



# Prevention in Focus Webinar Series

**Welcome!**  
**We will begin shortly.**

# Prevention in Focus Webinar Series

## Is It More than PMS? Learn About PMDD



**Marybeth Bohn**

International Association for Premenstrual Disorders



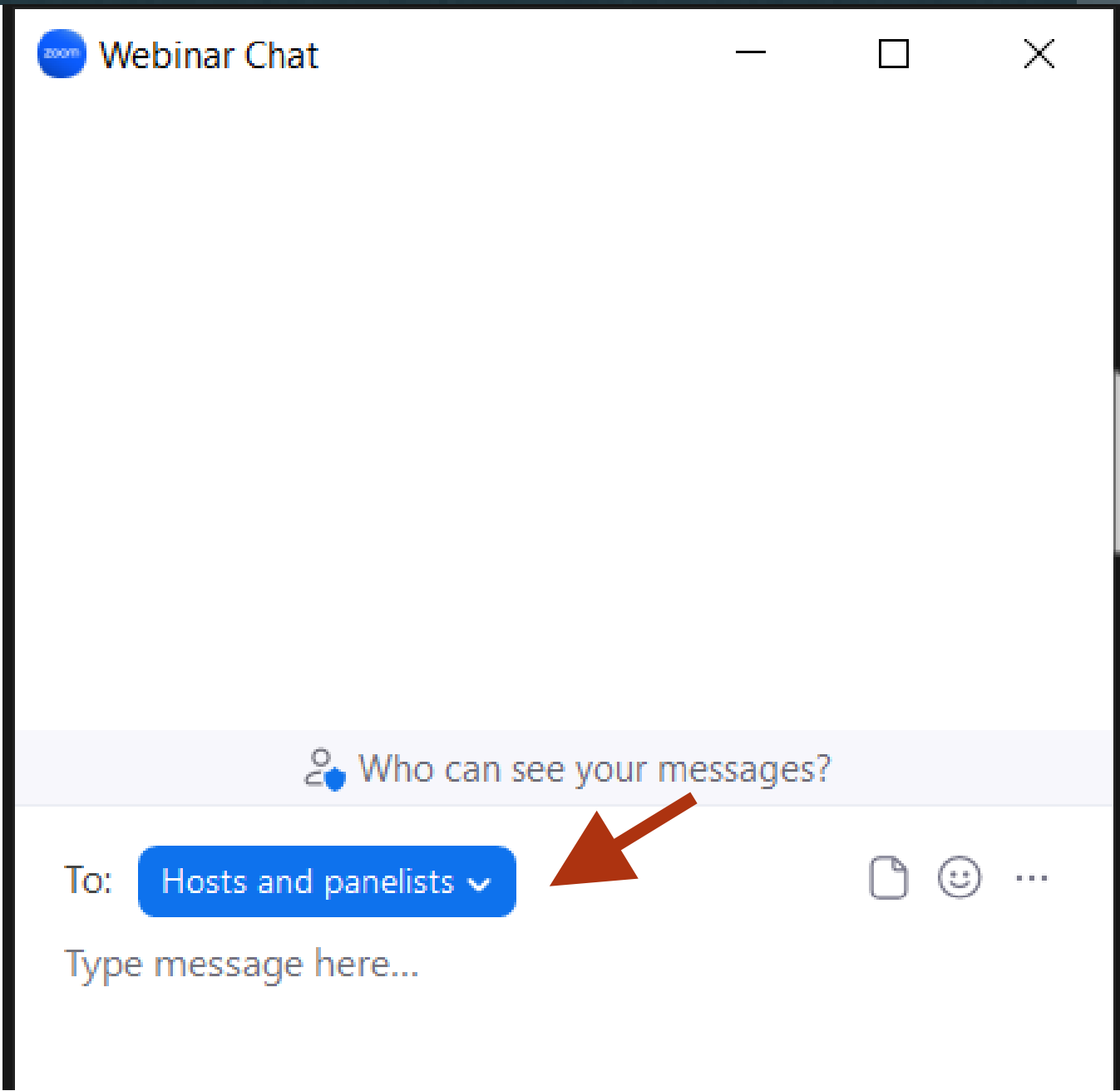
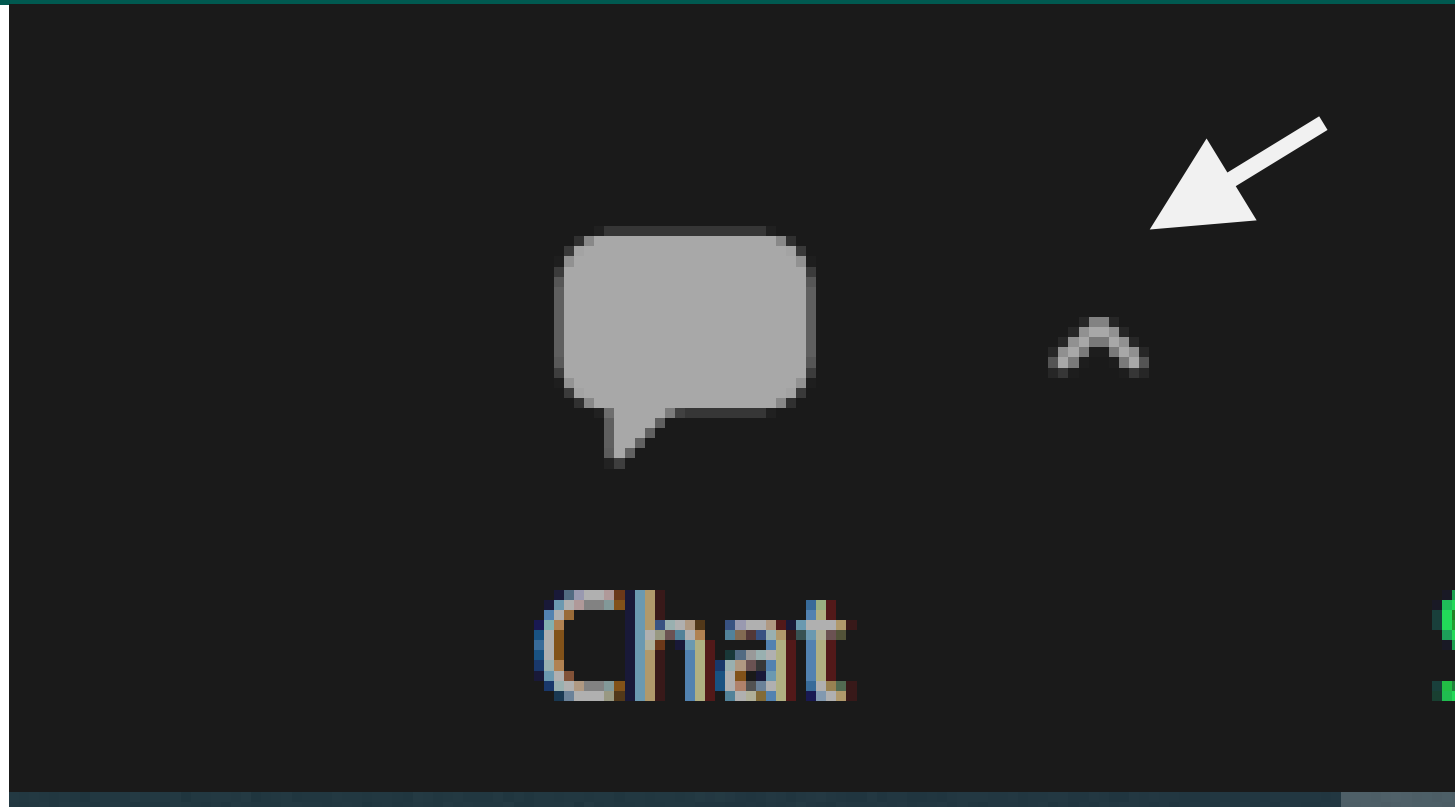
**Sandi MacDonald**

Co-Founder & Executive Director

International Association for Premenstrual Disorders

Introduction by: Andrea Wijtenburg, Ph.D.  
*NIH National Institute of Mental Health (NIMH)*

# Prevention in Focus Webinar Series



## Upcoming Q&A Session

**Please send us your questions  
via the **Chat pod** directed to  
**Hosts and Panelists****

Please use the Chat pod to request technical assistance

# Prevention in Focus Webinar Series

## Is It More than PMS? Learn About PMDD



**Marybeth Bohn**

International Association for Premenstrual Disorders



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**Introduction by:** Andrea Wijtenburg, Ph.D.  
Chief, Brain Circuitry and Dynamics Program  
*NIH National Institute of Mental Health (NIMH)*



# Is It More Than PMS? Learn About PMDD

NIH Prevention in Focus Webinar

March 27, 2024

Honored to be here



Sandi MacDonald  
IAPMD Executive Director  
and Co-founder



Marybeth Bohn  
IAPMD Board of Directors  
and Mother of Christina  
Elizabeth Bohn

# Disclosure



Sandi MacDonald

Marybeth Bohn

*I have NO financial disclosures or conflicts of interest in relation to this presentation.*



## Who is IAPMD?

- \* **Patient-Founded** - in 2013 by Sandi MacDonald & Amanda LaFleur
- \* **Patient-Led** - lifeline of support, evidence-based information, and resources for women/AFAB with Premenstrual Dysphoric Disorder (PMDD) and other Premenstrual Disorders (PMDs)
- \* **Patient-Focused** - Helped over a million people from more than 100 countries find answers, community, and hope
- \* **Patient Voices** - The leading voice in the PMDD community

*Support. Information. Resources.*



# Objectives

- \* To help you gain a deeper understanding of premenstrual conditions
- \* To bring the PMDD experience to life through first-hand experiences
- \* To generate “lightbulb” moments
- \* To inspire action



# Prevention

- \* NOT AN OPTION (at this time)
- \* Suspected cellular disorder
- \* May be some genetic influence
- \* Some studies suggest it is a combination of genetic factors and environmental factors
- \* Risk factors: family history of PMS/PMDD, depression, postpartum depression, or other mood disorders
- \* Awareness is critical
- \* Symptom management can help



# Is it PMS or PMDD?



<b>PMS</b>	<b>PMDD</b> <b>Severity &amp; Emotionality</b>
Normal set of physical (and sometimes mild emotional) symptoms	Severe, life-impairing emotional symptoms (and sometimes also physical symptoms) including depression, anxiety, mood swings or rejection sensitivity, and anger/irritability.
Symptoms occur in the week before menses onset	Symptoms occur anywhere from 1-2 weeks prior to menses onset
Usually doesn't cause much, if any, life disruption	Very disruptive to life and relationships; Typically requires medical management, prescription medication, including antidepressants

