



CENTER FOR PATIENT  
ADVOCACY LEADERS

NAMICON  
TOGETHER FOR MENTAL HEALTH

# Tardive Dyskinesia Education Grant Networking Session



*Generously hosted by*



CENTER FOR PATIENT  
ADVOCACY LEADERS

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NEUROCRINE<sup>®</sup>  
BIOSCIENCES



**PALs  
UNITED**

Patient Advocacy Leaders  
United for Movement Disorders

# Agenda

**NAMICON**  
TOGETHER FOR MENTAL HEALTH

## Tardive Dyskinesia Education Grant Networking Session



5:00 – 5:25 PM

*NSO/NA Networking*

5:25 – 6:05 PM

*Best Practices, Lessons Learned,  
Next Steps and Q&A*

6:05 – 6:30 PM

*NSO/NA Networking*

# Center for Patient Advocacy Leaders (CPALs)

- ❖ **An outgrowth of the Patient Advocacy Leaders Summit (PALS) started in 2002, CPALs formed in 2016 working in a collaborative agreement with The AIDS Institute**
- ❖ **Collaboration with advocacy leaders to implement programs at the national and state levels**
- ❖ **Guided by Health Advocate Advisors, By Advocates, For Advocates**
- ❖ **PALs United for Movement Disorders launched in 2021 to address TD awareness**
- ❖ **3 events conducted in 2021-2022; advocacy report produced with focus on future education/advocacy and advocacy work**
- ❖ **3 convenings planned for 2023**
  - ✓ **2023 TD Grant Orientation (March 22)**
  - ✓ **NAMIcon Networking Session (May 26)**
  - ❑ **Mental Illness Awareness Week (October 1-7) – Date TBD**

# Why TD Grants

**Year Initiated:** 2021

**Why:** Despite affecting ~600k people in the US, alone, TD has lacked the public awareness, it deserved. Those living with TD have often felt alone, embarrassed, and judged, while dealing with their condition.

**NAMI Families:** Often loved ones experienced TD; interest in doing something about it; Education, Advocacy and Support

**Funding Source:** Neurocrine Biosciences, Inc.

**Purpose:** To increase awareness and education about TD, its impact on individuals and treatments available.



The image is a screenshot of a social media post from NAMI. At the top left is the NAMI logo, which includes a blue circle with a white '4' and the text 'NAMI'. To the right of the logo, it says 'Published by Sprout Social [?] · May 8 at 9:25 AM · 3'. Below this is the main text of the post: 'This week is Tardive Dyskinesia Awareness Week. Raven's story is just one of the many reasons we need to improve medications and treatment for those with symptoms of psychosis.' The central part of the post is a dark blue box with white text that reads: '“My symptoms progressed from me gently rubbing my leg to thinking there were moths in my house because I had actually rubbed holes through the fabric in my shirts.”'. The phrase 'rubbed holes through the fabric' is highlighted in a green box. At the bottom left of the post, it says 'NAMI.ORG' and 'Facing Tardive Dyskinesia'. Below that, it starts a sentence: 'Getting diagnosed with TD was a watershed moment for me. It broug...'. There is a small white circle with a lowercase 'i' in the bottom right corner of the post area.

# **Building a TD Awareness Community - Objectives:**

- **Facilitate interactive dialogue among Networking Session participants to stimulate new approaches and ideas to further enhance TD awareness and education**
- **Illustrate best practices for TD awareness and education that have been successfully used by previous grantees**
- **Highlight ways to integrate TD awareness and education into the ongoing NAMI programs and organization for more sustained awareness and education**
- **Explore future collaborative partnerships and opportunities (i.e., Mental Illness Awareness Week/October 2023)**

