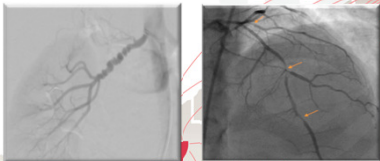



## FMD/Arterial Dissection Information and Support Group




**University Hospitals  
Virtual Meeting  
July 18, 2023  
6:00-7:30 pm**

 **University Hospitals**  
Harrington Heart & Vascular Institute  
Cleveland | Ohio


### Agenda

Welcome, Intros, Polling	Dr. Heather Gornik/All
Patient Stories	Multiple
Updates from the FMDSA	Pamela Mace, RN, Executive Director, FMDSA
Menopause and Women's Health	Jean Marino, APRN-CNP, NCMP
Q&A	All
Adjourn	

 **University Hospitals**  
Harrington Heart & Vascular Institute


Cleveland | Ohio

***We are recording tonight's session to prepare a written transcript of tonight's content. No video will be used and no names will be included in the transcript.***

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### Introductions and Check-in, Polls

 **University Hospitals**  
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### Polls

1. Where are you joining us from tonight?
2. If you are joining us from outside the US/Canada, where are you (chat box)?
3. Have you attended the University Hospitals FMD/dissection information/support group before?
4. Do you have FMD?
5. Are you a member of the FMD Society of America (FMDSA)?
6. Did you attend the FMDSA meeting in Cleveland, Ohio in May (Yes, No)?
7. If you are OK sharing, what is your menopausal status? (pre-menopause with regular periods/peri-menopausal/post-menopausal/not sure!)
8. Put in chat: In 5 words or less, what is one fun thing you have done in the past month.

### Patient Stories

### FMDSA Updates

*Pamela Mace, RN*



# FMDSA

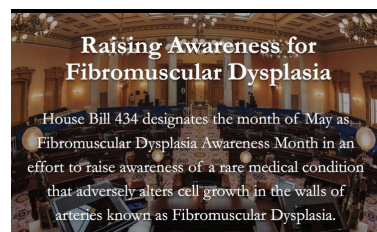
• FIBROMUSCULAR DYSPLASIA SOCIETY OF AMERICA •

**Pamela Mace, RN**  
**Executive Director**  
**FMD Patient**  
**216-834-2410**

**July 18<sup>th</sup>, 2023**



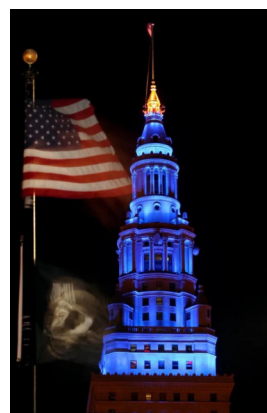
May was  
FMD  
Awareness  
Month

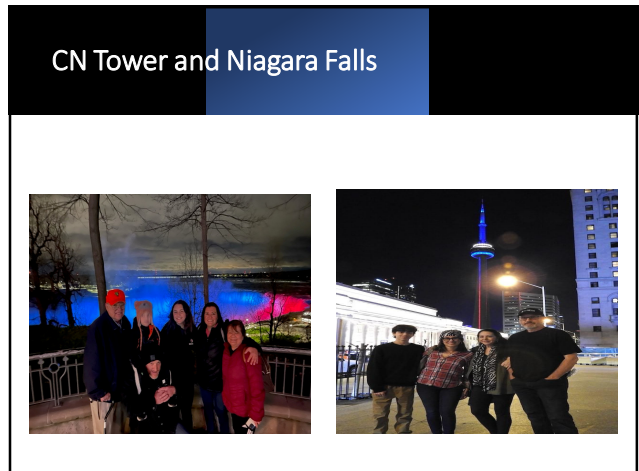
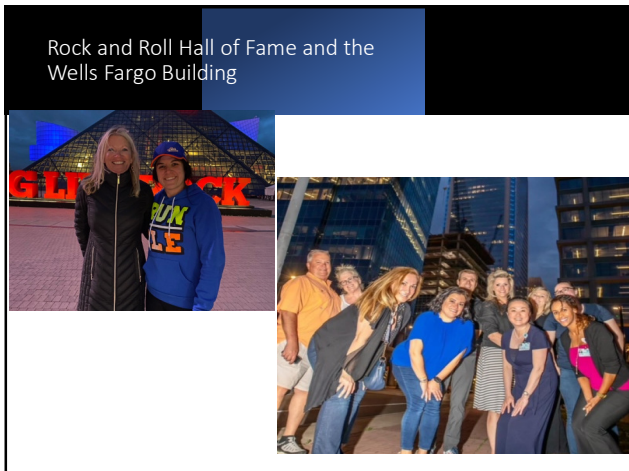
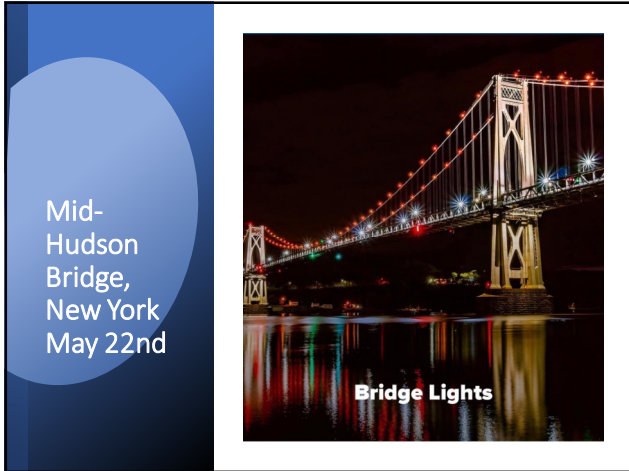