# PMDD



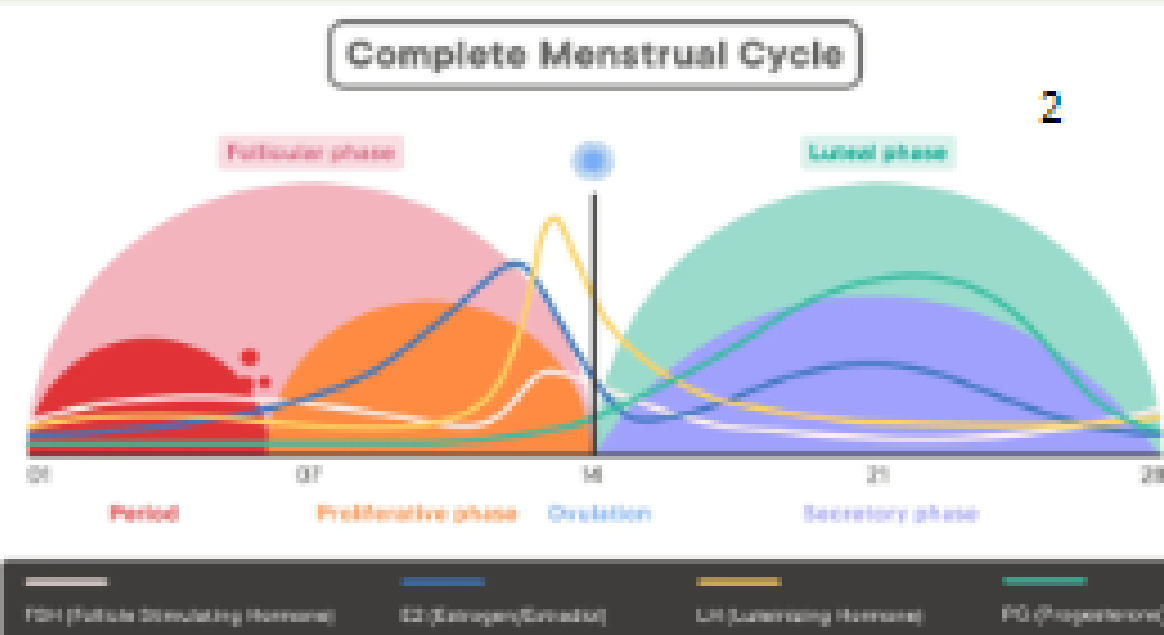
Premenstrual Dysphoric Disorder (PMDD) is a **cyclical, hormone-based mood disorder** with symptoms arising during the **premenstrual, or luteal phase** of the menstrual cycle and **subsiding within a few days of menstruation**.<sup>1</sup>

A **severe negative reaction** to the natural rise and fall of estrogen and progesterone each month between ovulation and menstruation.



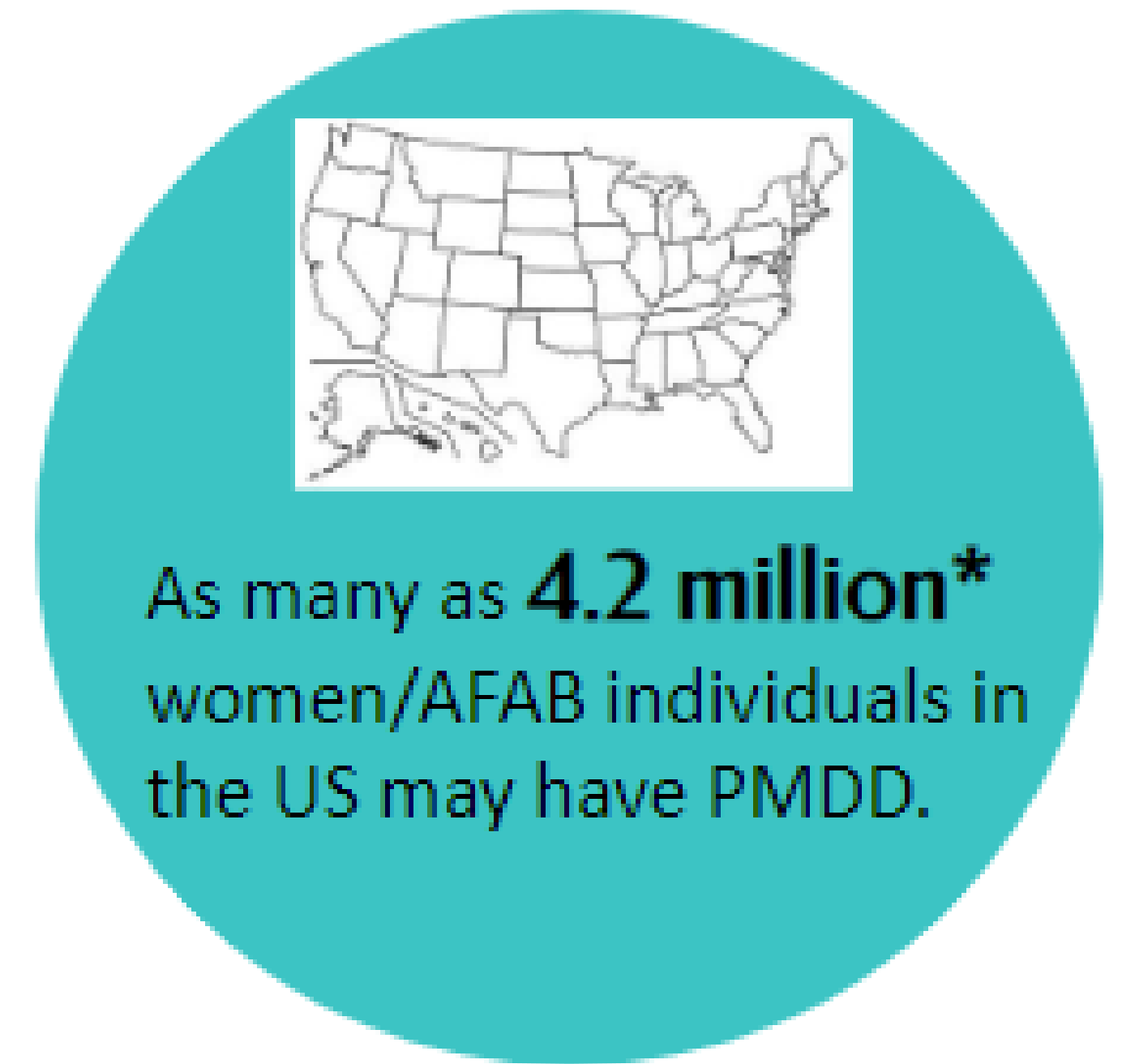
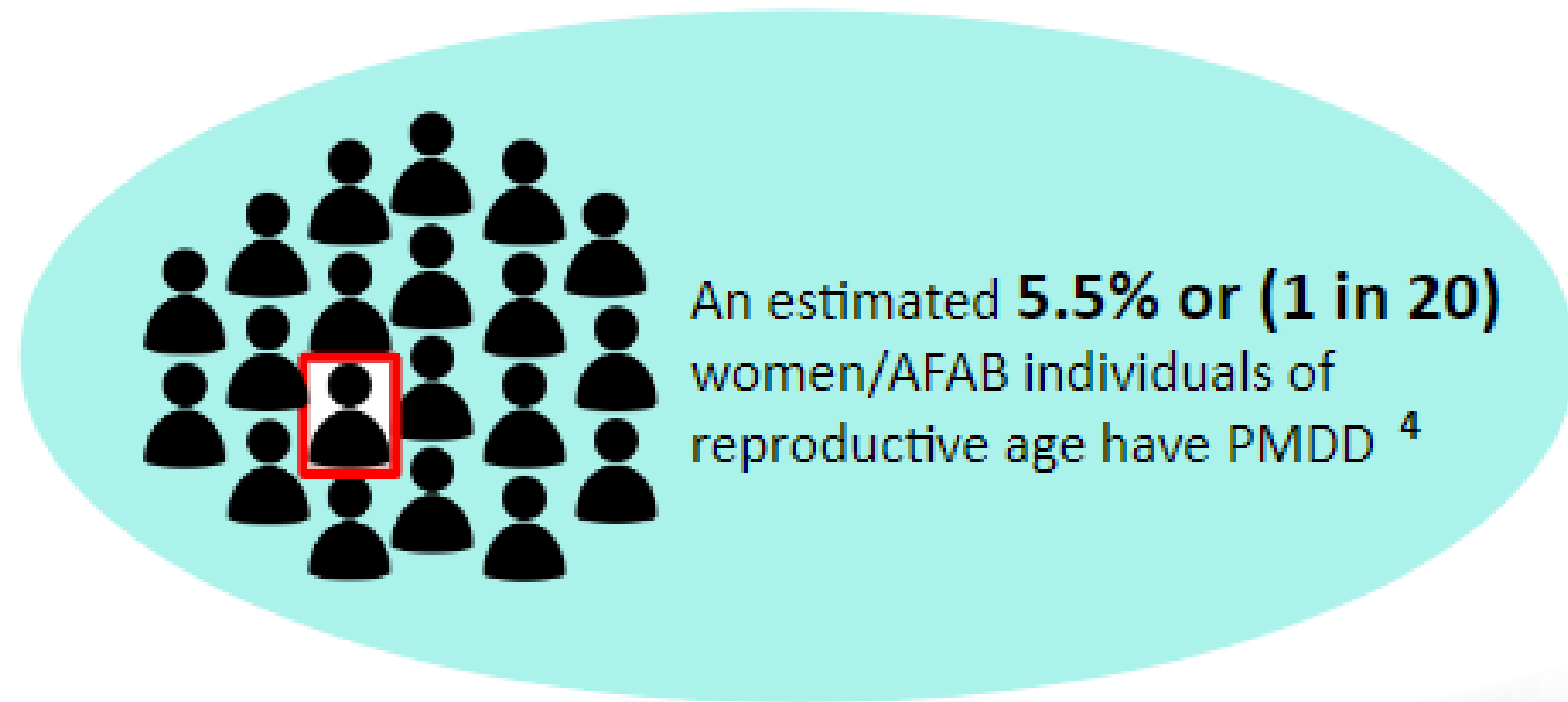
It is a **suspected cellular disorder** in the brain. Symptoms can worsen over time and/or around reproductive events.

