Greg Hansch)
- If you want to share your caregiver stories, please email Lisa Winstel at LWinstel@caregiveraction.org

Finding Common Ground to Collaborate for Collective Impact

- Slides shared by Carlos Larrauri

Supplemental materials:

- www.fogdogmusic.net
- https://www.youtube.com/watch?v=dBdPPHrdZ7w
- https://www.movementdisorderspolicy.org/

Making it Happen – What Now?

- Link mentioned: htpps://tdhelp.org/