Rock and  
Roll Hall of  
Fame May  
1st



Terminal  
Tower  
Cleveland,  
Ohio  
May 20th







FMDSA Annual Conference  
Reception-Raffle-Research and  
Entertainment



FMDSA 2023 ANNUAL CONFERENCE	
Celebrating 20 Years!	
May 20th, 2023	
Grand Park Hotel, Cleveland	
7:00 - 8:00 am	Breakfast and Registration - Palace Ballroom, 2nd Floor
8:00 - 8:20 am	FMDSA Welcome
8:20 - 8:45 am	What is Fibromyalgia Anyway? <i>Dr. James Fournier</i>
8:45 - 9:20 am	Headache and Treatment: 2023 State of the Art Update <i>Dr. Deborah Reed</i>
9:30 - 9:40 am	Begin and End - Managing Brain Neurons and <i>Dr. Shazam Hussain</i>
9:40 - 9:55 am	Panel Discussion
9:55 - 10:10 am	Break
10:10 - 10:30 am	Real FMD: When Do I Need an Intervention? How am I <i>Dr. Natalia</i>
10:30 - 11:00 am	managed? FMD? <i>Priscilla Miller</i>
10:30 - 11:00 am	Serotonergic Common Anion: Discussion and Update <i>Dr. Esther Kim</i>
11:00 - 11:30 am	on SCLC Research: What are we Learning through the <i>Dr. Heather Gank</i>
11:30 - 11:45 am	SCAD Registry <i>Dr. Heather Gank</i>
11:45 - 12:45 pm	Updates from the North American Registry for FMD: New <i>Dr. Heather Gank</i>
11:45 - 12:45 pm	Data on FMD Outcomes <i>Dr. Heather Gank</i>
11:45 - 12:45 pm	Panel Discussion
11:45 - 12:45 pm	Lunch and Salsa Collection
12:45 - 1:10 pm	Choosing Genes for FMD: What We Currently Know, <i>Dr. Santhi Ganesh</i>
1:10 - 1:35 pm	What We Do Not Know, and How We Use Genetic <i>Dr. Santhi Ganesh</i>
1:35 - 1:50 pm	Information in the Clinic <i>Dr. Santhi Ganesh</i>
1:50 - 1:55 pm	Challenging Research: What We Have Learned About How <i>Dr. Jason Kovacic</i>
1:55 - 2:00 pm	Genetics Cause FMD <i>Dr. Jason Kovacic</i>
2:00 - 2:05 pm	Panel Discussion
2:05 - 2:30 pm	Break
2:30 - 3:00 pm	Panel Discussion <i>Alan Strassman, PhD</i>
3:00 - 3:10 pm	Paradoxes of Health, Stress, and Healing: Connecting <i>Michelle, MD, and Soul</i>
3:10 - 3:20 pm	A Tribute <i>Eve Anne Riggs, MD, MSP</i>
3:20 - 3:30 pm	Chasing Remarks <i>Eve Anne Riggs, MD, MSP</i>