- ✓ The first period
- ✓ Pregnancy
- ✓ Birth
- ✓ Miscarriage
- ✓ Perimenopause



While PMDD is directly connected to the menstrual cycle, **it is not a hormone imbalance.**

| 1 in 20!



Underdiagnose  
Misdiagnosed



\*824,000 in the UK; 475,000 in Canada; 328,000 in Australia; 19,700 in The Netherlands; 1.3 million in Japan; 20 million in India

# An official diagnosis worldwide

- \* PMDD was added to the **DSM-5 in 2013** as a depressive disorder. Previously, PMDD was included in the appendix of the DSM as a condition for further study. The symptoms of PMDD are remarkably similar to those of Major Depressive Disorder (MDD).
- \* PMDD was added to the **ICD-11 in 2019** as a disease of the genitourinary system, cross-listed as a depressive disorder. This classification helped to validate PMDD as a legitimate medical diagnosis worldwide.

# PMDD Symptoms (DSM-5)



In the majority of menstrual cycles, at least **five** symptoms below must be present in the final week before the onset of menses, start to improve within a few days after the onset of menses, and become minimal or absent in the week postmenses.

*At least ONE of the following core emotional symptoms (**in bold**) MUST be present*

- \* **Marked depressed mood, feelings of hopelessness, or self-deprecating thoughts.**
- \* **Marked anxiety, tension, and/or feelings of being keyed up or on edge.**
- \* **Marked affective lability (e.g., mood swings; feeling suddenly sad or tearful or increased sensitivity to rejection).**
- \* **Marked irritability or anger or increased interpersonal conflicts.**
  
- \* Decreased interest in usual activities (e.g., work, school, friends, hobbies).
- \* Subjective difficulty in concentration.
- \* Lethargy, easy fatigability, or marked lack of energy.
- \* Marked change in appetite; overeating; or specific food cravings.
- \* Hypersomnia or insomnia.
- \* A sense of being overwhelmed or out of control.
- \* Physical symptoms such as breast tenderness or swelling, joint or muscle pain, a sensation of “bloating,” or weight gain.

# Difficult to diagnose

- \* No blood test
- \* A diagnosis of PMDD requires the presence of at least five "emotional symptoms" as included in DSM
- \* The use of oral contraceptives suppresses natural ovulation, which makes it impossible to diagnose PMDD
- \* To confirm the diagnosis, two months of daily symptom ratings are recommended to differentiate between PMDD, PME, and non-cyclical symptoms.
- \* Diagnostic resources are available at [iapmd.org/provider-resources](https://iapmd.org/provider-resources).



# Limited treatment

- \* Complex
- \* Every patient is unique - no “one size fits all”
- \* Evidence-based therapies: SSRIs, oral contraceptives, GNRH Analogues, total Hysterectomy with Bilateral Salpingo-Oophorectomy, Cognitive Behavioral Therapies
- \* Treatment Guidelines are available on [iapmd.org](https://iapmd.org)

# Is it PMDD or Premenstrual Exacerbation (PME)?

## Symptoms of Existing Disorder



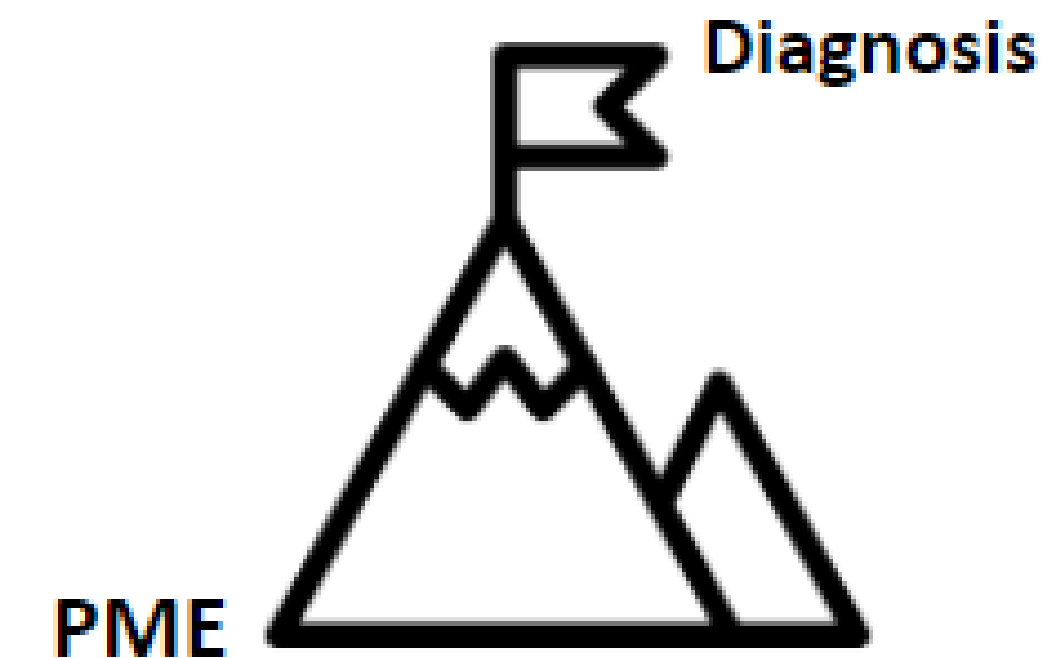
Premenstrual Phase

Refers to the **worsening of the symptoms of another disorder**, such as major depressive disorder or generalized anxiety disorder.

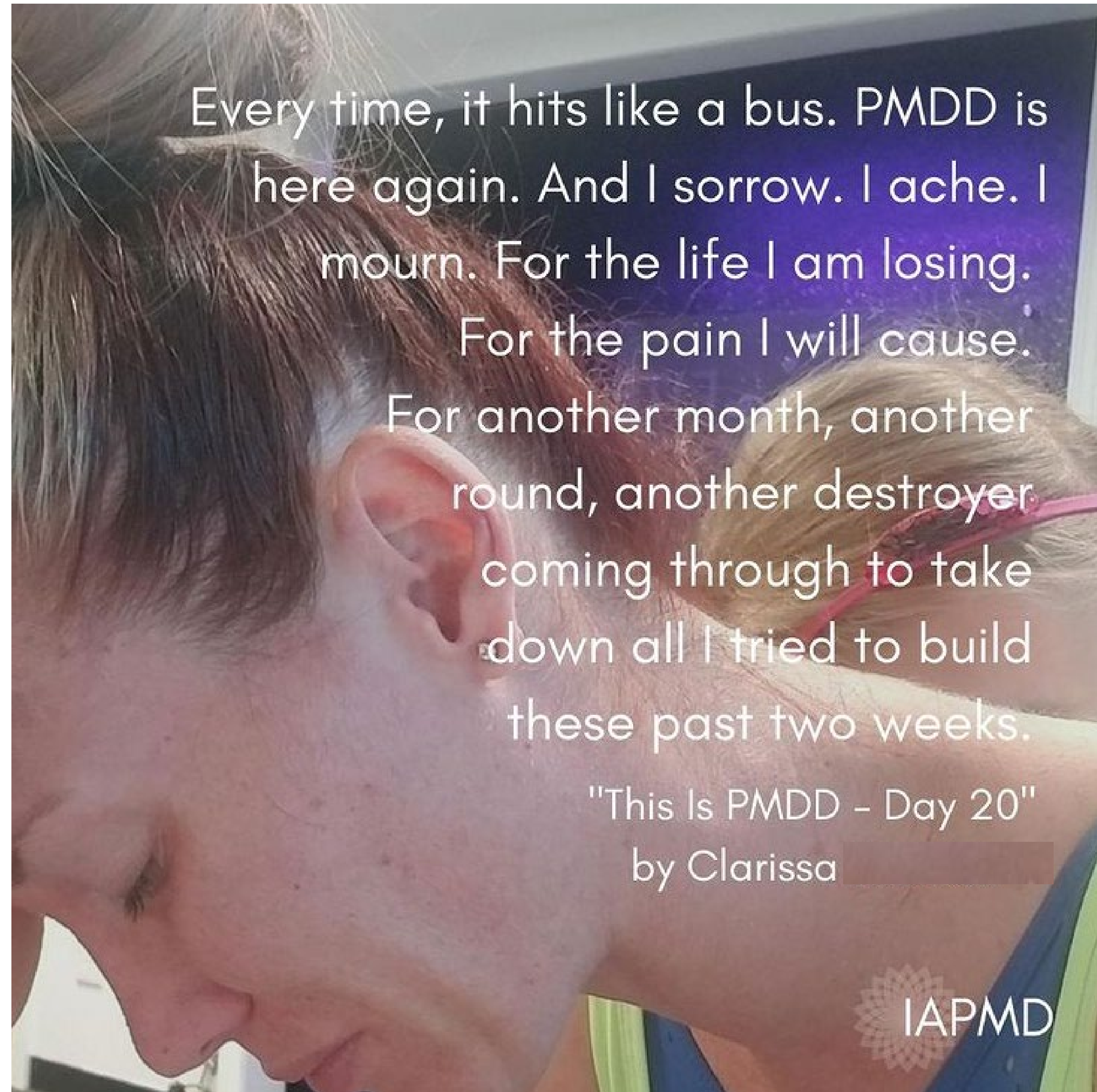
Symptoms are present throughout the entire cycle but **become more severe** in the premenstrual phase (before your period).<sup>3</sup>

## Research on PME is Lagging Behind

PME remains a phenomenon studied in research but not yet diagnosed and treated clinically



# Patients are struggling



Every time, it hits like a bus. PMDD is here again. And I sorrow. I ache. I mourn. For the life I am losing. For the pain I will cause. For another month, another round, another destroyer coming through to take down all I tried to build these past two weeks.

