

# Connection RX

The Social Health

Prescription for Chronic Illness



# BROKEN SYSTEM

**KNOW HOW TO MAKE YOURSELF INVISIBLE?**

*Walk into the average doctor office*

**80% OF RARE DISEASE PATIENTS**

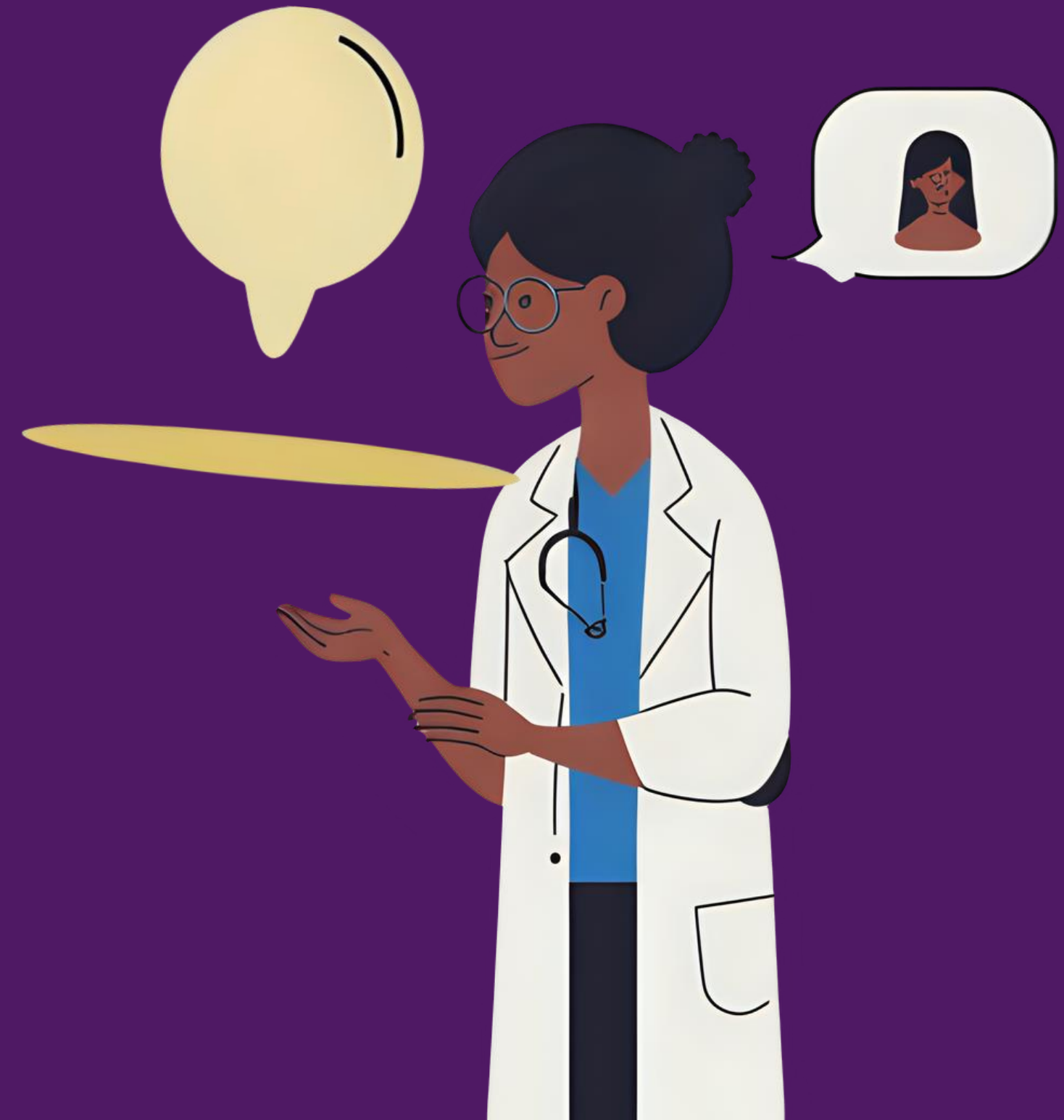
*Experience at least one misdiagnosis (dx)*

**CHRONIC ILLNESS PATIENTS WAIT**

*Average of 12–14 yrs correct dx (per research)*

**HEDS PATIENTS AVERAGE WAIT**

*20+ years (per patient data)*



# I BELIEVED I JUST NEEDED A DX

The biggest missing prescription in chronic illness care isn't another medication...  
**it's connection!**

**Isolation** common in chronic illness can hurt us.  
Discuss how to turn to each other for health & healing –  
no copay required!



