Virginia Stroke Systems Task Force

Quarterly Meeting (Virtual Available)

Meeting Location:

Virginia Hospital and Healthcare Association

4200 Innslake Drive, Glen Allen, VA

October 20, 2023 | 10:00am – 3:00pm

VSSTF
Virginia Stroke Systems Task Force

Agenda

10:00-10:20 am	**VSSTF Business,** Co-Chairs: Melanie Winningham, MD, Sentara Healthcare and David Long, Tidewater EMS Welcome and Introductions, Approval of Meeting Minutes, Work Groups
10:20-10:35am	**Stroke Among Female Populations in Virginia,** Allie Sedon Lundberg, VDH
10:35-10:55am	**Moms Under Pressure,** Breana Turner, Huddle Up Moms
10:55-11:45 am	**Women and Stroke,** Mary Amatangelo, DNP, ACNP-BC, NW University Feinberg School of Medicine, Dept. of Neurology, Chicago, IL
11:45 am-12:00 pm	**Questions/Answers – Speaker Panel**, Melanie Winningham and David Long
12:00-12:30 pm	**Networking and Industry Sponsored Lunch**, Jefferson Room
12:30-1:00 pm	**Management of Hemorrhagic Stroke in the Setting of Factor Xa Inhibitors,** Andrew Wilsey, Pharm D
1:00-1:20 pm	**Stroke Smart Medical Practice Updates,** Alan Stillman, Kwikpoint, and Amy Swierczewski, Medical Society of Virginia
1:20-1:30 pm	**UVA Stroke ECHO Announcement**, Christine Buttenshaw, SCOPES Program Coordinator
1:30-1:35 pm	**Stroke Registry Updates,** Stacie Stevens, VCU Health
1:35-1:50 pm	**Refresh and Retreat Stroke Camp,** Stacie Stevens, VCU Health
1:50-2:00 pm	**Final Remarks and Wrap Up,** Melanie Winningham and David Long, co-chairs
2:00-3:00pm	**Virginia Stroke Coordinators Consortium Meeting – Stroke Survivor's Perspective – Sean Riley**

Special thanks to AstraZeneca Pharmaceuticals for sponsoring today's meeting!

CEUs will not be provided for the industry sponsored speaker on the Management of Hemorrhagic Stroke in the Setting of Factor Xa Inhibitors

VSSTF Virginia Stroke Systems Task Force

Virtual Housekeeping

- Participants will be muted automatically at the start. **Please remain on mute for the duration of the meeting, unless speaking.**
- **Please turn your camera on!** It's always nice for the speaker to be able to see faces instead of talking to a bunch of blank squares.
- **Open the chat box** so you can view the discussion and ask any questions of the speaker. The chat box will be monitored by meeting hosts to ensure the questions are brought to the speakers' attention.
- If you want to speak to contribute to the conversation or ask a question, **please use the "raise hand" feature** found along the bottom of the participant's box.
- If joining the meeting over the phone only, you **can mute and unmute yourself by pressing *6** on your phone's keypad.

Introductions

Introductions in order of:

VSSTF Voting Members

VSSTF Non-Voting Members

Name, Title, Organization/Hospital, City/County

For those joining virtually, introduce yourselves using the chat box to let your colleagues know you are here

VSSTF
Virginia Stroke Systems Task Force

VSSTF Business

- Approval of meeting minutes from July 21st meeting.

VSSTF
Virginia Stroke Systems Task Force

Work Groups

- Teleneurology
- Standardization of EMS Screening Tools
- EMS Destination Protocols
- Messaging to Address Social Disparities
- Stroke Smart Communities
- Quality Management
- May Day for Stroke Awareness Event
- Primary Care Interface in Stroke Systems
- Leveraging Care with EMRs
- Post-Acute Discharge Disposition

Requests from VSSTF leadership:

1. Each person should limit participation to no more than 1-2 groups.
2. Members will sign up on Google Docs live pages.
3. Groups should have 15 or fewer members.
4. Members who are interested in serving as a lead for a particular workgroup should email us no later than 7/31. Send email to STROKE@vdh.virginia.com.
5. Leads will be responsible for outlining the goals / scope of the group and some preliminary objectives – interim progress and items for approval by voting members will be submitted by leads to VSSTF leadership at least two weeks prior to each quarterly meeting.
6. If there are groups with limited numbers of interested participants, we may combine groups (if applicable) or retire a proposed workup group.

Master List: VSSTF Work Groups Live Master List

Teleneurology Work Group

- **Overall Focus: Standardize telestroke processes and Educate about the benefits of Telestroke to Improve Patient Outcomes**

Goals:

- Establish accepted metrics and processes/workflow for telestroke and standardization of the process.
- Educate hospitals that currently use telestroke on these best practices and educate non-telestroke programs on the benefits of setting up a telestroke program.
- Improve patient outcomes by using telestroke to increase the use of thrombolytics in appropriate patients and route correct patients quickly for endovascular thrombectomies.

EMS Destinations Work Group

Purpose: The EMS Destination workgroup will develop a coordinated system for selecting the appropriate destination for stroke patients using best available evidence to optimize patient outcomes. Destinations will be defined based on alignment of patient needs with appropriate facility capabilities, using standardized screening tools. Destination capabilities must be identified using common terminology, regardless of accrediting or designating organization.

Goals:

1. Determine stroke screening tools used in each region of Virginia
2. Differentiate appropriate destinations based on category of stroke (LVO, hemorrhage, etc.)
3. Identify stroke designation/accreditation (JCAHO, DNV-GL, etc.) terminology used across Virginia's hospital systems.
4. Establish recommendations for timelines in determining "closest appropriate facility" for each category of stroke.
5. Develop sample protocol
6. Assess any barriers to EMS systems with implementation of new protocol.

Focus: The focus of the EMS Destination Workgroup is to identify the best screening tools and make recommendations for statewide coordinated protocols on management of stroke patient destinations, while considering the variables encountered in each region of the Commonwealth.

Messaging to Address Social Disparities Work Group

Summary Scope of Work Statement

Non-clinical factors such as housing, food access, access to care, economic security, and interpersonal safety, heavily influence health outcomes and are significant drivers of health disparities.[1] Therefore, when working to improve the quality of care for stroke patients and their families, it is critical that these Social Drivers of Health (SDoH) are taken into consideration. The Messaging to Address Social Disparities workgroup will:

- Review available stroke data, stratified by race/ethnicity, payor, zip code, and other socio-demographic factors
- Provide education to partners along the continuum of care about the impact of SDoH on health outcomes, how to identify health-related social needs, and how best to connect patients and their families to resources that address social needs
- Identify practices and frameworks that promote community collaboration on initiatives to address SDoH

Goals

- Review available data and literature to identify disparities in Stroke outcomes and share findings with the VSSTF
- Create a multi-modal communication plan to educate partners about the impact of SDoH on health outcomes, the importance of standardized screening for health-related social needs, and how to connect patients and their families to social care resources in the community.
- Make available "best-practice" education and resources to foster collaboration and support statewide, regional, and community-level efforts to address the social drivers of health impacting Stroke patients and their families.

Stroke Smart Communities Work Group

- Summary: Most stroke patients don't receive treatment because they arrive at the ER beyond the treatment window. This results in preventable death and disability, through the Stroke Smart Program, we plan to reduce pre-hospital delay and increase timely treatment. The Stroke Smart program has two parts: local communities and our health system communities.
- For local communities, our focus is to create more Stroke Smart Cites and counties and create Stroke Smart Community, action groups.
- For our health systems, our focus is to introduce Stroke Smart Medical Practice (SSMP) pilots and support their system-wide expansion.

May Day for Stroke Awareness Work Group

- Annual regional stroke awareness event and fundraiser.
- Funds allocated to AHA/ASA or local stroke-related causes.
- Concept is a field day themed event with food venders, live entertainment (as feasible), and a variety of stroke and CV education / screening / demonstration booths.
- Corporate sponsors and fundraising (t-shirts, team fundraising for events). Format similar to Relay for Life.
- Reproducible format for other regions, states.

Post-Acute Discharge Disposition Work Group

- Need group lead, goals and scope TBD.

Retired Work Groups

- Teleneurology
- ~~Standardization of EMS Screening Tools~~
- EMS Destination Protocols
- Messaging to Address Social Disparities
- Stroke Smart Communities
- ~~Quality Management~~
- May Day for Stroke Awareness Event
- ~~Primary Care Interface in Stroke Systems~~
- ~~Leveraging Care with EMRs~~
- Post-Acute Discharge Disposition

Retired groups with < 4 interested members. Possible to consolidate groups with shared goals.

Still need leads/co-leads for Post-Acute Discharge and May Day Work Groups.

Please email stroke@vdh.virginia.gov if you are interested in leading a work group.