"This Is PMDD - Day 20"  
by Clarissa

# Families are struggling



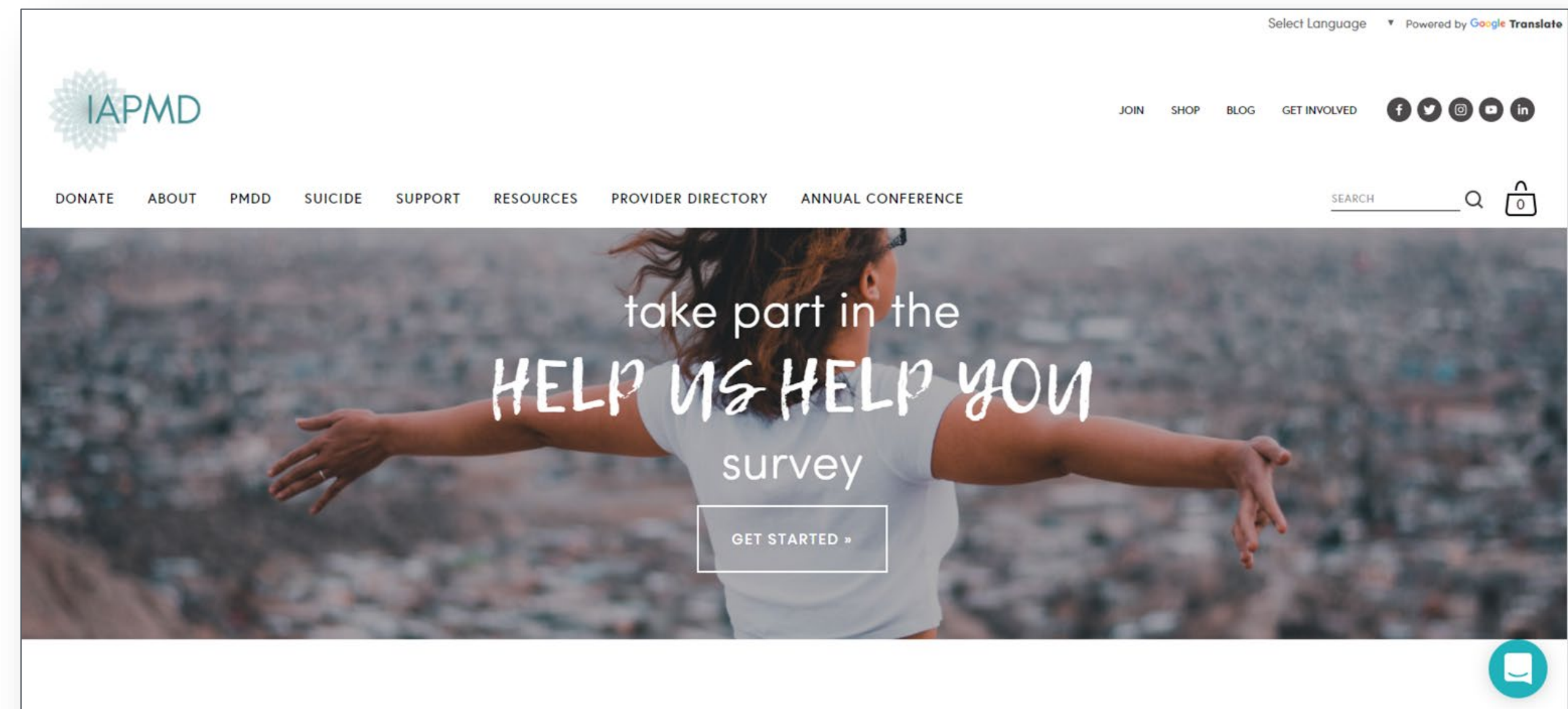
"My fiancé suffers with PMDD, and it's crushing how debilitating it can be. Sometimes it feels like she needs to put her life on hold for a week or two at a time to deal with the symptoms and the fallout..."



# IAPMD – Bringing the patient’s voice to the conversation



- \* 2018 – Global Survey of Premenstrual Disorders (GSPD)
- \* 3,153 people from over 56 countries participated anonymously in the online questionnaire survey
- \* 1,425 of those were prospectively-confirmed patients with PMDD



# Findings



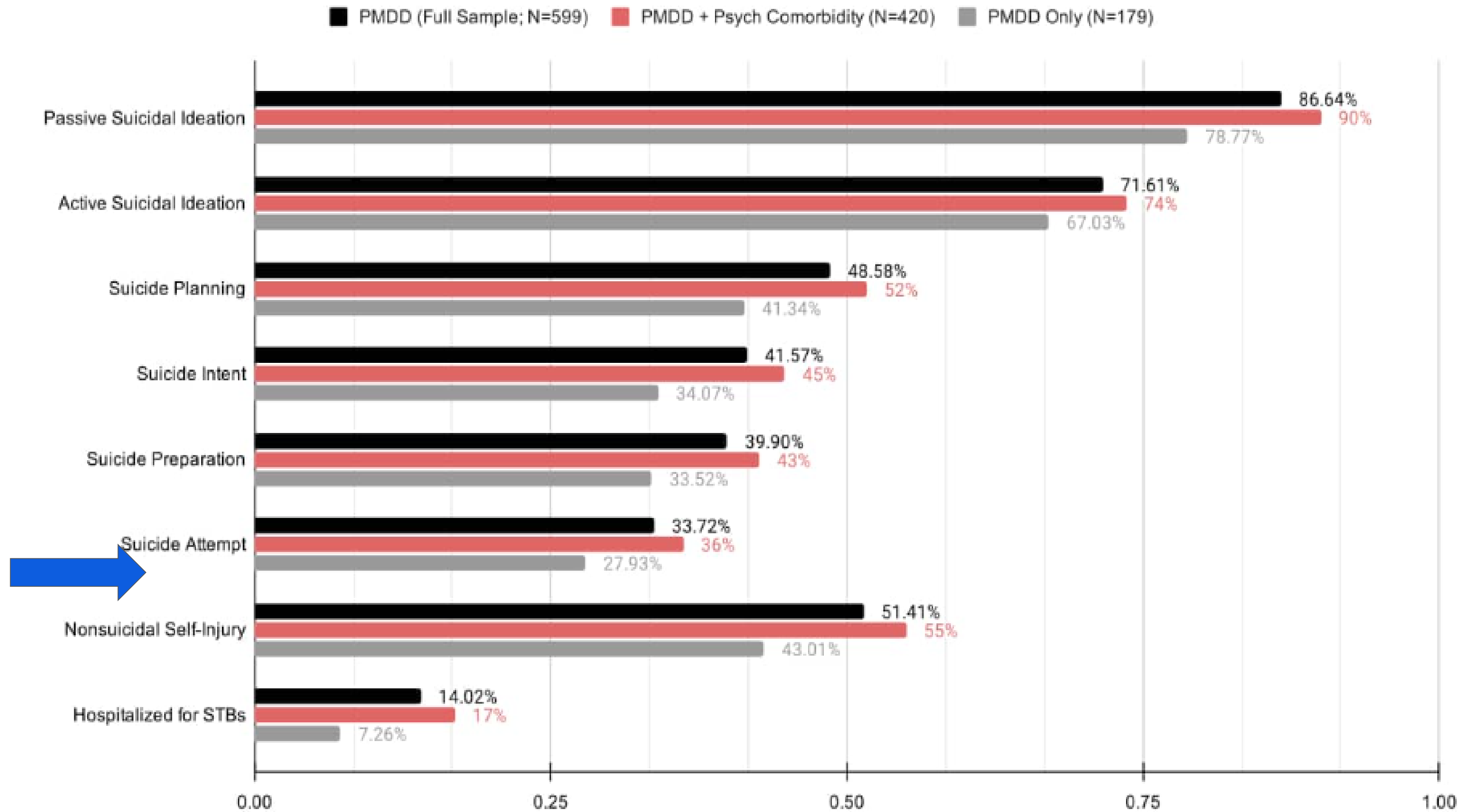
- \* 12 years average to get a correct diagnosis
- \* 6 providers before gaining an accurate diagnosis
- \* Clear knowledge gap exists across medical specialties and the ability of providers to deliver quality care to PMDD sufferers <sup>1</sup>
- \* 19% hospitalized while in PMDD crisis
- \* 57% lost an intimate partner or significant other
- \* 16.8% reported having lost a job due to PMDD

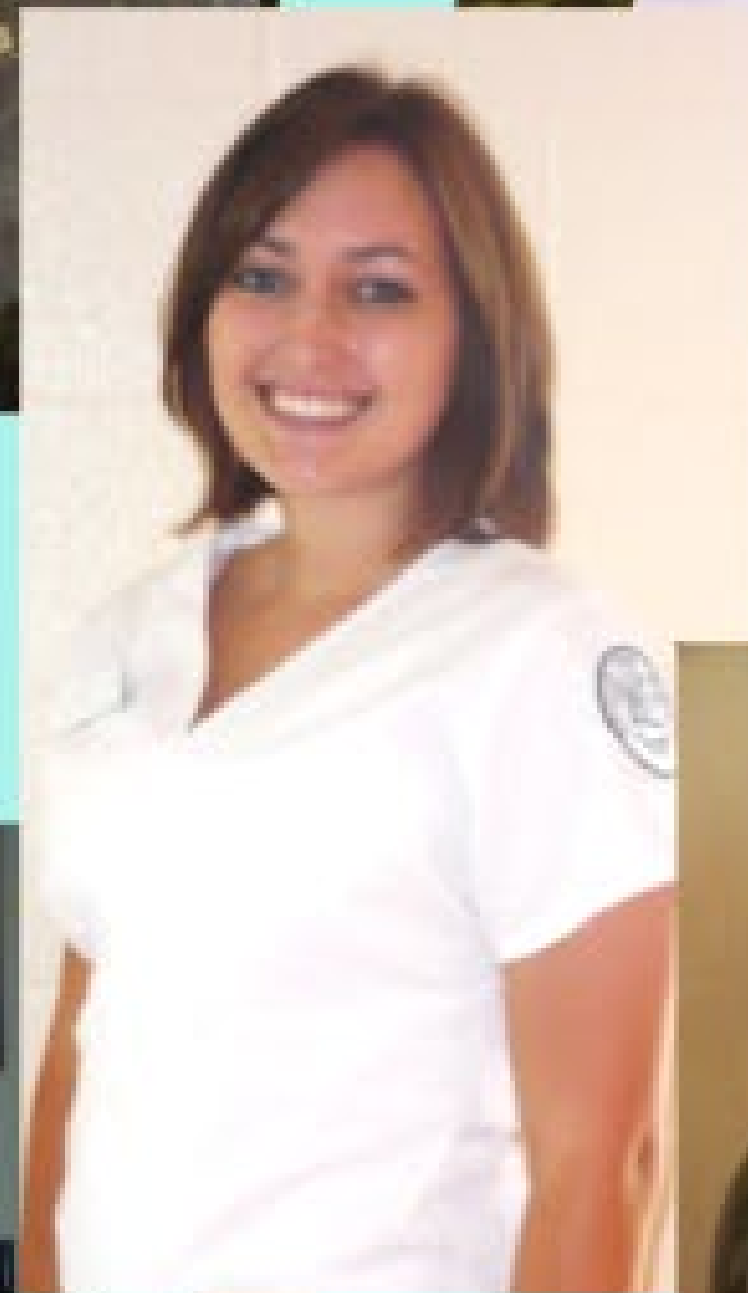
1. Hantsoo L, Sajid H, Murphy L, Buchert B, Barone J, Raja S, Eisenlohr-Moul T. Patient Experiences of Health Care Providers in Premenstrual Dysphoric Disorder: Examining the Role of Provider Specialty. *J Womens Health (Larchmt)*. 2022 Jan;31(1):100-109. doi: 10.1089/jwh.2020.8797. Epub 2021 Apr 1. PMID: 33978482; PMCID: PMC8785767.