## FMDSA YouTube Channel

- Dr. Natalia Fendrikova (Cleveland Clinic, Ohio)
- Dr. Jason Kovacic (Victor Change, Australia)
- Dr. Elizabeth Ratchford (John Hopkins)
- Dr. Santhi Ganesh (University of Michigan)
- Dr. Shazam Hussain (Cleveland Clinic, Ohio)
- Dr. Barry Katzen (Baptist Health, Miami)



Dr. Esther Kim receiving the FMDSA Founders Award



Meeting attendees had the opportunity to participate in research  
Ganesh Lab –[ganeshlab.org](http://ganeshlab.org)







Dr. Jason Kovacic and Karena from Australia

### The North American Registry for FMD

Sponsored by FMD Society of America (FMDSA)




Coordinating Center: U of Michigan Cardiovascular Outcomes Research and Reporting Program (MCOORP)

Initial enrollment January, 2009 at 7 clinical centers

Currently 18 active and enrolling centers in the US and 1 in Canada (Ottawa)

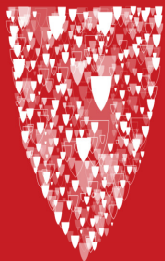

Enrolls adult patients with FMD; pediatric enrollment at selected centers

**As of July 12, 2023, there are 4000 patients enrolled in the North American Registry for FMD**

## Let's Talk About Menopause (in a short amount of time)



Jean Marino APRN-CNP, NCMP, IF

## Let's Talk About Menopause

### Women Have Been Mised About Menopause

Hot flashes, sleeplessness, pain during sex: For some of menopause's worst symptoms, there's an established treatment. Why aren't more women offered it?

### What is perimenopause and menopause?

Time period	Hormones-estrogen and progesterone	Ovulation	Menses
Premenopausal	Fluctuating, but in a predictable pattern	monthly	monthly
Perimenopausal	Fluctuating, but more erratic	irregular	irregular
Menopausal	Low levels	none	none

### What symptoms are due to perimenopause and menopause?



### Signs and symptoms of perimenopause and menopause

- Vasomotor symptoms
- Change in menstrual pattern
- Mood changes
- Brain fog/difficulty concentrating
- Difficulty sleeping
- Vulvar and vaginal dryness
- Thinning hair
- More hair on chin/chest
- Acne
- Dry skin/hair/nails
- Weight gain/abdominal
- Joint pain
- Urinary frequency/urgency
- Frequent bladder infections

### What is hormone therapy?

- First: change "replacement" in hormone therapy:
  - **"Menopausal Hormone Therapy"**
- Gold standard for treating vasomotor symptoms
- Estrogen and Progestogen

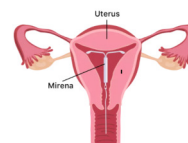


## Estrogen

- Estrogen-treat symptoms
  - Conjugated equine estrogen/Premarin
  - Estradiol
- Oral Hormone Therapy:
  - Benefit: less expensive, treat acne/hirsutism
  - Risk: blood clot in high risk women
- Transdermal: patch, gel, spray, vaginal ring
  - Benefit: less risk of a blood clot in high risk women
  - Risk: more expensive; skin irritation (patch)

## Progestogen

- Progestogen-protect the uterine lining
  - Micronized progesterone
  - MPA-medroxyprogesterone acetate
  - Norethindrone
- Oral
- Combined in a patch with estrogen
- Progesterone releasing IUD-off label



## Duavee

- Conjugated estrogen + Bazedoxifene
- Oral estrogen + SERM
- "tissue selective estrogen complex"
  - TSEC



## Is menopausal hormone therapy safe?

Menopause: The Journal of The North American Menopause Society  
 Vol. 25, No. 7, pp. 767-794  
 DOI: 10.1097/GME.0000000000002029  
 © 2022 by The North American Menopause Society

### NAMS POSITION STATEMENT

The 2022 hormone therapy position statement of The North American Menopause Society

### Safety of menopausal hormone therapy:

- \*Benefits are likely to outweigh risks for symptomatic women who initiate hormone therapy aged younger than 60 years or within 10 years of menopause onset
- When adequate progesterone is used, no increased risk of uterine cancer
- Risk of breast cancer related to HT use is low
  - < 1 additional case/1,000 women per year of HT use
  - 3 additional cases/1,000 women used for 5 years (CEE+MPA)
  - Risk similar to that of modifiable risk factors such as 2 daily alcoholic beverages, obesity, or low physical activity.