# ATTENTION ECONOMY STEALING FOCUS



Online habits and  
time spent on phones



Anxiety about going  
out into the world



Average person checks  
their phone 344 x day  
= more than 6.5 hours of 16  
waking hours



# TEXTING IS EVERYDAY INTIMACY

This morning I texted my friend: "Hi! How are you?" "Good!  
Busy! You?" she replied.  
"Same!" I typed.

We have had this exact text exchange about 1,473,502  
times.

Sometimes we talk by phone... if the matter is serious.  
We Zoom if we're feeling ambitious...and took a shower.  
But mainly we text. Constantly.

Little digital burps of pseudo-connection floating through  
space. Beep-boop. Friendship achieved.

**This is friendship in 2025.**

Ask your doctor if it's right for you.  
Side effects may include persistent hollow feelings, and the  
nagging sense that something essential is missing.  
Unfortunately, this passes for intimacy now.

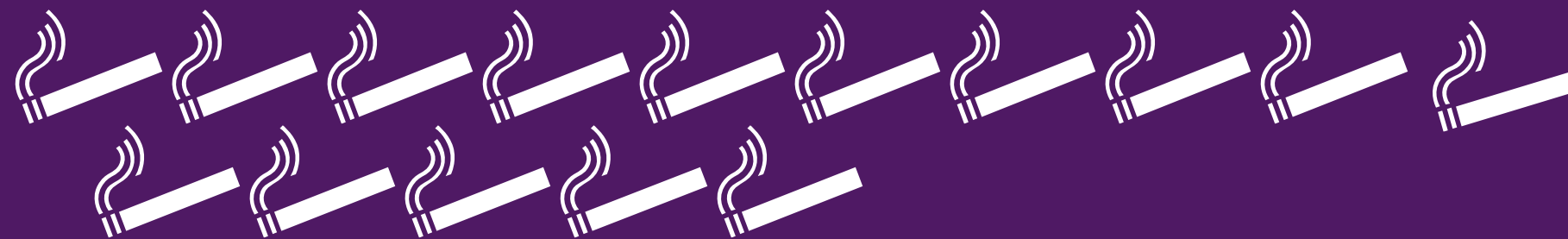
# SHOCKING STATS

1:3  
PTSD



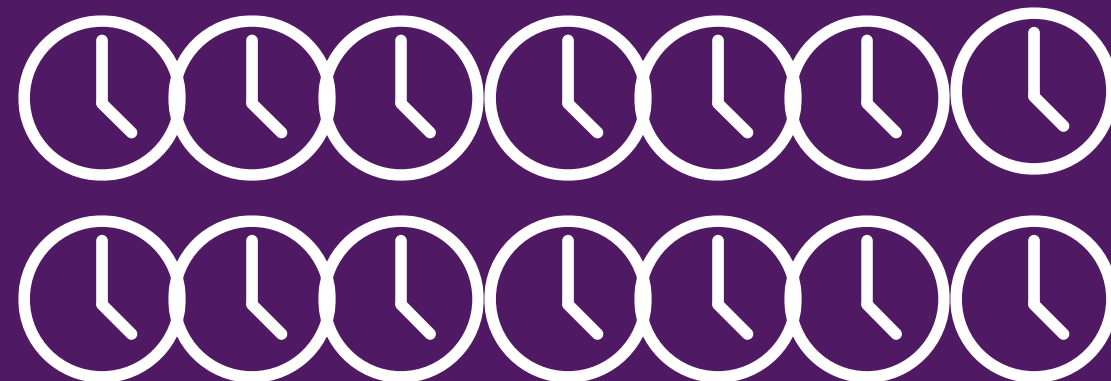
TOO  
OFTEN  
DISMISSED

15 CIGS  
DAY



UNHEALTHY  
HABITS NOT  
EVEN  
AWARE OF

14 MINS  
TO STOP  
BEHAVIOR



RETURN BRINK  
OF DESPERATION

US Surgeon General report on Loneliness Epidemic 2023



# ASK YOURSELF:

## QUIZ: Are you socially isolated?

Research suggests that having few close friends, no partner, and no group affiliations indicates social isolation. Answer the following questions, culled from a variety of questionnaires developed by researchers, to see if you might fit the criteria for someone who is socially isolated. But remember: the number of friends you personally need may be more or less than what other people need to feel well and thwart loneliness.

I have one or more close friends and relatives to whom I can talk about personal matters, who provide emotional support, and who help me make difficult decisions.	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I see my close friends and relatives at least once a month.	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I can call my close friends and relatives whenever I need to.	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I see friends and relatives as much as I would like to.	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I rarely feel lonely or left out of social gatherings.	YES <input type="checkbox"/>	NO <input type="checkbox"/>
I belong to a group that brings me pleasure, such as a community or religious group, self-help group, volunteer group, or sports group, and I attend meetings regularly.	YES <input type="checkbox"/>	NO <input type="checkbox"/>

## ► What factors put you at risk for loneliness?

One 2022 article, published in the journal *Nature Reviews Psychology*, reviewed the scientific literature on loneliness and singled out the following risk factors:

- a tendency to introversion
- emotional instability
- old age (mostly due to widowhood, illness, and poor mobility)
- being unemployed
- having a low income
- recently moving to a new place or starting a new job
- living alone
- poor health and mobility
- being single, divorced, or widowed
- having a small social network
- having low-quality relationships.