# 34% with PMDD have attempted suicide



Prevalence of Self-Injurious Thoughts and Behaviors in Prospectively-Confirmed PMDD





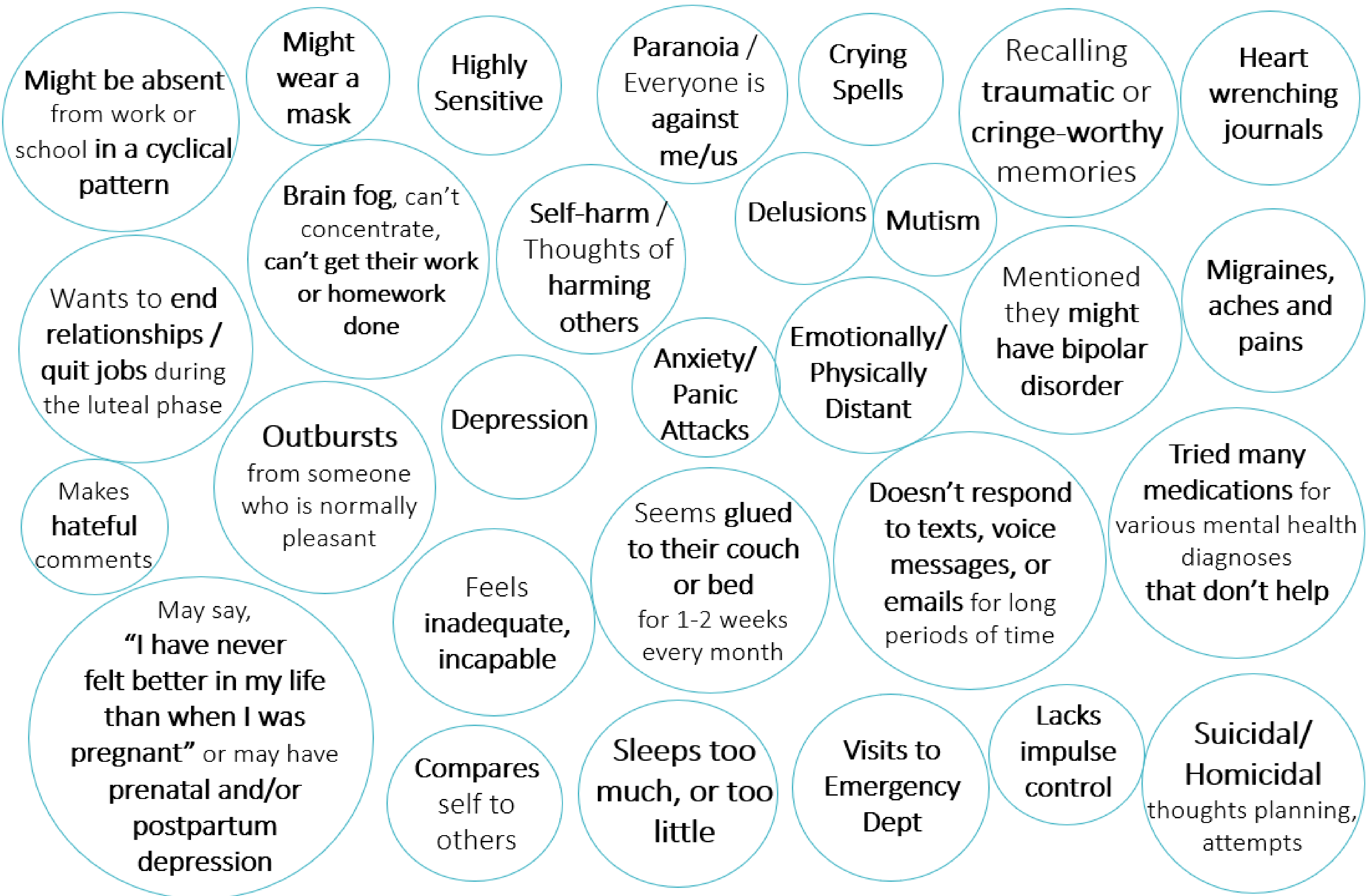


# Christina Elizabeth Bohn



How does PMDD look in everyday life?

What we witnessed.



# “A great liar and a great thief” –

*Marybeth Bohn*

- \* PMDD can strike at any age during the reproductive years
- \* PMDD is a spectrum disorder, but it can become worse the longer it is undiagnosed and untreated
- \* There are young girls/AFAB individuals who already have serious symptoms of PMDD, and many have been in behavioral health units for suicidality and delusions
- \* One size does not fit all. One treatment option may help one patient, but hurt another—careful monitoring is important

# Three potentially life-saving questions



Ask these three questions - Known as  
"Christina's Questions"

1. When was your last period?
2. When are you expecting your next period?
3. What is "PMS" like for you?

*"Christina's Questions" should be asked in ERs, doctors' offices, therapists' offices, and in schools (consider annual screenings)*



# American Psychological Association - The "Fifth Vital Sign"



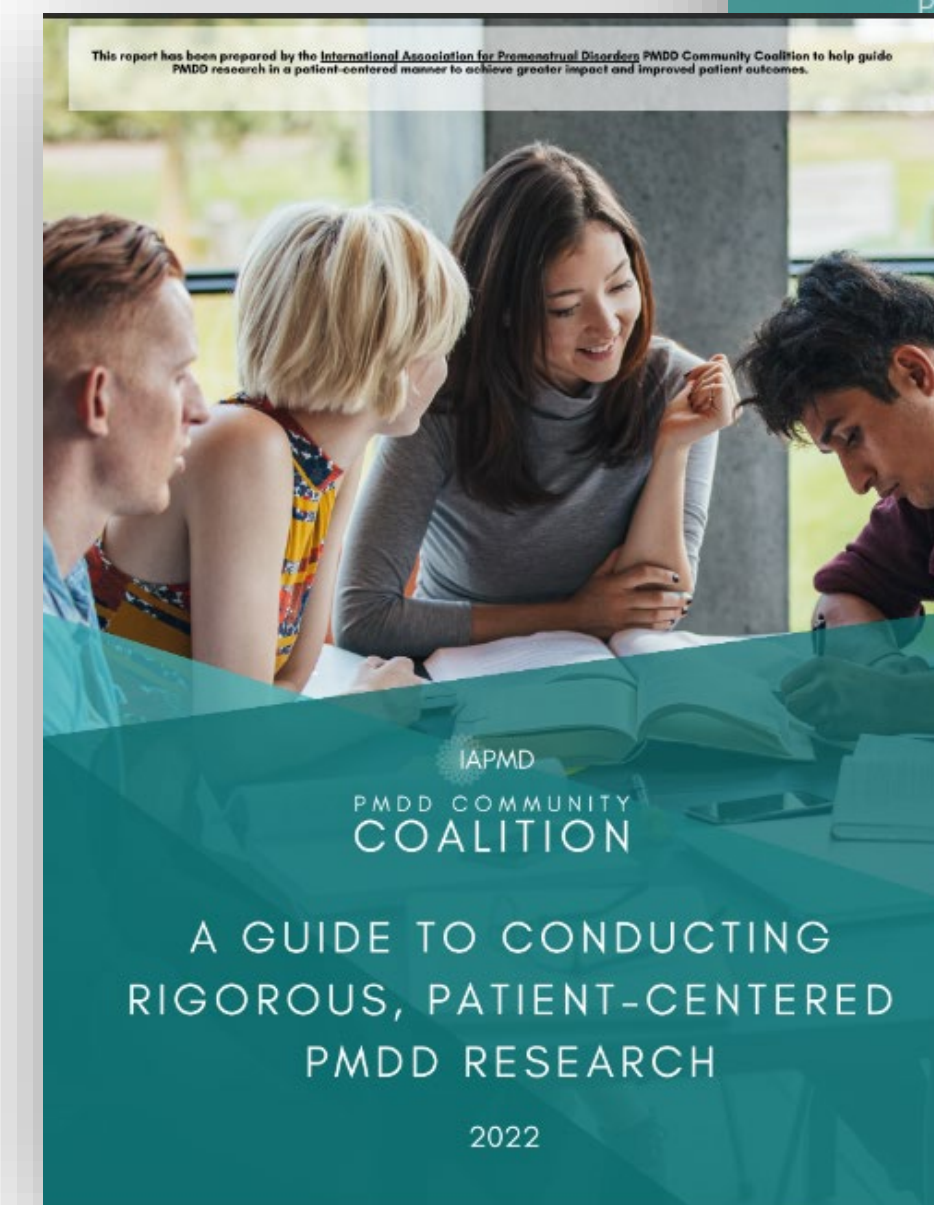
- \* July 2023 – the APA encouraged mental health providers to treat the menstrual cycle as a "fifth vital sign"
- \* IAPMD worked with the APA to develop questions patients should be asked about their periods to help psychologists improve diagnoses and identify treatments that work:
  1. Do you menstruate?
  2. Does your menstrual cycle affect your emotional health?
  3. Have you been diagnosed with any other emotional or behavioral disorder?
  4. Have you tried any PMDD treatments before?

APA thanks Tory Eisenlohr-Moul, PhD, Liisa Hantsoo, PhD, Jaclyn Ross, PhD, and the International Association for Premenstrual Disorders for helping to develop this fact sheet.