VSSTF Business

VSSTF Co-Chairs: Melanie Winningham, MD, Sentara Martha Jefferson Hospital and David Long, MA, NRP, Tidewater EMS Council

- **Next Meeting Dates Schedule:**
  - October 19-20, 2023 (Virginia Hospital and Healthcare Association - Richmond)
  - January 18-19, 2024 (Mary Washington Hospital – Fredericksburg)
  - April 18-19, 2024 (Edward Via College of Osteopathic Medicine - Blacksburg)
  - July 18-19, 2024 (Maryview Medical Center, Portsmouth, VA)

Meeting locations To Be Determined. Look for Calendar Invitations from Stroke@vdh.virginia.gov

VSSTF Virginia Stroke Systems Task Force

VDH VIRGINIA DEPARTMENT OF HEALTH

Stroke Among Female Populations

Virginia Stroke Systems Task Force (VSSTF) October Meeting

Allie Lundberg
10/20/2023

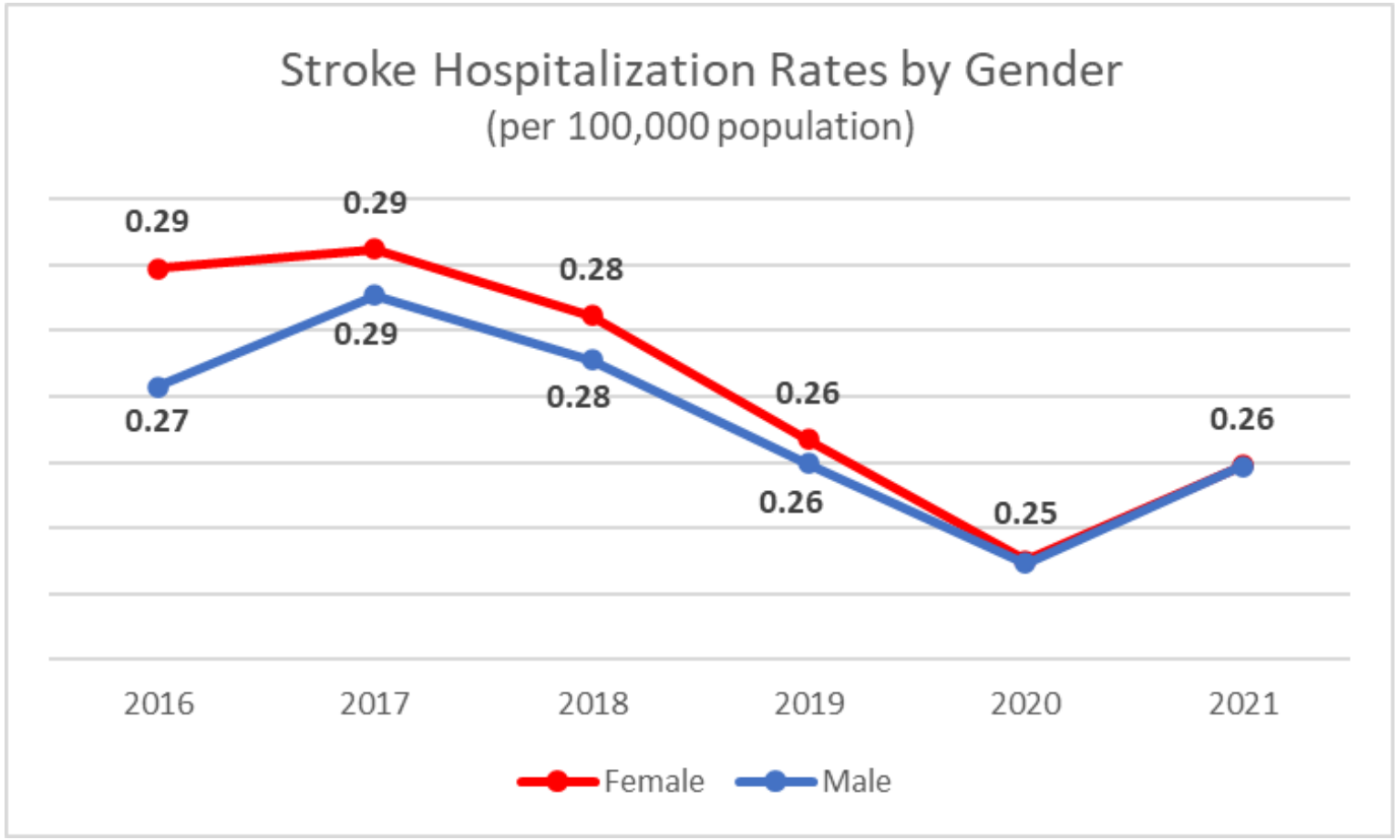
Hospitalization Data

About the Data – Hospitalization Data

- Virginia Department of Health (VDH) receives data on inpatient discharges from all Virginia-licensed hospitals
  - Includes **only Virginia residents hospitalized in Virginia**
- ICD-10-CM diagnosis codes are used to identify patients with a stroke-related hospitalization
  - Discharge billing data for each patient can include up to 18 diagnoses
- Data presented here are **preliminary**
- This data contains stroke patients hospitalized from **2016 through 2021.**

Gender Comparison

Females were found to have more stroke related hospitalizations than males until 2020, where there are equal rates.

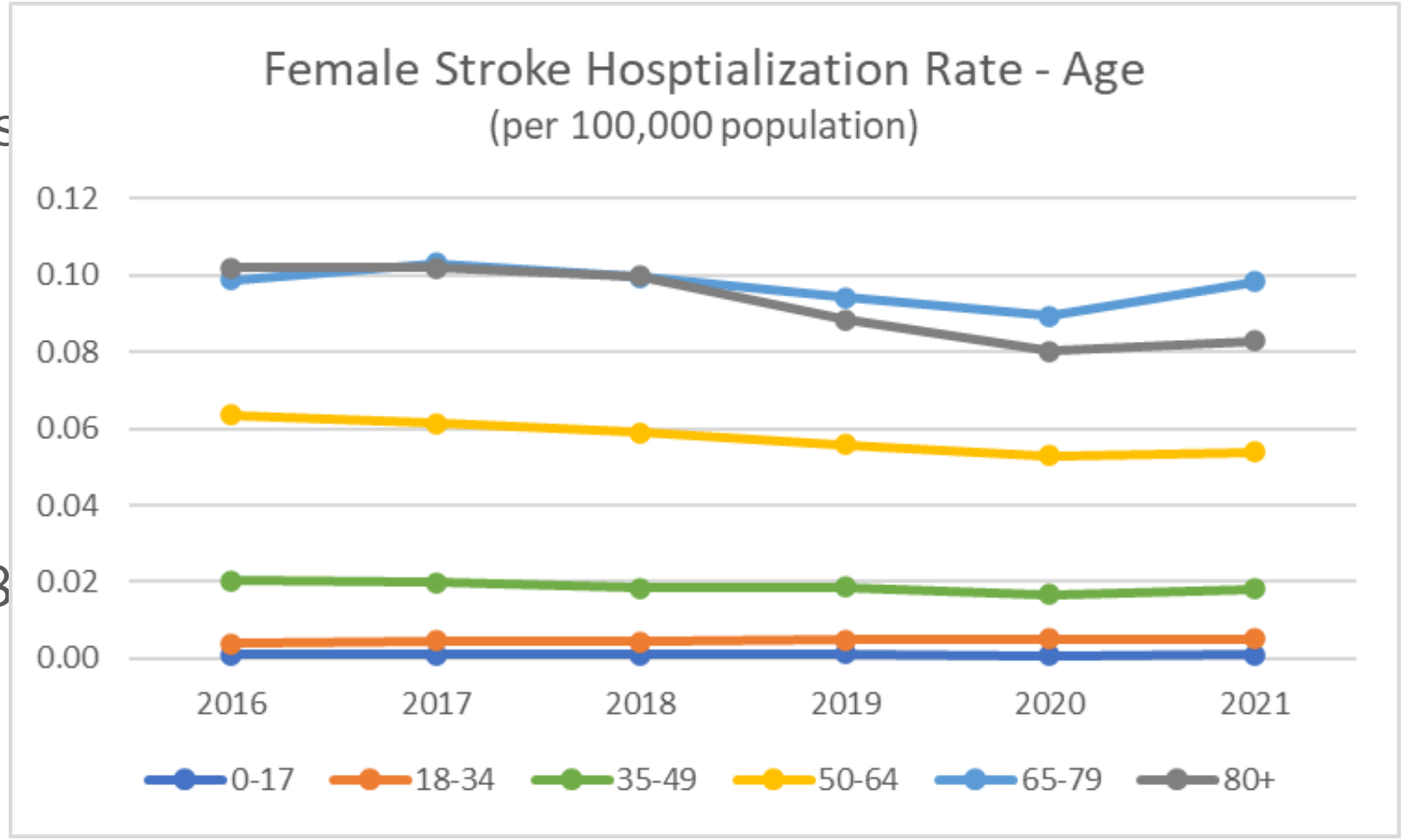


*COVID-19 may have disrupted healthcare service delivery and healthcare seeking behaviors in 2020.

Age Group

Most female stroke hospitalizations occur in thos aged 65 years and older.