### Safety of hormone therapy: heart

- Menopausal hormone therapy does **not** increase the risk of heart disease and may be beneficial in women who start early after menopause
  - Increases HDL and decreases LDL
  - Potent antioxidant
  - Causes vasodilation
  - May contribute to anti-inflammatory processes in the arteries
- Not indicated to protect the heart

### Safety of hormone therapy: heart

- *Timing hypothesis*
  - Increased risk of heart disease, stroke, and blood clots when HT initiated >10 years from menopause onset or after 60 years old
  - Estrogen introduced after arterial plaque has already become complicated can lead to rupture/instability

### Risk of a blood clot

- Higher risk
  - Oral estrogen
  - Higher doses
  - Medroxyprogesterone acetate
- Lower risk
  - Transdermal estrogen
  - Lower doses
  - Micronized progesterone

## Hormone therapy and women with high blood pressure

- Transdermal estrogen preferred
  - Beneficial effect in women with normal blood pressure
  - Neutral effect in women with high blood pressure
- Progestogen
  - Micronized progesterone

## Are there non-hormonal treatment options?

- Reasons to choose non-hormonal:
  - Contraindications to systemic menopausal hormone therapy:
    - Severe active liver or gall bladder disease
    - Blood clots
    - Stroke
    - Heart attack
    - Dementia
    - Personal history of estrogen dependent cancer
- Choice

## Non-hormonal options

Menopause: The Journal of The North American Menopause Society  
Vol. 36, No. 6, pp. 573-590  
DOI: 10.1097/MAE.0000000000002300  
© 2023 by The North American Menopause Society

### NAMS POSITION STATEMENT

The 2023 nonhormone therapy position statement of The North American Menopause Society

## Non-hormonal treatment options

- Brisdelle (7.5mg paroxetine salt)
  - AE: helping women sleep, no weight gain or sexual dysfunction
  - Does **not** treat moods
  - Cannot be used with tamoxifen
  - 10mg paroxetine often covered better by insurance
- SSRI: Paroxetine (Paxil), Escitalopram (Lexapro), Citalopram (Celexa)
- SNRI: Desvenlafaxine (Pristiq), Venlafaxine (Effexor)

### SSRI/SNRI adverse effects

- Decrease in sex drive
- Difficulty with orgasm
- Weight gain (paroxetine)
- Serotonin syndrome:
  - Symptoms: anxiety, agitation, delirium, diaphoresis, tachycardia, hypertension, hyperthermia, GI distress, tremor, hyperreflexia
  - Use with caution with other serotonergic medications

### Non-hormonal treatment options

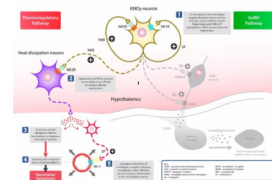
- Oxybutynin-treat vasomotor symptoms
  - AE: dry mouth
  - AE: increase risk of dementia, cognitive decline?
    - More likely in older adults, >65, taking multiple anticholinergics
    - CONCLUSION: risk of dementia with anti-cholinergic use should be considered for all ages

### Non-hormonal treatment options

- Gabapentin-treat vasomotor symptoms
  - 300mg at bedtime can increase up to three times/day
  - AE: drowsiness
- Clonidine-treat vasomotor symptoms
  - Less effective than Gabapentin, SSRI/SNRI
  - AE: low blood pressure

### Non-hormonal treatment options

- Veozah: 2<sup>nd</sup> FDA approved medication
- Blocks NK1
- Liver function tests



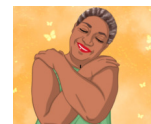
## My own goal: change the menopause narrative

- Our beliefs matter
- What does menopause mean to you?