# 2021 Patient Centered Outcomes Research Institute Work – Two Landmark Resources

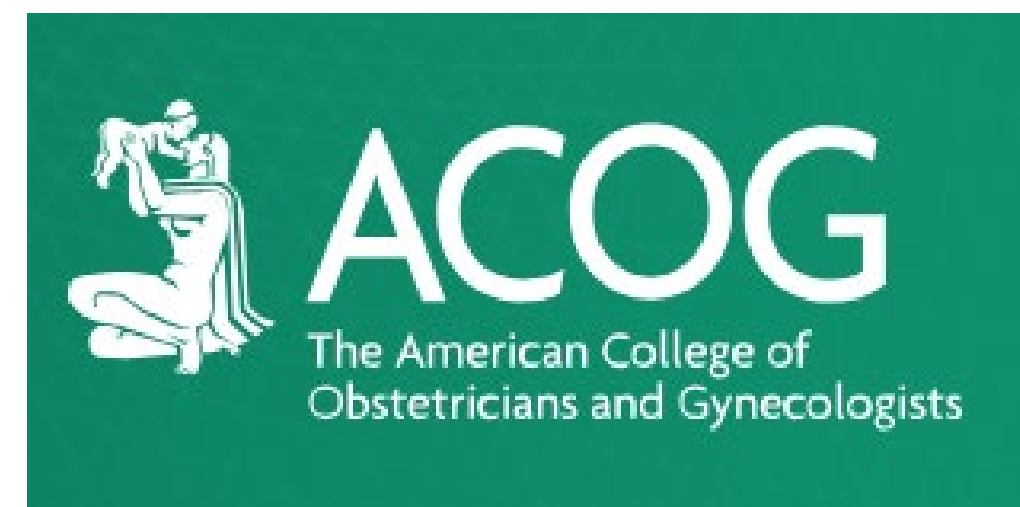


- \* **“A Strategic Plan To Advance Patient-Centered PMDD Research”** – an assessment of the current state of knowledge related to PMDD, previous and current research, and future directions for expanding the research, knowledge, and approaches that could address the gaps in PMDD research and treatment
- \* **“A Guide To Conducting Rigorous, Patient-Centered PMDD Research”** – This guide is designed to provide general guidance for researchers interested in learning how to conduct rigorous research on Premenstrual Dysphoric Disorder (PMDD) while taking a patient-centered perspective.



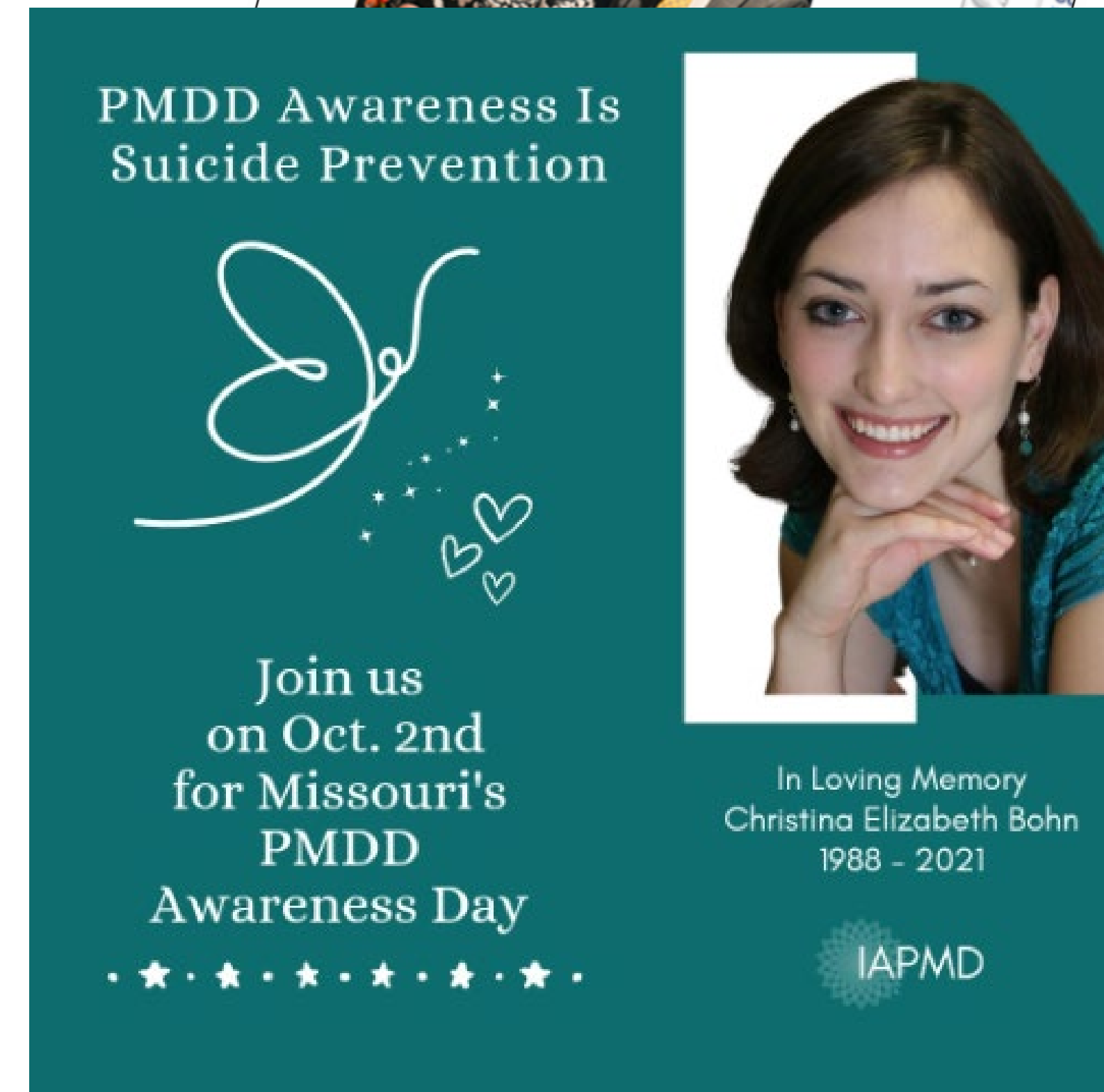
# ACOG Clinical Practice Guidelines

- Dec. 2023 - The American College of Obstetricians and Gynecologists released new Clinical Practice Guideline, Management of Premenstrual Disorders
- IAPMD's work helped inform these guidelines
- Our 2018 Global Survey of Premenstrual Disorders (2018 GSPMD) that found an extremely alarming number of people - 34% - with premenstrual dysphoric disorder (PMDD) have attempted suicide, published in BMC Psychiatry, is referenced
- IAPMD is included as a resource for patients and families



# Driving Awareness

- \* IAPMD partnered the Bohn family in the state of Missouri to pass the Nation's first **PMDD Awareness Day in Missouri** - October 2, 2023, Christina's birthday
- \* April is Annual PMD Awareness Month





# Shining a Light on PMDs

- \* **Build Evidence** – Grants, position papers, collaborations
- \* **Build Influence** – Global PMD Awareness Month, Influencer Meetings, advocacy work
- \* **Build Empowerment** – Peer Support, education and training, website resources, eBook, workplace strategy



PMDD in the News  
22 hrs · 🌐  
ADHD特性の女子高校生は月経前不調に - 大学ジャーナルオンライン  
し、場合によっては、日常生活活動や対人関係を損  
る月経前不快気分障害 (PMDD) につながることも  
translation

PMDD in the News  
January 16 at 12:43 PM · 🌐  
Shaneequa vertelt over PMDD 'Nachtdieren' - LINDA.nl  
Shaneequa heeft last van PMDD. Dat staat voor PreMenstrual Dysphoric Disorder. Dit artikel gaat over psychische klachten ...  
See Translation

PMDD in the News  
22 hrs · 🌐  
Your PMS Might Be Something Else—A D  
PMDD - Forbes  
statistics show 50% of women struggle with co  
pms, up to 5% endorse a hidden struggle with de

PMDDs are in the news every day!

PMDD in the News  
December 27, 2023 at 4:30 PM · 🌐  
PMS: patriarchal menstrual stigmas - The Daily Texan  
condition that causes severe hormone imbalances the two weeks prior  
... it causes symptoms like severe ...

PMDD in the News  
September 13, 2023 · 🌐  
Emmerdale spoilers tonight: Cathy's distraught when she finally gets a diagnosis for her health ordeal  
There's an initial sigh of relief when she's officially diagnosed with PMDD. Bob does his best to support Cathy as he shares his sympathy for her ...



PMDD in the News  
22 hrs · 🌐  
Woman comot her womb at 22 sake of severe pre-menstrual symptoms - BBC News Pidgin  
Nichole turn 20, she find wetin dey do am, dem dey call di menstrual dysphoric disorder, or PMDD. Na di elder and ...

PMDD in the News  
December 27, 2023 at 4:30 PM · 🌐  
Social Media Is Helping Nigerian Women Discover A Lesser-known Premenstrual Disorder  
menstrual Dysphoric Disorder (PMDD). "It popped up on my timeline, then I searched and found out what it was," Kemi remembers. The problem ...