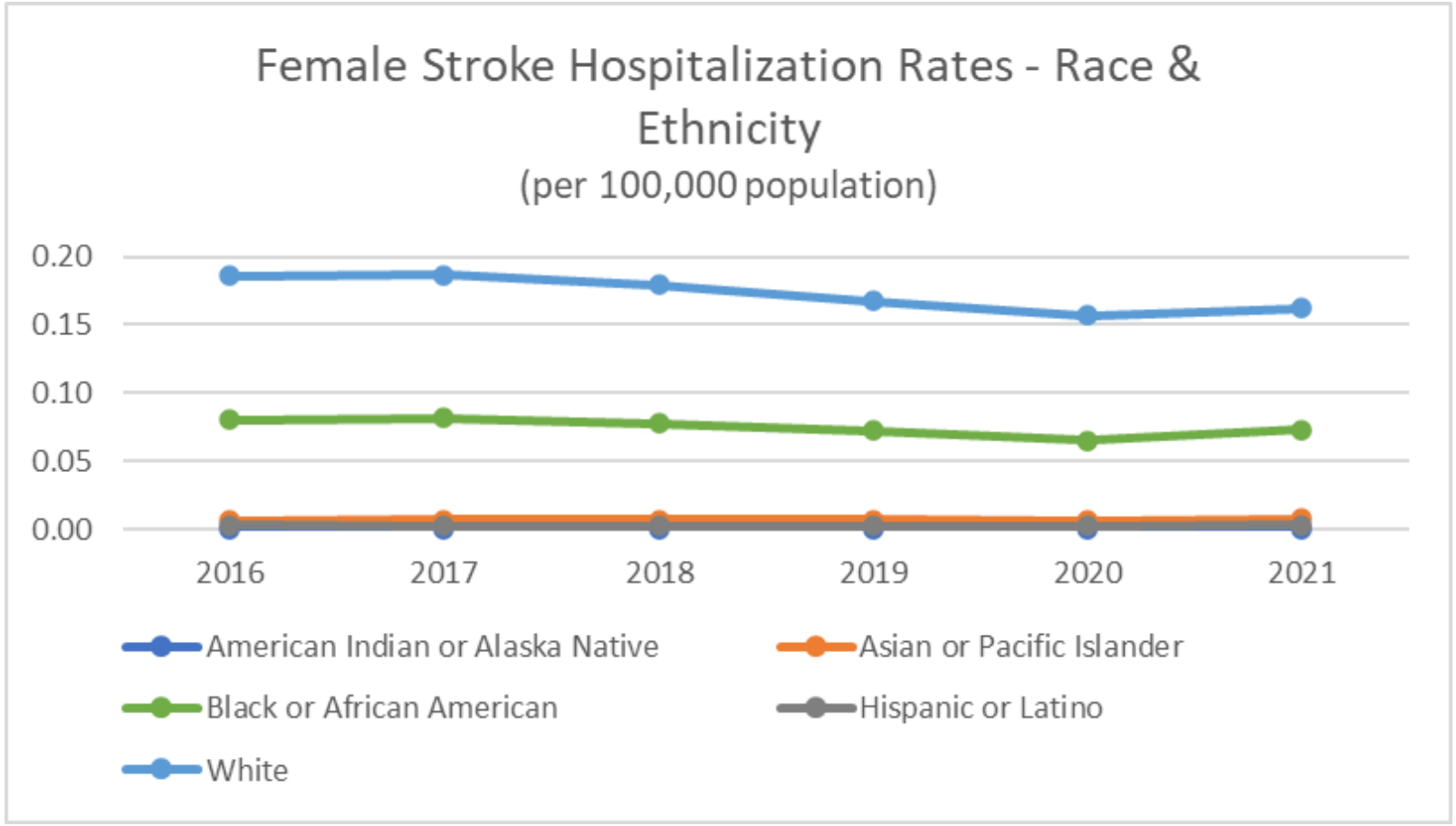
However, females between 65 and 79 years are experiencing more hospitalizations than those 8 and older.



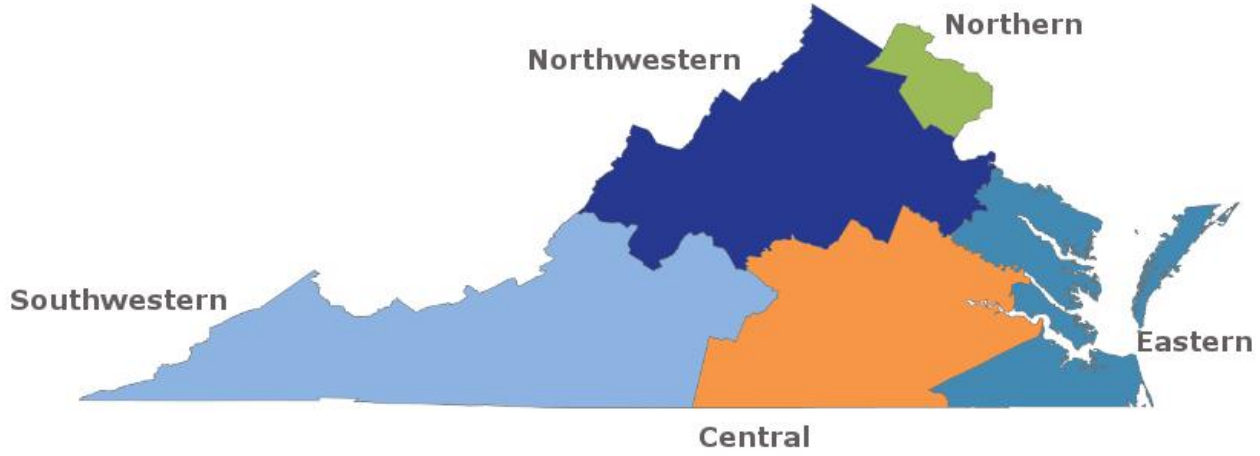
Race & Ethnicity

Most female hospitalizations occur among White females, followed by Black or African American females.

Since 2020, there has been an increase among Asian or Pacific Islander and Hispanic or Latino females.

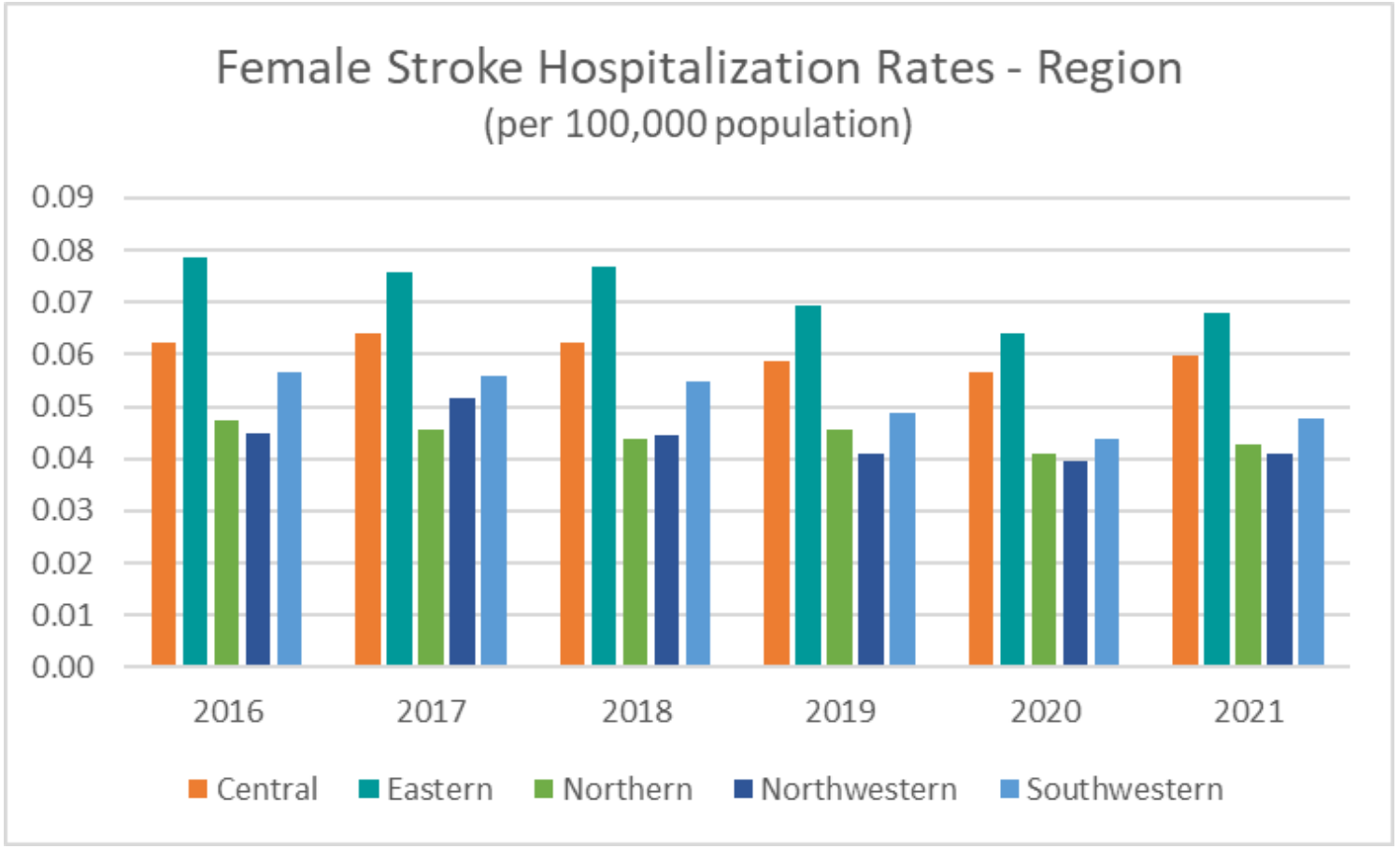


Health Region



Health Region refers to the region of Virginia where the patient lives.

The Eastern Region has the highest hospitalization rates, however rates in the Central Region are increasing closer to those reported in the Eastern region.