## Changing the menopause narrative

- Spot the negativity and then remember:
  - Your body is not betraying you
  - You have options
- Find gratitude
  - No more menses, cramping
  - No fear of an unplanned pregnancy
  - Wisdom, time for yourself
  - *Menopause is a **privilege***



## Resources

- The Menopause Retreat:  
[www.menopauseandsexualhealth.com](http://www.menopauseandsexualhealth.com)
- The (North American) Menopause Society:  
[www.menopause.org](http://www.menopause.org)

## References

- Venetkoski M, Savolainen\_peltonen H, Rahkola-Soisalo P, et al. Increased cardiac and stroke death in the first year after discontinuation of postmenopausal hormone therapy. *Menopause.* 2017;25(4):375-379.
- Wild RA, Hovey KM, Andrews C, et al. Cardiovascular disease (CVD) risk scores, age, or years since menopause to predict cardiovascular disease in the Women's Health Initiative. *Menopause.* 2021;28(6):610-618.
- North American Menopause Society. The 2022 hormone therapy position statement of the North American Menopause Society. *Menopause.* 2022;29(7):767-794.
- Langer RD. The evidence base for HRT: what can we believe? *Climacteric.* 2017;20(2):91-96.
- North American Menopause Society. The 2023 nonhormone therapy position statement of the North American Menopause Society. *Menopause.* 2023;30(6):573-59.
- Hodis HN, Mack WJ. Menopausal hormone replacement therapy and reduction of all-cause mortality and cardiovascular disease: It's about time and timing. *Cancer J.* 2022;28(3):208-223.

## References

- Vinogradova Y, Coupland C, Hippisley-Cox J. Use of hormone replacement therapy and risk of venous thromboembolism: nested case-control studies using the Qresearch and CPRD databases. *BMJ*. 2019;364.
- Kapoor E, Kling JM, Lobo AS, Faubion SS. Menopausal hormone therapy in women with medical conditions. *Best Practice & Research Clinical Endocrinology & Metabolism*. 2021.

## Menopause: Why is this topic relevant for the patient with FMD/arterial dissection

Heather Gornik, MD

## FMD and Menopause – Key Considerations

- There is clearly a link between hormones and FMD/SCAD -- > 90% of patients with these conditions are women
- Average age of dx of FMD (North American Registry) is 53.3 years and 68% of patients report being post menopausal at the time of enrollment in the Registry
- No clear association of OCP use in past and development of FMD in case-control studies
- One pathology-based study suggested abnormal balance between estrogen/progesterone receptors (↑increased progesterone receptors) in surgical renal artery samples. Clinical applications of this are uncertain, ? Role of progesterone (Silhol, et al. 2015)
- HRT, especially estrogen-based, is associated with thrombosis risk and it is generally recommended that this be d/c after thrombotic episodes
- There remains uncertainty about safety of HRT for patients with FMD/SCAD

## FMD and Menopause – Key Considerations

- There remains uncertainty about safety of HRT for patients with FMD/SCAD
- From 2018 AHA Scientific Statement on SCAD (Hayes/Kim/Saw, et al).
- *...It is necessary to individualize recommendations through the use of relevant consensus statements, guidelines, and indications for use and to take into account patient preferences, known and perceived risks and benefits, and symptom severity while recognizing that the risks of HT differ depending on type, dose, duration of use, route of administration, timing of initiation, and whether a progesterone is used.*
- *Patients who experience SCAD while receiving HT should have their indications for HT reassessed, and unless there are compelling reasons to continue, HT should be discontinued.*
- *If severe vasomotor symptoms or genitourinary syndrome of menopause develop at menopause or return on stopping the use of HT, consideration of the use of HT can be made in collaboration with cardiovascular and menopause specialists. The appropriate, often lowest, effective dose of systemic HT consistent with treatment goals that provides benefits and minimizes risks for the patient should be the therapeutic goal.*
- *Locally applied vaginal estrogen is generally thought to be safe because there is minimal systemic absorption.*



### FMD and Menopause – Key Considerations

- There remains uncertainty about safety of HRT for patients with FMD/SCAD
- From 2019 International Consensus on FMD (Gornik/Persu, et al).  
*FMD is predominantly a disease of women, and concern has been raised for exogenous hormone therapies in these patients (e.g. oral contraceptive pills or hormone replacement therapy). To date, however, these concerns remain theoretical, as no data exist to support the safety or harm associated with exogenous female hormones in FMD.*

#### Every patient's circumstances are different

- Severity of FMD/SCAD
- Severity of menopausal symptoms
- History of prior vascular events (just FMD “beads” vs. SCAD/MI or stroke)
- Prior history of blood clots in legs/lungs
- Uterine considerations
- Discuss your circumstances with your medical team and discuss various treatment options and risks/benefits



Cleveland, Ohio | 57

## Open Q & A

Please Enter Your Questions into the “Chat” Box



Cleveland Ohio

## Save the Date and Register Now!

Next Meeting: October 17, 2023

Topic: SCAD



Cleveland Ohio