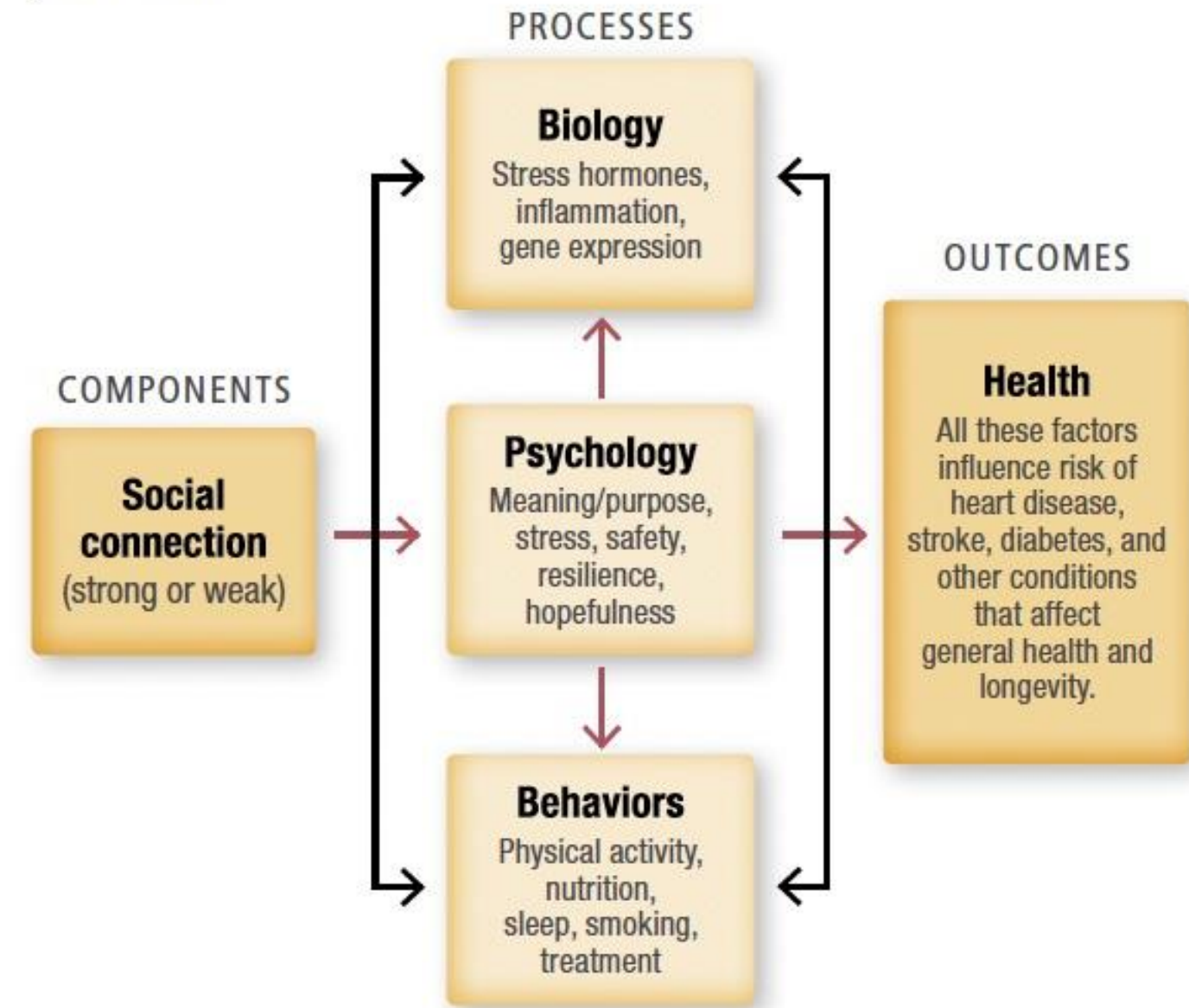


# IMPACT

AAPR 2017 report  
found that social  
isolation among  
older adults  
accounts for an  
extra \$6.7B in  
Medicare spending  
annually

## Figure 3: How your degree of social connectedness influences your health and well-being

The strength—or weakness—of your social network can influence biological, psychological, and behavioral factors related to your health.



Source: Adapted from Our Epidemic of Loneliness and Isolation: The U.S. Surgeon General's Advisory on the Healing Effects of Social Connection and Community (2023), based on Holt-Lunstad J. "The Major Health Implications of Social Connection," *Current Directions in Psychological Science* (June 2021), Vol. 30, No. 3, pp. 251–59.



# TURNING IT AROUND



- Take the initiative. Introduce yourself to new people even if it feels awkward. If you stand in a corner by yourself, you send out signals that you're not approachable.
- Be the planner—decide on an event or activity and then invite others to join you.
- Block out two or three days a week or several days a month to socialize with friends.



# ADULT FRIENDSHIP RULES

Mel Robins 'Let Them Theory' on why friends fade 3 reasons