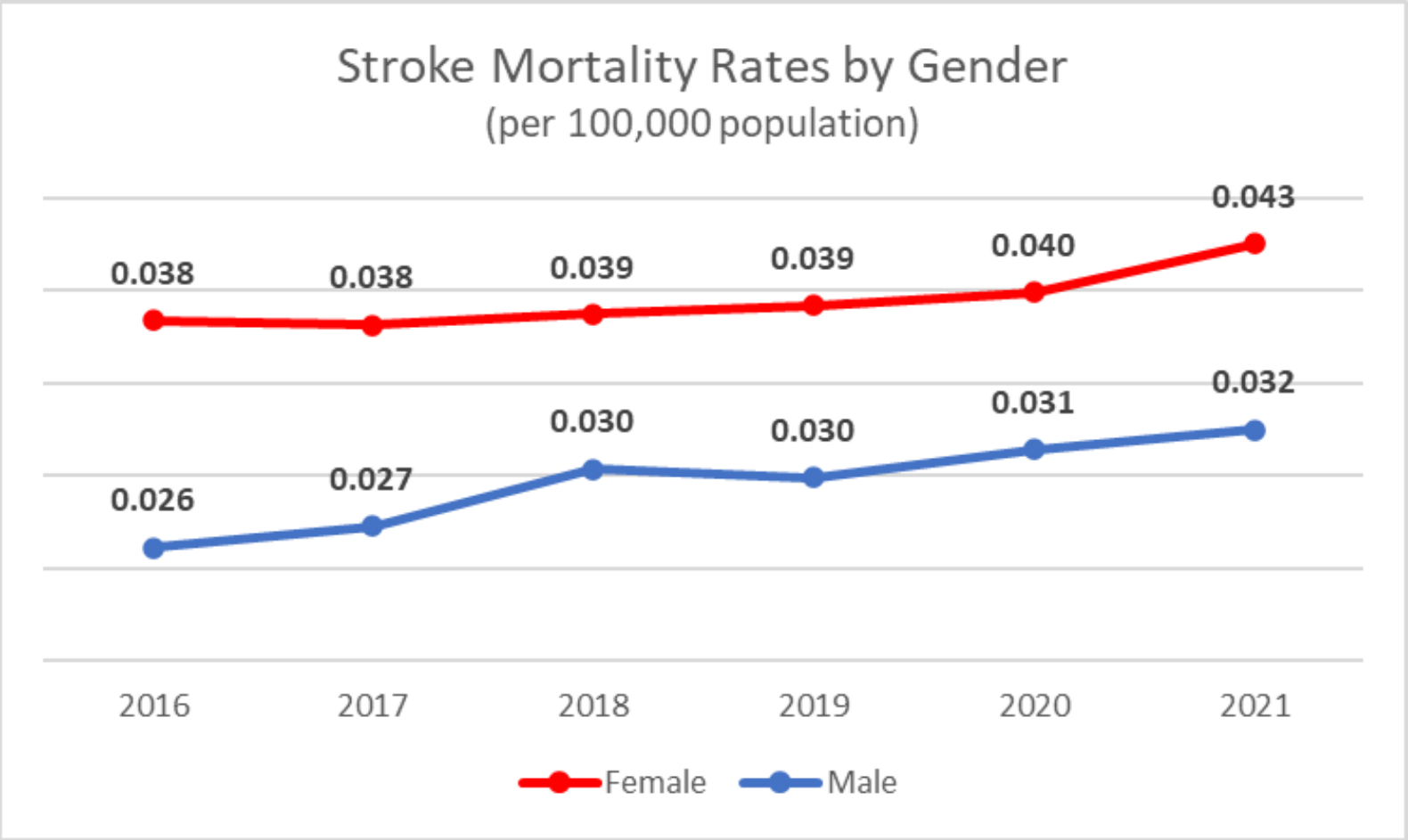
Mortality (Death) Data

About the Data – Mortality (Death) Data

- Mortality data includes death certificates of Virginia residents from the VDH Office of Vital Records.

Gender Comparison

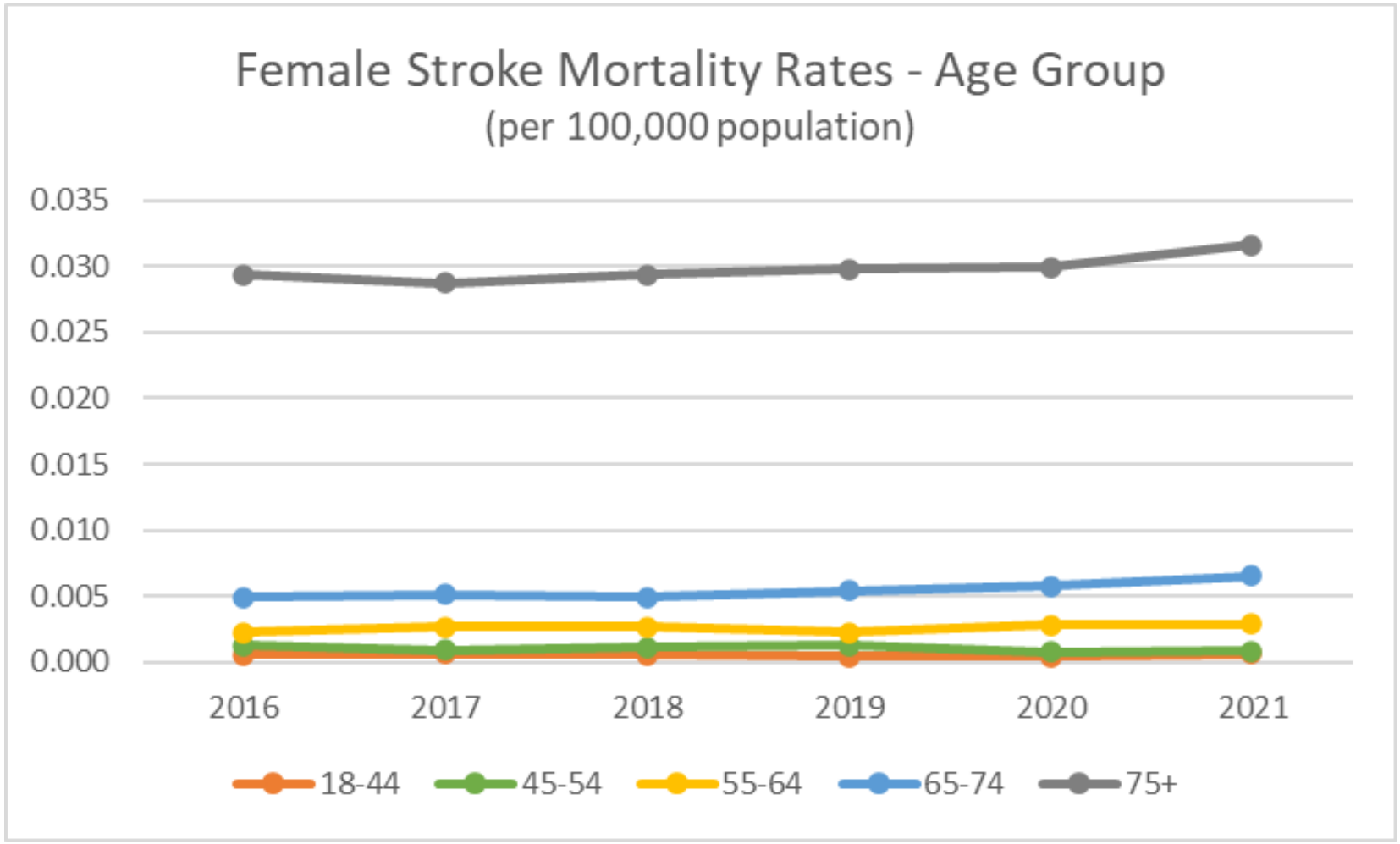
Females are found to have higher death rates than males.



Age Group

Deaths occur most commonly among those aged 75 years and older.

In 2021, there was an increase in mortality rates among the 65–74-year-old age group.

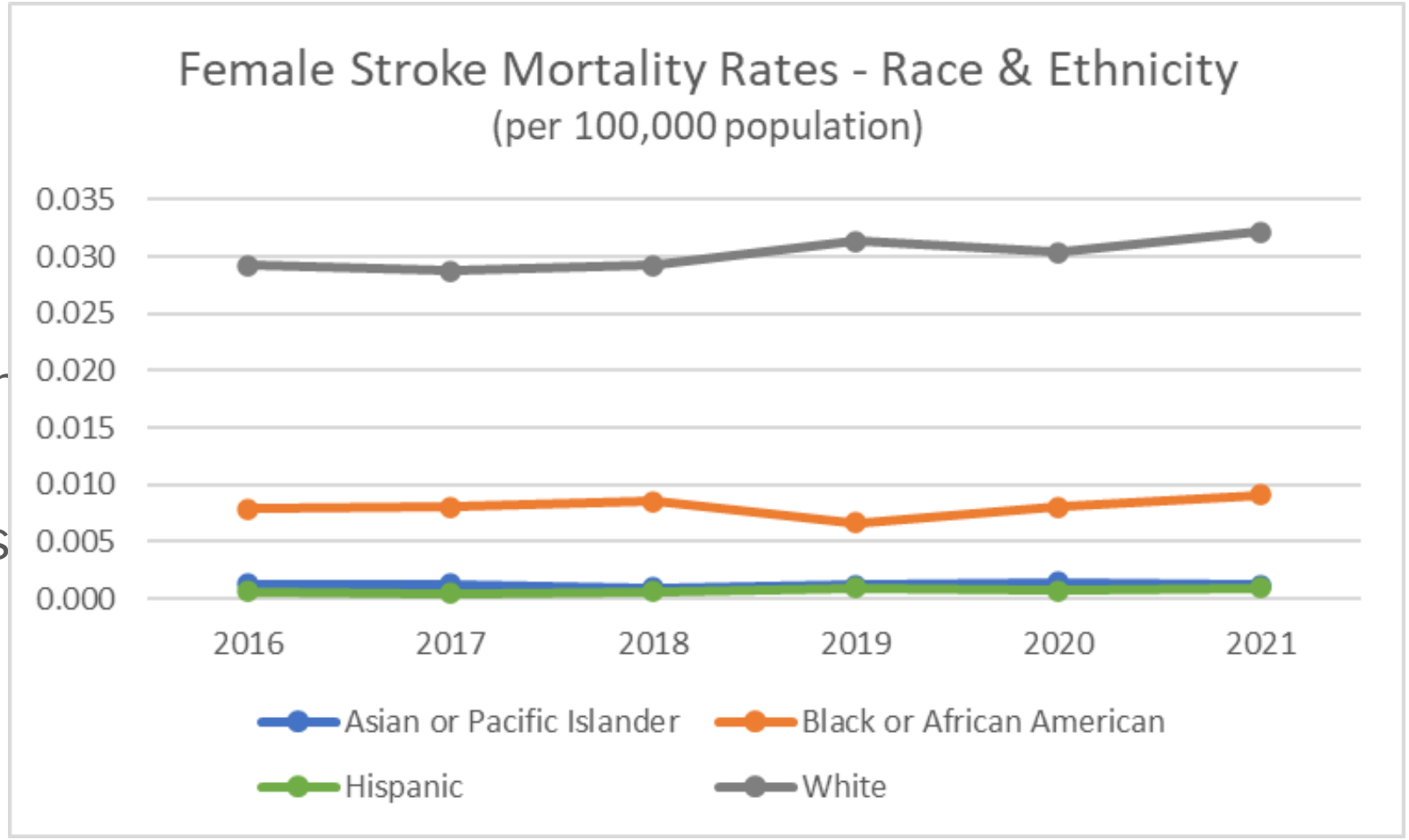


Note: Deaths younger than 18 years old are not presented on this graph due to data suppression guidelines. There were a total of 5 deaths during this 5-year period.