# Patient Treatment Guidebook

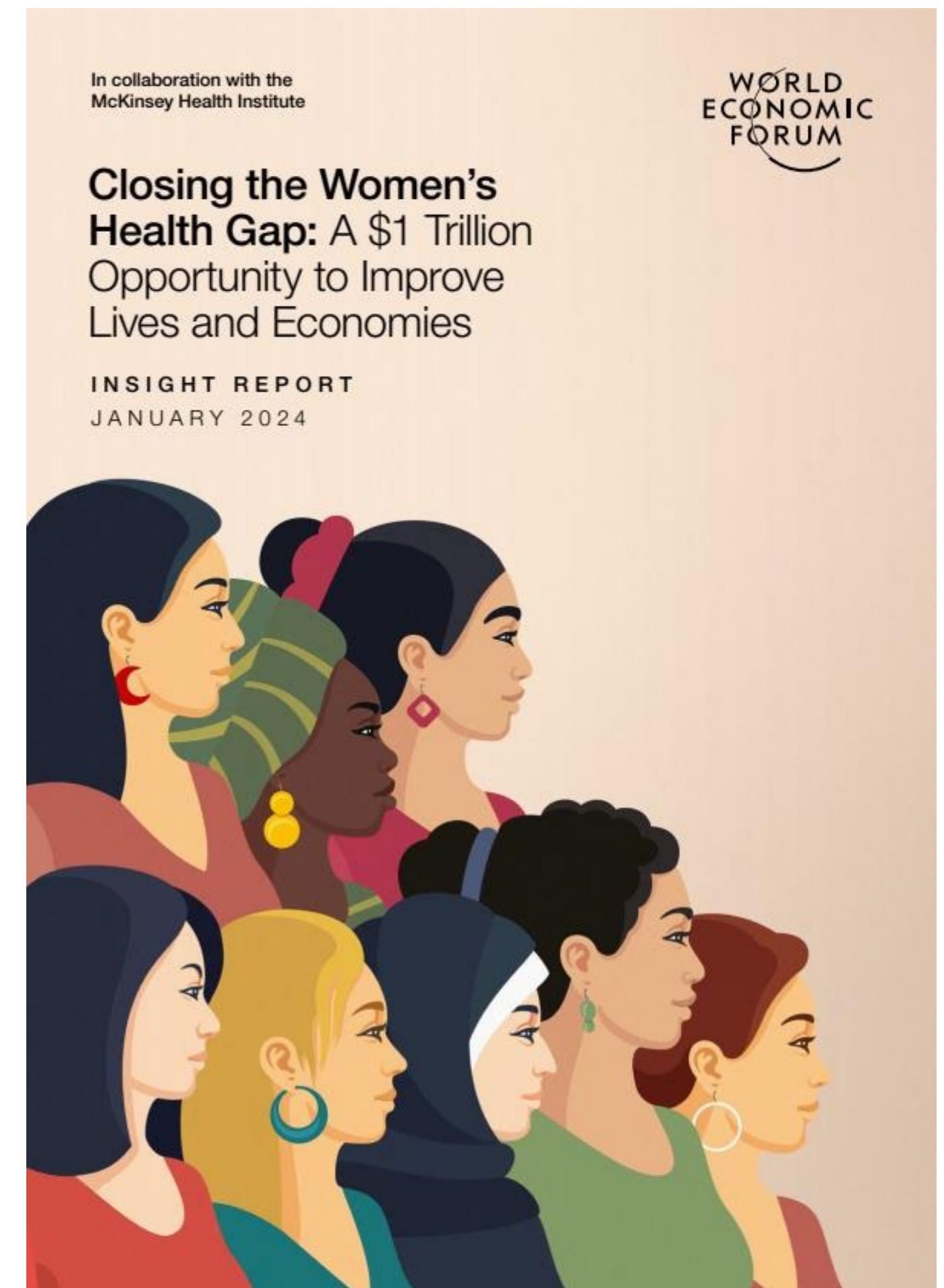
- \* April 2024 Release
- \* First-ever guidebook for patients on evidence-based treatment options
- \* “Take Charge!” Empowering
- \* Patient-focused
- \* Interactive



# Closing the Women's Health Gap – a \$1 Trillion Opportunity!



- \* 2024 McKinsey Global report “Closing the Women’s Health Gap” cites PMDs as key economic factor
- \* “Health education, including menstrual education, is one of the most effective ways to help women learn about their bodies.”
- \* “Premenstrual syndrome (PMS), depressive symptoms, and migraines—could make up more than **50 percent of the economic impact**”

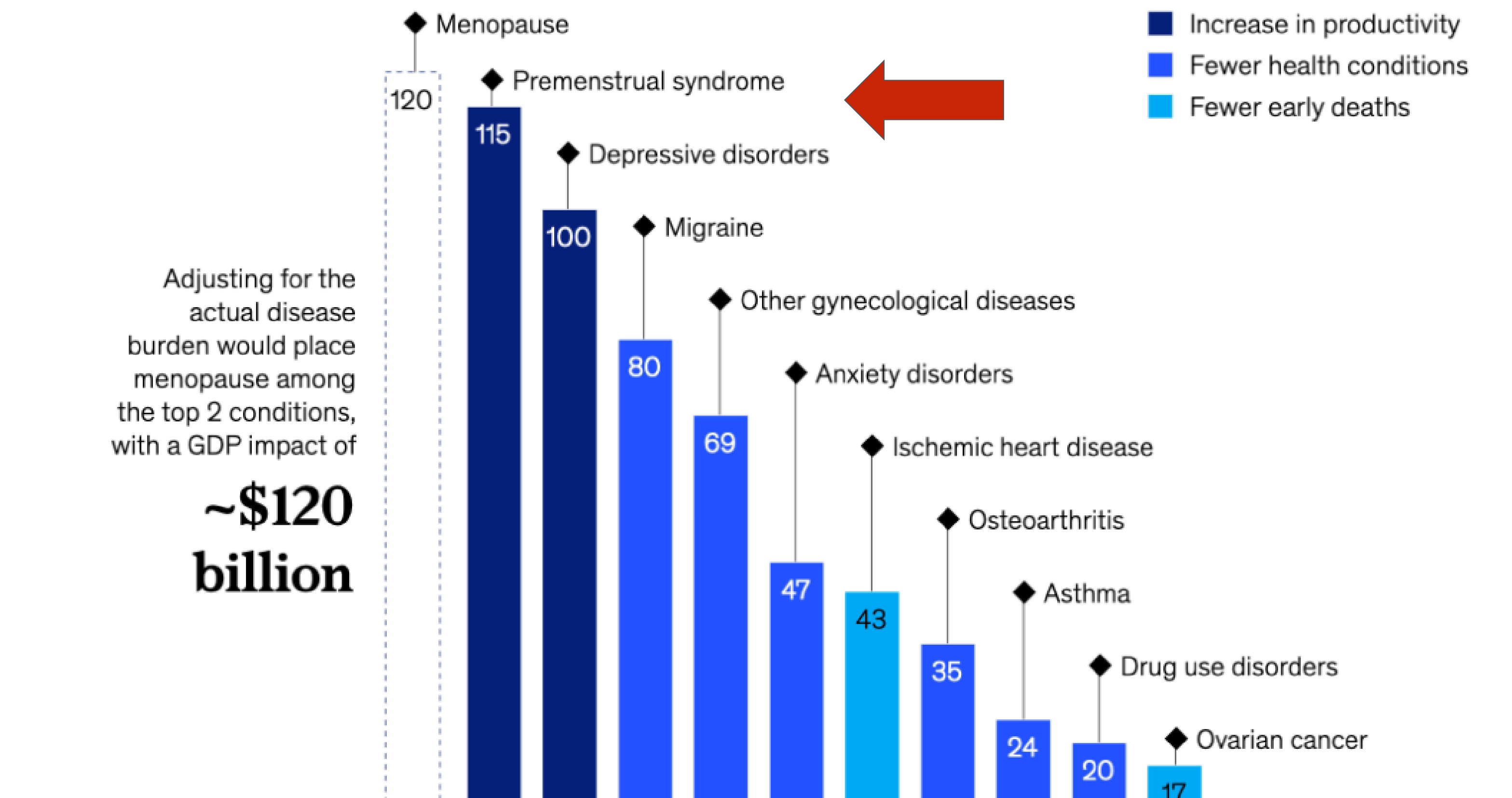


# Addressing PMS (PMDs) – a \$115 billion impact!



Ten conditions would contribute more than 50 percent of the total GDP impact related to closing the gap in women’s health.

Top 10 conditions by GDP impact of closing the women’s health gap,<sup>1</sup> \$ billion



Adjusting for the actual disease burden would place menopause among the top 2 conditions, with a GDP impact of **~\$120 billion**

# PATIENT ORGANIZATIONS NEED MORE FUNDING!



- *“Every woman I know has a story about leaving her doctor’s office with more questions than answers. Not because our doctors are withholding information, but because there’s just not enough research yet on how to best manage and treat even common women’s health conditions. In 2023, that is unacceptable,”*  
– Dr. Jill Biden
- **New White House Initiative – investment of \$12 billion in new funding for women’s health research.**
- Create a Fund for Women’s Health Research at the NIH to advance a cutting-edge, interdisciplinary research agenda and to establish a new nationwide network of research centers of excellence and innovation in women’s health

# IAPMD.org

- \* Go to [IAPMD.org](https://iapmd.org) website
  - Education/Resources
  - Self-Diagnostic Test
  - Symptom Tracker/App
  - Appointment Sheets
  - Support Groups
- \* Find the right doctor – [IAPMD.org](https://iapmd.org)
- \* Talk about PMDD
- \* Ask how you can support someone and what they need from you



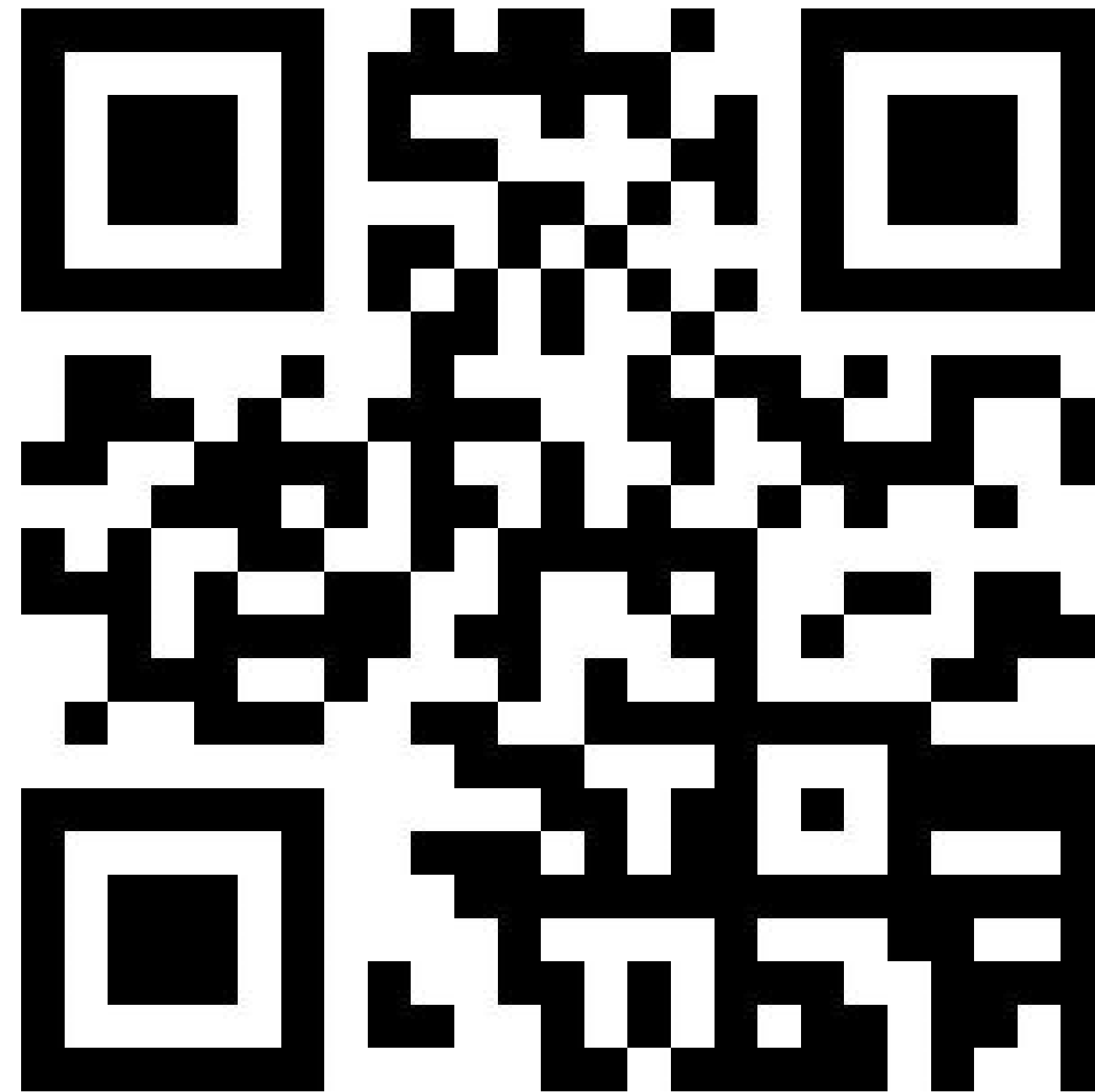
# Resources for the- Professional Community