**1. Timing** – Different life paths, having kids, life events different timeframes distance us

**2. Proximity** – Out of sight, out of mind. Not living nearby, not seeing at work

**3. Energy** – Some don't have capacity for the relationship effort

Just what the doctor ordered lesson...

**Let them go. Prioritize people who show up.**



# THE 3 PILLARS OF HEALING CONNECTIONS CHRONIC ILLNESS



## Medical

Finding providers who  
actually listen.

## Community

Finding other people  
who get it.

## Personal

Learning to trust your own  
intuition. Forgiving yourself and  
your body for betrayal.  
**Learning self-advocacy skills.**



# SOCIAL HEALTH

Red flags to watch for:

1. Dismissive doctors who tell you “it’s all in your head”
2. Friends/loved ones who ghost when you’re no longer ‘fun’
3. Social media doomscrolling that fuels anxiety, fear



The wrong people  
will make you  
sicker.

The right people  
will help you heal!

Find people who  
lift you up and fill  
your cup.

# PRIORITIZE INTENTION VS ATTENTION



We don't need more  
\*time/energy\*—we need  
more intention to be more  
present with what we have



Attention is passive,  
sucked in without your  
true will



Intention is proactive  
presence, to cherish

# THE STEPS TO BUILDING CONNECTION



## Audit Your Cirlce

Who fills your cup?  
Who drains it?  
Prioritize fullness!