Race & Ethnicity

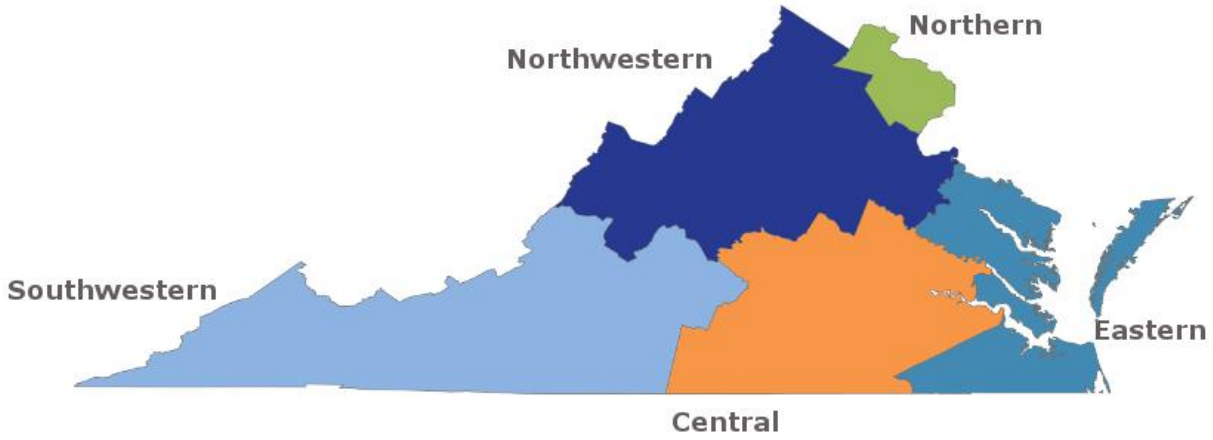
Most deaths occur among white female patients.

There has been in increase in mortality rates among Black or African American females since 2019.



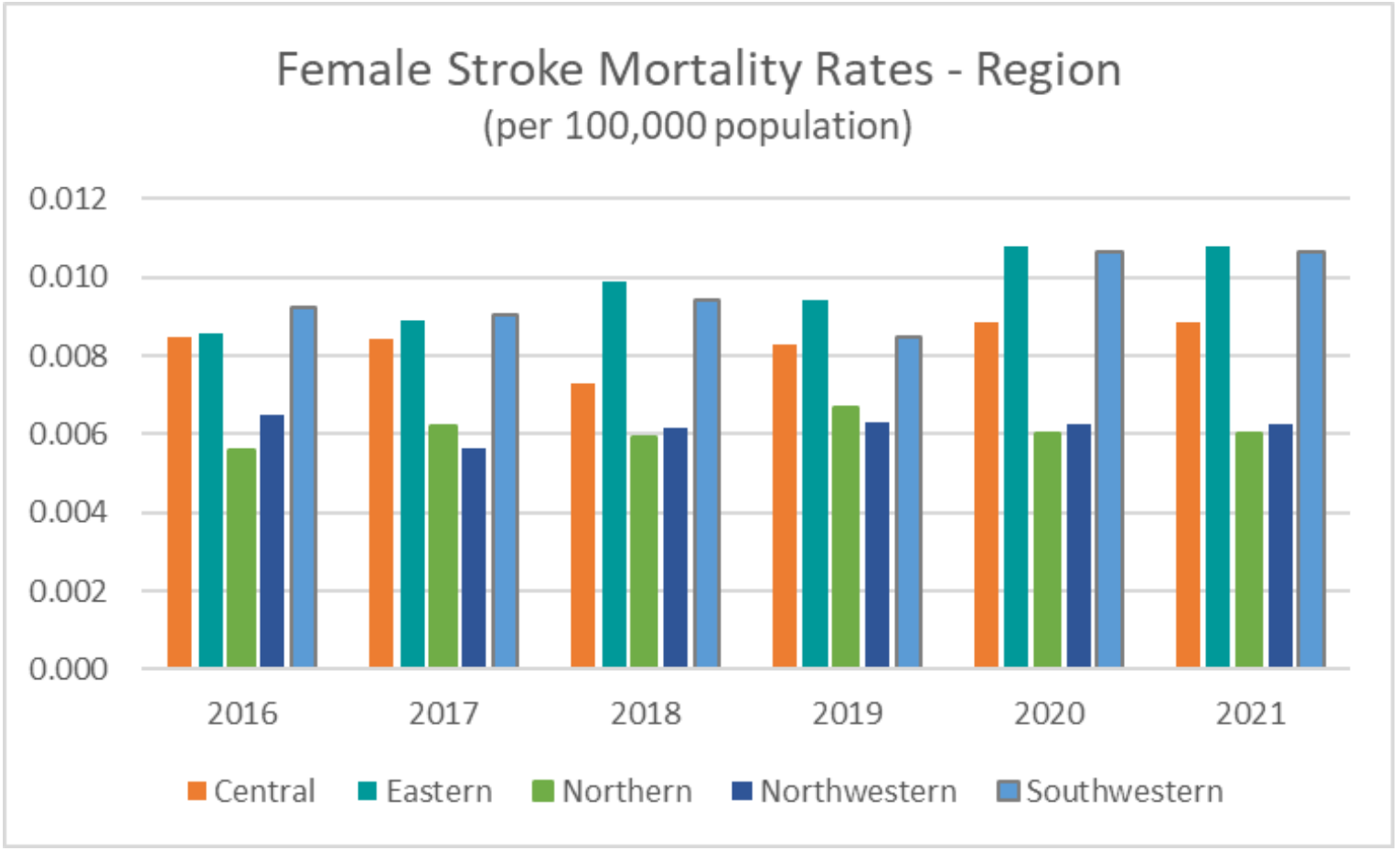
Note: American Indian or Alaskan Native are not presented on this graph due to data suppression guidelines. There were a total of 7 deaths during this 5-year period.

Health Region



Health Region refers to the region of Virginia where the patient lives.

Eastern and Southwestern regions have the highest mortality rates among females.



Identified Other Significant Conditions

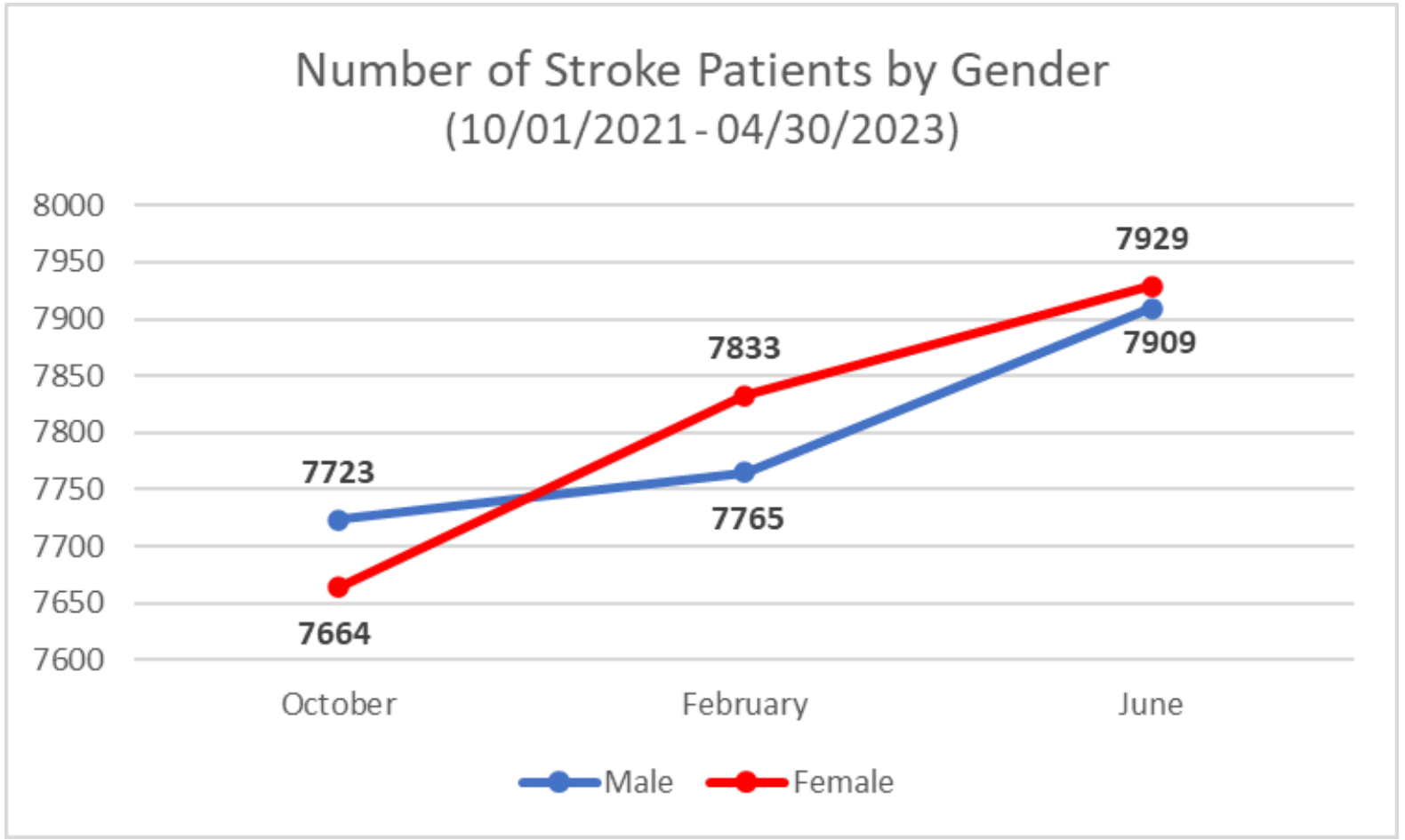
- Alzheimer's dementia
- Atrial fibrillation
- Cardiovascular diseases
  - Congestive heart failure, Coronary artery disease
- Dementia
- Diabetes
- Hyperlipidemia
- Hypertension
- Seizures
- Palliative Care
- Parkinson's Disease
- Vascular dementia