- \* Monthly educational webinars on PMDD and PME covering both Cycle Science and Clinical Practice.
- \* Webinar Library
- \* eNewsletter – best practices, latest research, new information on PMDs
- \* Provider Directory
- \* Full array of provider resources



Visit us at [IAPMD.org](https://iapmd.org)



# References



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9. [IAPMD.org/facts-and-figures](https://iapmd.org/facts-and-figures)



IAPMD

THANK  
YOU



# Prevention in Focus Webinar Series

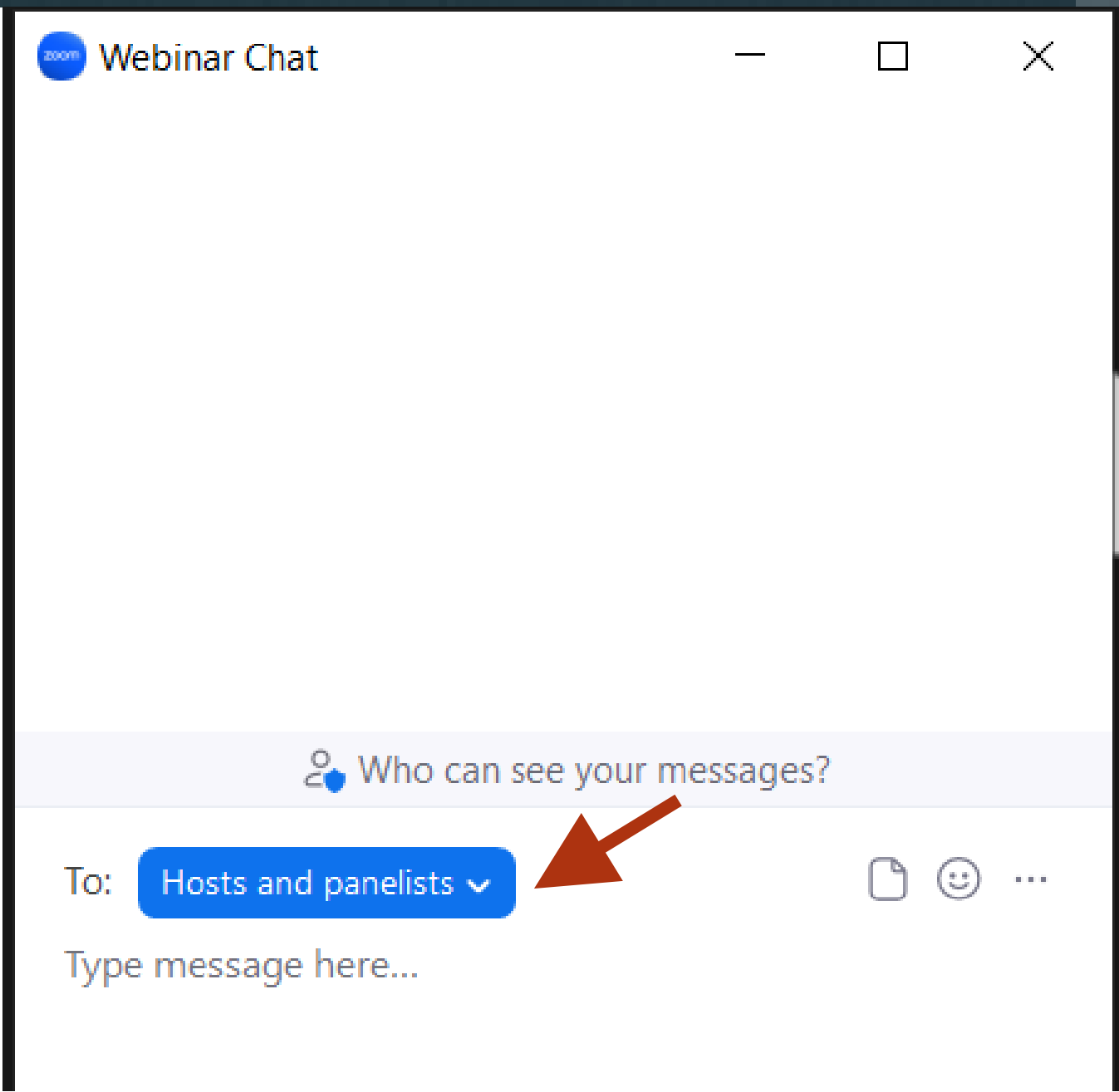
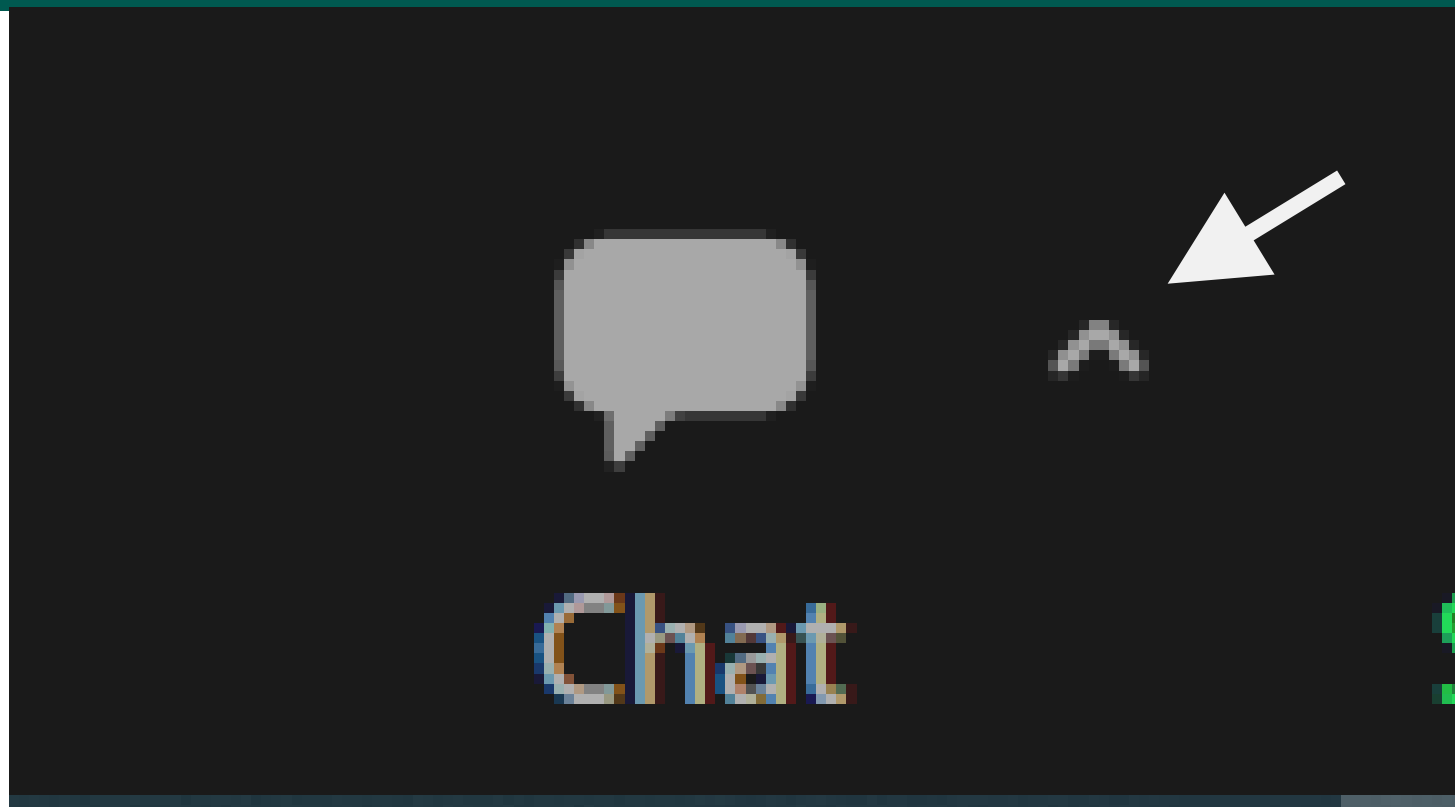
SAVE THE DATE!

**June 3, 2024**

**1 pm – 2 pm EST**

**Webinar Topic: Intimate  
Partner Violence and Abuse  
Screening Among Pregnant  
and Postpartum Women**

# Prevention in Focus Webinar Series



## Q&A Session



# Thank You!

See you for our next webinar  
on June 3, 2024!



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[PreventionInFocus@nih.gov](mailto:PreventionInFocus@nih.gov)



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