# CPALs Advocate Advisors

★ **Krystian Clayton** – NAMI on Campus, NAMI Kentucky

★ **Todd Donovan** – President, NAMI New Hampshire

★ **Athena Kabylafkas** – Finance Director, NAMI Colorado

★ **Ray Merenstein** – Executive Director, NAMI Colorado

★ **Ann Ringstad** – Executive Director, NAMI Alaska

★ **Matthew Shapiro** – Senior Director, Government Affairs, NAMI New York State

★ **Leslie Stoyer** – Executive Director, NAMI Summit County Ohio

# Growth of NAMI TD Grants:

## 2021

\$144,000

12 NAMI State Orgs, 21 NAMI Affiliates

## 2022

\$305,000

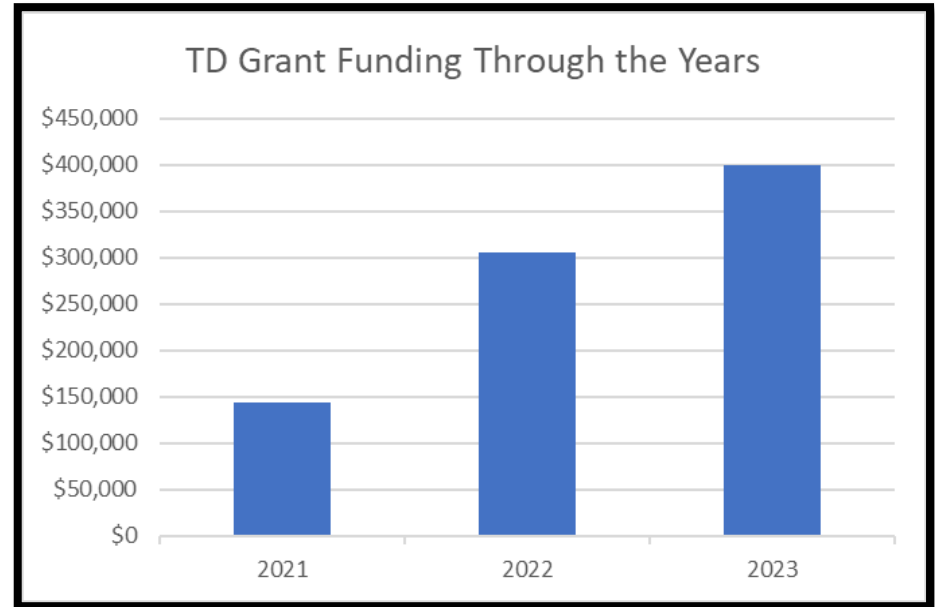
40 NAMI State Orgs, 40 NAMI Affiliates

## 2023

\$400,000 (each site receiving \$5K)

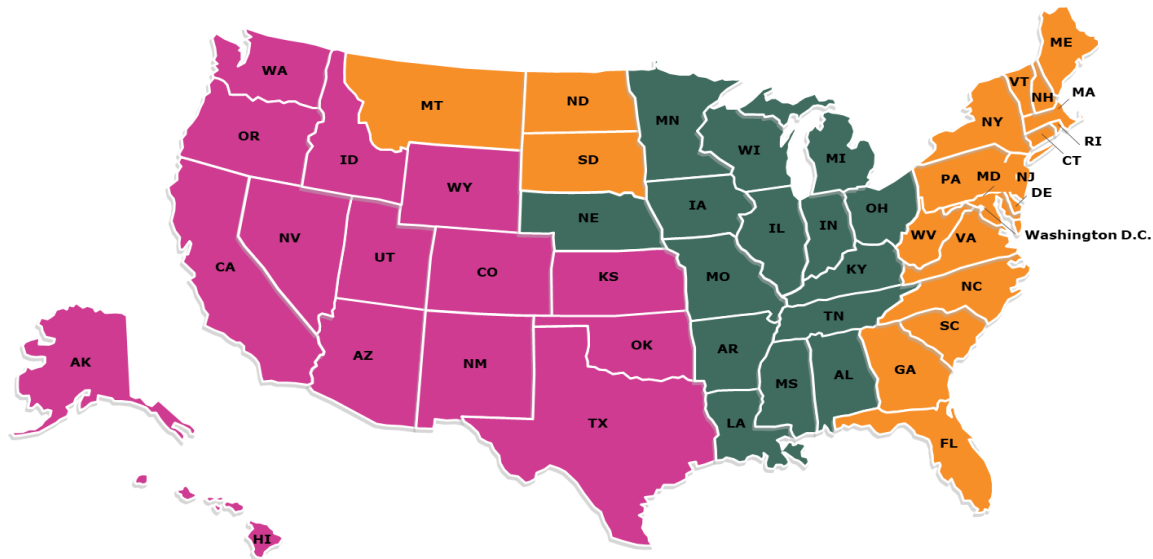
20 NAMI State Orgs, 60 NAMI Affiliates




46 repeat awards



**TDAW and ongoing TD educational activities are now implemented in all 50 States + D.C.**

# Neurocrine Partners



| Neurocrine Regions  |                           | Regional Staff   | Email  |
|---|---------------------------|------------------|--|
|  | West                      | Donna Erwin      | <a href="mailto:derwin@neurocrine.com">derwin@neurocrine.com</a>       |
|  | Central                   | Suzanne Robinson | <a href="mailto:srobinson@neurocrine.com">srobinson@neurocrine.com</a> |
|  | East + Upper Great Plains | Chuck Harman     | <a href="mailto:charman@neurocrine.com">charman@neurocrine.com</a>     |



# Tardive Dyskinesia Toolkit & Resources



# Implementing a TD Awareness Program

## Experiences from the Field

★ **Leslie Stoyer – Executive Director, NAMI Summit County Ohio**

★ **Ray Merenstein – Executive Director, NAMI Colorado**

★ **Matthew Shapiro – Senior Director, Government Affairs, NAMI New York State**

# Q & A

# You Are Not Alone

- ❖ **An experienced network of NAMI Leaders throughout the US to help enhance implementation and sustainability of TD Education & Awareness Program**
- ❖ **Available resources for implementing a TD Education & Awareness Program**
- ❖ **Technical assistance available from NAMI National and Affiliate colleagues**
- ❖ **Help from Neurocrine Biosciences & CPALs partners in preparing for TD Awareness & Education activities, during TDAW and throughout the year**
- ❖ **National Organization for Tardive Dyskinesia (<https://tdhelp.org>)**

# CPALs Advocate Advisors & Partners

- ★ **Krystian Clayton** – NAMI on Campus, NAMI Kentucky
- ★ **Todd Donovan** – President, NAMI New Hampshire
- ★ **Athena Kabylafkas** – Finance Director, NAMI Colorado
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- ★ **Matthew Shapiro** – Senior Director, Government Affairs, NAMI New York State
- ★ **Leslie Stoyer** – Executive Director, NAMI Summit County Ohio
- ★ **NAMI National Staff**
- ★ **Neurocrine Biosciences Partners**



# THANK YOU!



# Networking