## Activate Lo-Fi Hacks

Small actions that keep  
relationships alive, more  
on that momentarily

## Take the Connection Challenge

One meaningful touchpoint  
per day with these ideas...



# CONNECTION RX: SOCIAL HEALTH PRESCRIPTION IDEAS



Get the full list



## Connection RX

### 20 Social Prescription Ideas for Enhanced Health With Chronic Illness Isolation

- **Send a T-O-Y Text**

No, not a stuffed bear. Just a quick “Thinking of You” message that says, “Hey, I’m still alive and moderately functional. You good?”

- **Scroll to the Bottom of Your Messages**

Like digital archaeology. Unearth that ghosted convo from 2022 and revive it with: “Hey, I didn’t die—just had a few organ-level malfunctions.”

- **Voice Note Instead of Text**

You sound adorable. Let them hear your real voice instead of assuming you’re ignoring them because you hate them. (You don’t, right? Ghosting hurts!)

- **Send a Ridiculous Meme**

Nothing says “I love you” like a screaming possum in a wheelchair wearing sunglasses. Bonus points if it relates to pain, flares, or MyChart rage.

- **Make a “Couch Connection List”**

Start a note of people who don’t drain your soul. Text one a week. You don’t need a spreadsheet. Or maybe you do. We support neurodivergent coping.

- **Use the “React” Button**

Low energy? Just ❤️ their message like a cryptic breadcrumb that says “I’m alive, and your existence matters, but typing is too hard today.”

- **Book a ‘Flare Zoom’**

Lay flat. Pajamas encouraged. Camera optional. Call it “Horizontal Hangout Therapy.” No small talk. Just vibes or rants. Extra points for sharing your MRI images.

- **Forward a Link with Zero Context**



# ASKING FOR HELP AND NOT FEELING LIKE BURDEN

- Foster compassion from others and give it to yourself a permission slip
- Instead of saying the hard words to choke out “I need help,” try:

“Would you be up for keeping me company on this rough day?”

“Would you send me funny memes? I’m feeling off”

“I don’t have energy for a long convo, but I’d love a quick chat check-in”

“Are you crushed by the weather changes today too?”

# YOUR NEW RX: CONNECT



## TAKE DAILY AS NEEDED

One small intentional connection. Refer to list of ideas on brain fog days when you don't know how.

## REFILLS UNLIMITED

Social health is a lifelong treatment you should invest in for increased longevity, health and happiness.

## SIDE EFFECTS

Feeling seen, heard, and supported.

Improved health outcomes may include: joy, laughter, mutual compassion and understanding



# IT DOESN'T END WITH THE CONFERENCE

You don't have to lose that feeling when the event ends!  
The community you crave can go with you!



# PATIENTS NEED INFO & CONNECTS

**Patients are finding purpose in paying it forward.**  
Some are scientists and researching searching for answers. Some are leading boards and running support groups. Others curate content and call people who need a helping hand.



You can join in to find a new way to pay it forward!  
**The Connective Club** part of the  
**EDS JOINT EFFORT**

**LIVE NOW**



EDS Joint Effort



The best of EDS related credible medical and social support information you can trust to learn about any stage in the EDS diagnostic journey. Guided tours!