Coverdell Data

About the Data – Coverdell Data

- The Coverdell data repository contains data submitted by participating Virginia hospitals.
  - 47 hospitals
- This presentation contains stroke patient data from October 1, 2021, through April 30, 2023.
  - June 2023 data submission

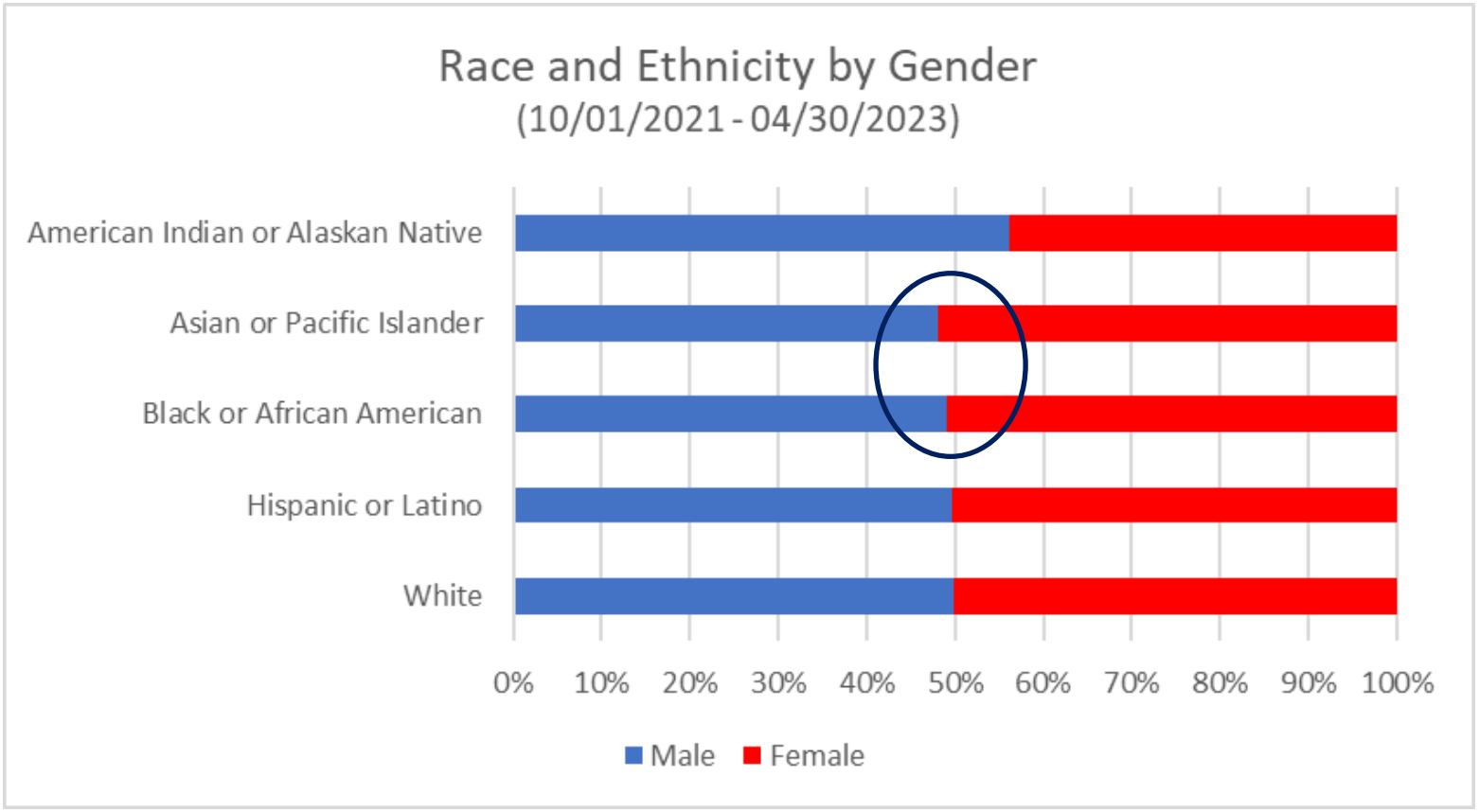
Number of Stroke Patient Records



Race & Ethnicity by Gender

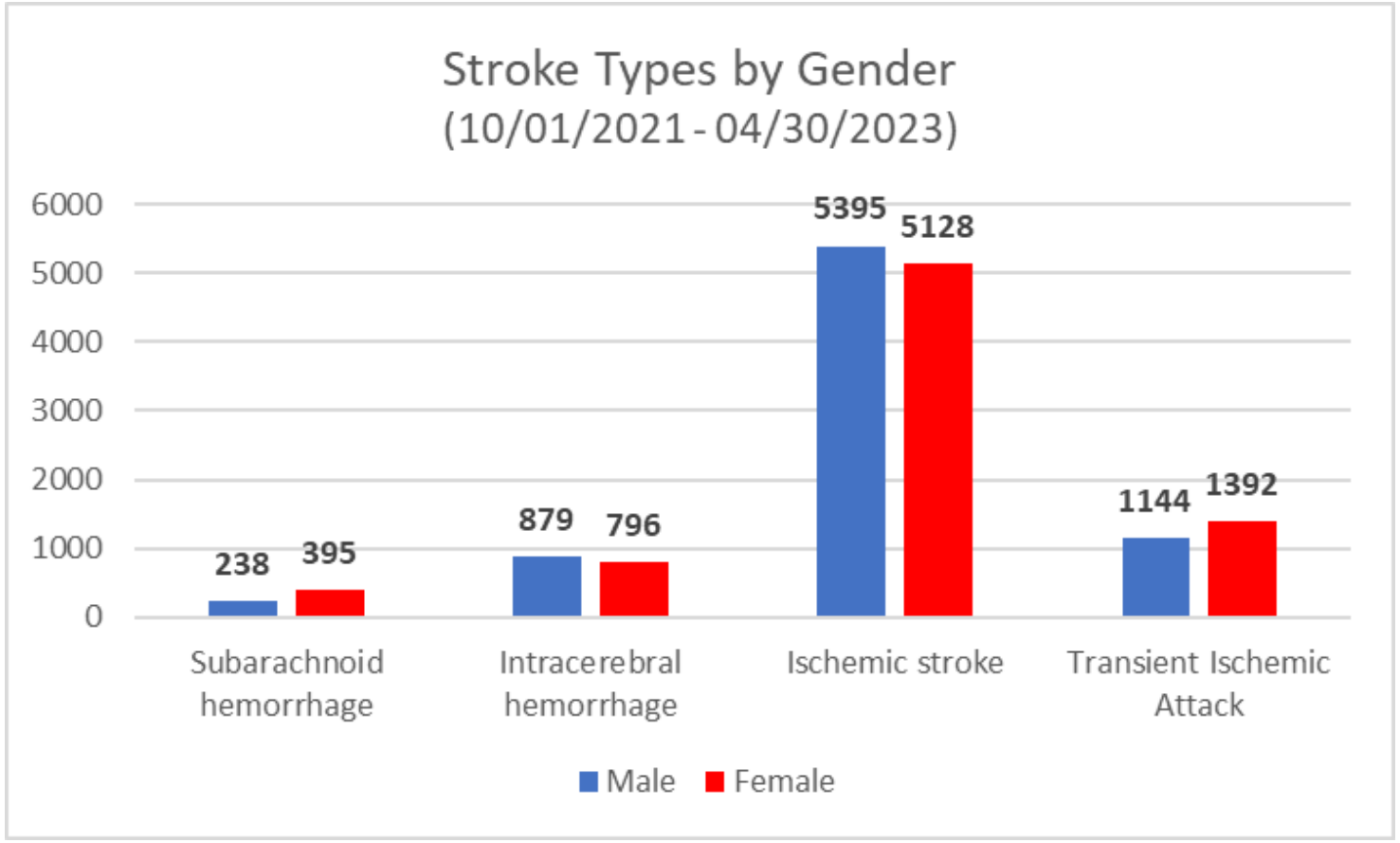
There are more American Indian or Alaskan Native males than females who experience strokes.

However, there are slightly more Black or African American and Asian or Pacific Islander females than males.