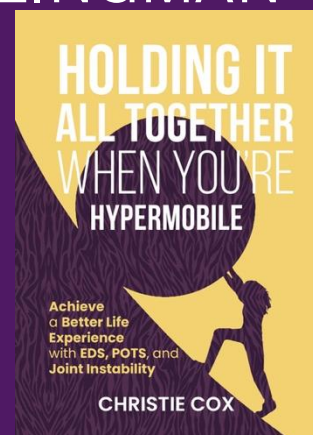
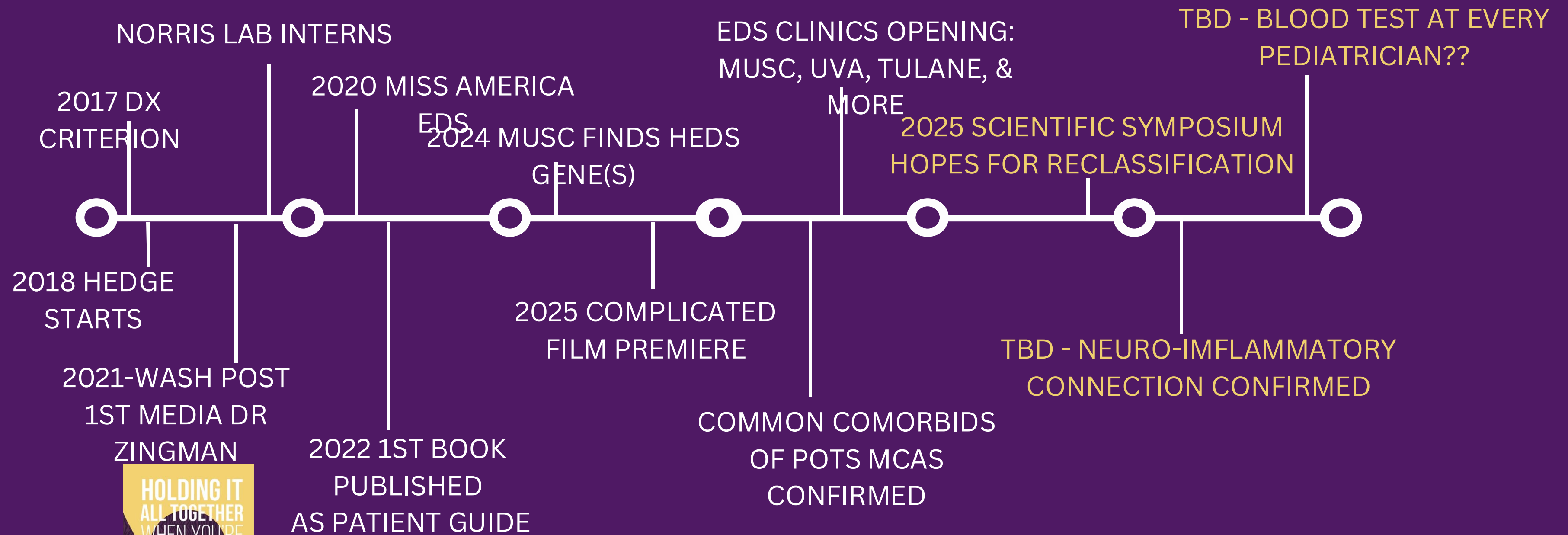


Decades of deep research collaboratively gathered by and for the EDS patient community. Open access to new research alerts, shorts of expert doctor webinars, YouTube recents and much more.



Dynamically growing every day. **EDS411 Living Library** plus courses on hope for hypermobility, the best of podcasts, books and resources to navigate. A great single-source to send those seeking help.

# INSPIRATION IGNITES PASSION & PURPOSE = **HEDS HAS HOPE**



**QUESTION: CAN NONPROFITS, PROVIDERS & PATIENTS  
COME TOGETHER TO COLLABORATE SOLUTIONS?  
AN EDS JOINT EFFORT IS BORN!**



# CALL TO CONNECT CHALLENGE

For the next 7 days, reach out to one person per day:

- Whether it's a text, a voice memo, or just a simple TOY 'thinking of you'
- Exchange numbers with 3 people at this conference, commit to staying connected
- See how it changes your energy, your mood, and your sense of support
- Chronic illness isn't just about what's happening inside your body and your mind—it's about what's happening around it. And when you change your connections, you change your care.

## **Connection can be the cure!**

Maybe its not just loneliness, but feeling invisible that can harm. Stop your disappearing act!

**STOP STRUGGLING SOLO. FIND YOUR PEOPLE. FIND YOUR POWER.**

# REFERENCES

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**MESSY PRESENCE > PERFECT  
ABSENCE.**

**You're not a burden. You're a  
beacon FOR THE RIGHT PEOPLE.**

*Let's do coffee talk!*



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