Stroke Types

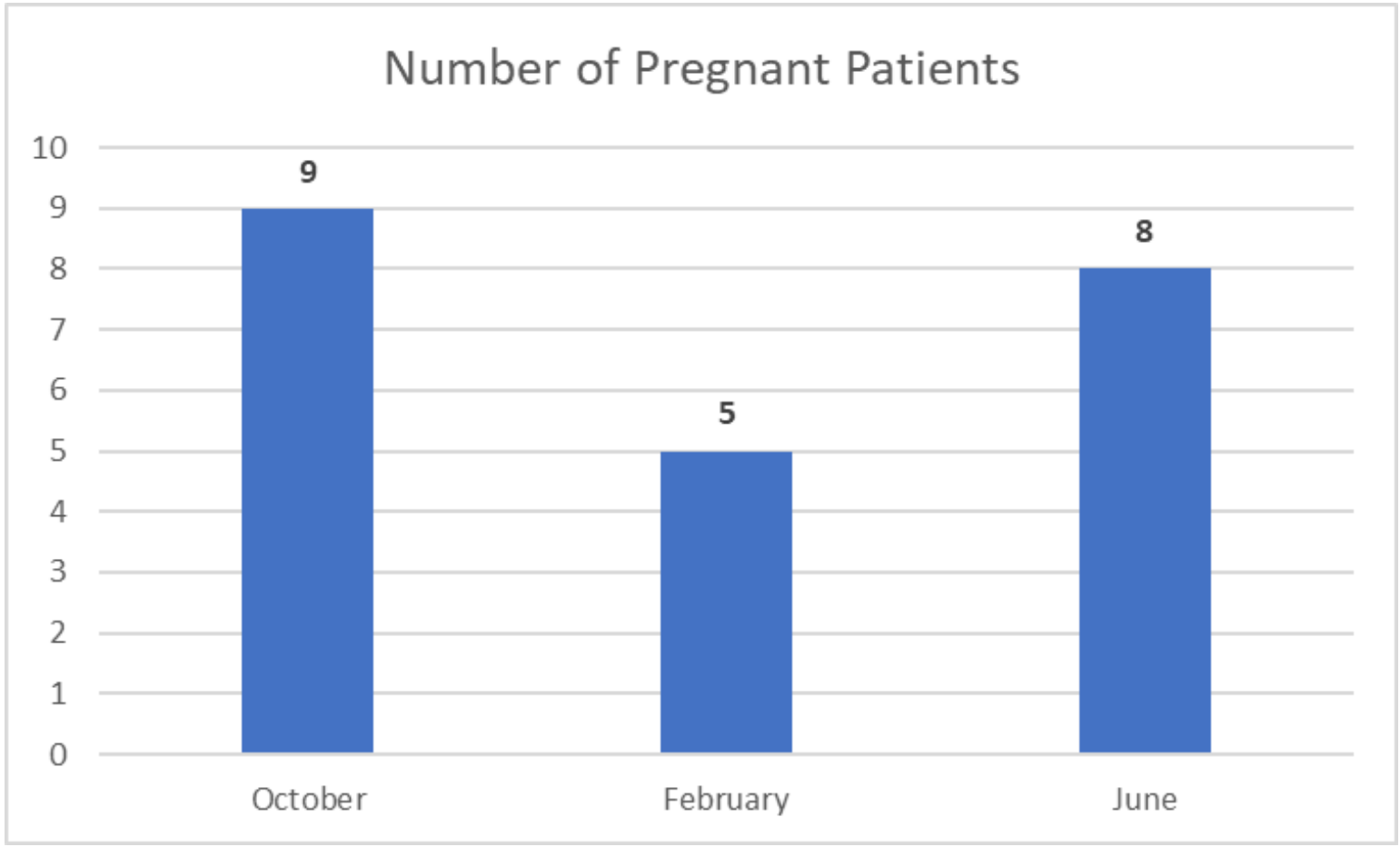
Female stroke patients experience Subarachnoid hemorrhages and Transient Ischemic Attacks (TIAs) more than males.



Pregnancy Data

- Hospitalization data pregnancy indicator is harder to find – search through ICD-10 codes.
- CDC Coverdell Data Dictionary definition: "Did this event occur during pregnancy or within 6 weeks after a delivery or termination of pregnancy?"

Strokes Among Pregnant Patients



Questions?

allie.lundberg@vdh.virginia.gov

stroke@vdh.virginia.gov

Stroke Smart Medical Practice Update

ALAN STILLMAN, KWIKPOINT CEO, STROKE SMART VIRGINIA
AMY SWIERCZEWSKI, ASSISTANT DIRECTOR OF PROGRAMS, MSVF

Stroke Smart VIRGINIA

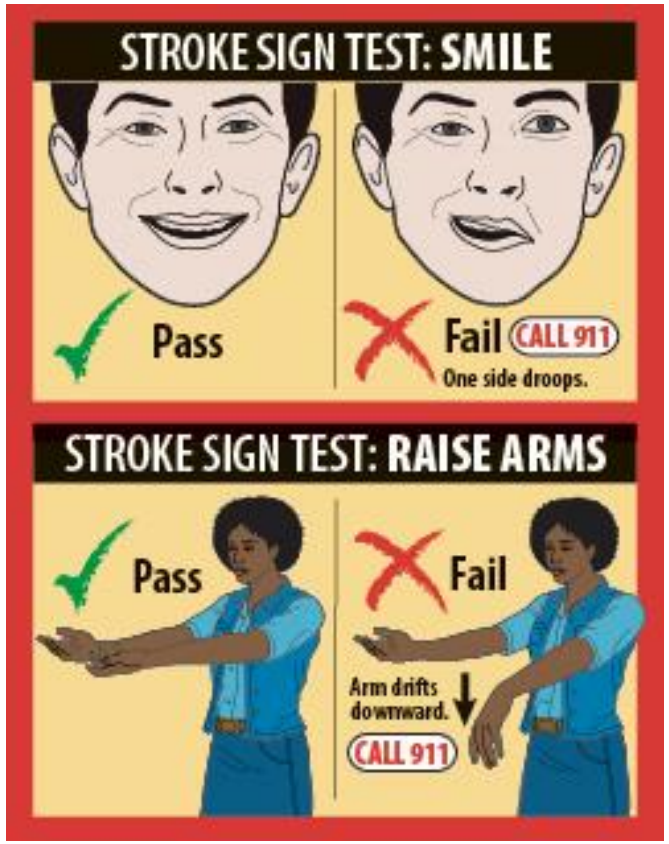
MSV FOUNDATION

In Memory of Grandma Rose

Today's Objective

- Update VSSTF on progress with Stroke Smart Medical Practice
- Encourage additional participation in initiative

Stroke Smart Medical Practice – Objective



Build stroke awareness and literacy among patients and medical practice staff to reduce pre-hospital delay and facilitate timely treatment of strokes

Why Medical Practice Focus?

1. Studies suggest 1/3 of patients with ischemic strokes first called their doctor for an appointment*
2. 80% of population see a medical professional annually; if high risk, even greater frequency
3. Patients trust their doctors
4. Patient attention is focused (vs. multitasking, phone distractions, etc.)

**Journal of American Heart Association, Sept 2019 ♦ Frontiers in Neurology, November, 2017 ♦ Stroke Management, May, 2008*

Stroke Smart Medical Practice - Elements

1. Train all office staff to spot strokes and follow the practice protocol if a stroke is suspected *suggested: minimum annually*
2. Provide *Stroke Smart* education and materials for all patients
   Examples: wallet cards, magnets, posters, PSA videos
3. Identify high risk patients and provide (intentional) *Stroke Smart* education and materials
4. Incorporate *Stroke Smart* script in voicemail to spot and instruct calling 9-1-1 *suggested*
5. Track metrics on practice *Stroke Smart* effectiveness

Health System Practices - Activities:

Mary Washington Healthcare

- Piloting implementation of all elements in a primary care site
- Developed online Stroke Smart course to train staff
- *Stroke Smart Information Sheet* provided to all patients
- Coding Epic system to flag high risk stroke patients
- Phone system voice recording has been completed

Inova

- Piloting (all elements) in (3) primary care practices and (2) neurology practices
- Produced testimonial video
- New voice recording for phone system (in process)

VCU Health

- Focused on workflows and how to effectively incorporate patient education
- Implemented patient education and staff training at largest Richmond clinic (ACC-2)

- Implemented patient education and staff training in 40 Richmond clinics
- Created a PSA video that is shown in offices
- Implemented patient education at Maryview Medical Center (Portsmouth)

- Implemented patient education in (12) primary care practices

Independent Practices

- Patient education materials sent to 16 independent practices and wellness centers through our marketing efforts

Other Notable- Activities:

Stroke Smart Medical Collaboration Formed

Purpose:

- Identify and curate resources to facilitate the adoption of SSMP elements in practice, minimizing duplication of efforts and sharing best practices
- Identify opportunities to expand the initiative to practices and systems with an emphasis on areas with high stroke prevalence

Stroke Smart VIRGINIA

MSV℠ MEDICAL SOCIETY OF VIRGINIA FOUNDATION

VIRGINIA HOSPITAL & HEALTHCARE ASSOCIATION
An alliance of hospitals and health delivery systems

VDH VIRGINIA DEPARTMENT OF HEALTH

Collaboration - Activities:

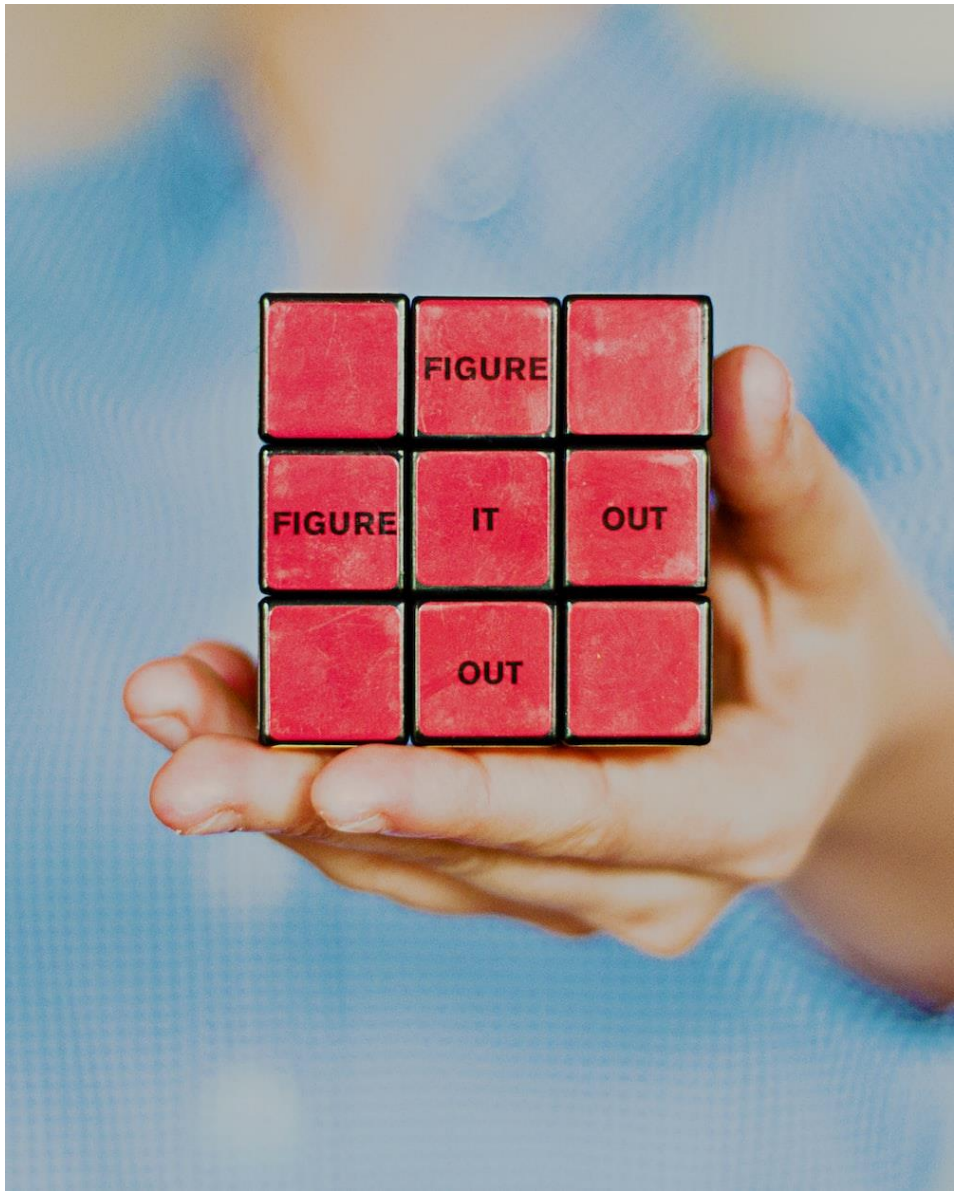
Proposed changes to VDH webpage to house all materials

- Stroke Smart Medical
  Stroke Smart Medical Practice ♦ Stroke Smart Hospitals/Health Systems
  Stroke Smart Urgent Care ♦ Stroke Smart Assisted Living ♦ Stroke Smart Rehabilitation Centers
- Stroke Smart Communities
  Stroke Smart Schools ♦ Stroke Smart Business ♦ Stroke Smart Senior Centers
- Stroke Smart Faith Based Organizations
- Stroke Smart Pharmacy

Collaboration Activities Cont'd:

Stroke Smart Medical – Website Elements:

- **Overview and Implementation Resources**
  - Stroke Smart Medical Practice Overview (video)
  - Implementation "roadmap
- **Staff Training**
  - 30 Minute Video (with actual stroke presentation examples)
  - Post Assessment
  - 911 Hesitancy roll-play video and script
- **Patient Training**
  - 3 minute and 9 minute videos
  - Stroke Smart Information Sheet-- provided to patients
- **High Risk Patient Training**
  - Assessment Tools
  - Nurse education script
- **Phone System**
  - Sample phone scripts



Assistance Available:

- Provide information from others' efforts
- Share resources
- Offer to meet and discuss

Where do I start if I'd like to adopt SSMP in my health system?

Step 1: Identify service line leadership for primary care

Step 2: Go through chain of command to get meeting

Step 3: Present and educate on SSMP

Step 4: Identify pilot site and begin implementation discussion

Questions?

How to help?

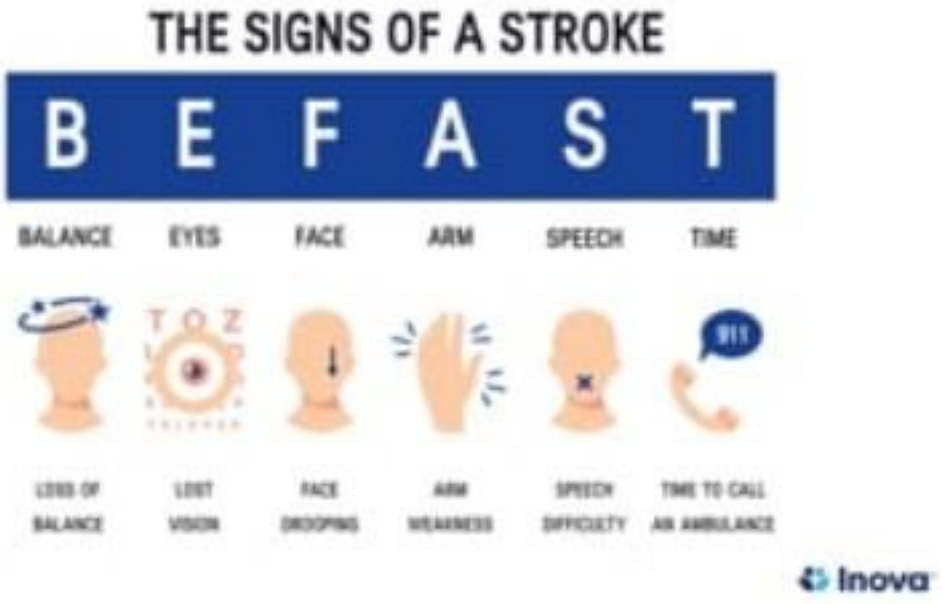
Help us grow the program by piloting in practices

Email:

Alan@kwikpoint.com

OR

Foundation@msv.org


THE SIGNS OF A STROKE
B E F A S T
BALANCE
EYES
FACE
ARM
SPEECH
TIME
911
LOSS OF BALANCE
LOST VISION
FACE DROOPING
ARM WEAKNESS
SPEECH DIFFICULTY
TIME TO CALL AN AMBULANCE
Inova

SCOPES PROGRAM

INTRO TO SCOPES

The SCOPES Program is funded by the US Healthcare Resources and Services Administration (HRSA) through a $1.5 million rural healthcare workforce development grant. The three-year funding period will ensure operation of SCOPES through August 2025. This program will provide education and training opportunities on stroke, pre-hospital emergency care, and post-hospital follow-up care for paramedics, emergency medical technicians, nursing and EMS trainees, community health workers and other rural healthcare providers. Program partners include EMS agencies and community health organizations in Buckingham, Culpeper, Greene, Louisa, Madison, Nelson and Orange counties.

The SCOPES Team

Nina Solenski, MD
Program Director/PI
UVA Dept of Neurology

George Lindbeck, MD
Co-Program Director/PI
UVA Dept of Emergency Medicine

Brett Schneider, NRP, FP-C
Program Manager
UVA Dept of Neurology

Christine Buttenshaw, MPH, AEMT
Program Coordinator
UVA Dept of Neurology

SCOPES Programs

ECHO Education Series

1. Prehospital and Community Medicine ECHO Series
2. Stroke Education ECHO Series for Physicians (MD/DO) and Advanced Practice Providers (NPs, PAs etc)

Telemedicine Enhancements for EMS

1. iTREAT
2. Join Mobile App

Coming Soon: January 2024

1. Community Paramedic Certification Course

Departments of Neurology
and Emergency Medicine

UVA Health

Emerging Technology in EMS

Speakers from Hawaii, Texas and Germany are discussing how their EMS systems use technology to enhance pre-hospital emergency care.

Monday, November 13 at 4pm
Monday, November 27 at 4pm
Monday, December 11 at 4pm
Monday, December 18 at 4pm

Project ECHO®
Presented by the
UVA SCOPES Program
With support from:
HRSA Health Resources & Services Administration

For more Information contact:
Christine Buttenshaw, MPH, AEMT
UVA Teleneurology Coordinator
cmc9dp@uvahealth.org

Prehospital and Community Medicine ECHO Series

- Stroke Series (May - June)
- Community Medicine (July-Aug)
- Mental Health Series (Sep-Oct)

Coming Soon (Nov-Dec)

- Emerging Technology in EMS
  - Foundations of Telehealth
  - Mobile Stroke Units (Houston, TX)
  - International Telestroke Models (Germany)
  - Novel EMS Technology

Stroke Ready Primary Care

- Begins November 8, 2023
- 2nd Wednesdays at 12pm
- For Primary/Specialty Care Physicians, APPs and RNs
- Topics include:
  - Stroke Mimics and Chameleons
  - Novel Concepts in Stroke Care
  - New Trends in Risk Factors

Stroke Registry Update

Virginia Stroke Registry Update

Stacie Stevens

- Data dictionary has been completed (!!) and was sent to software engineers beginning of October
  - Hoping to have a Beta/testing portal beginning of 2024
  - Total of 1,012 data elements in the registry; 430 required fields, about 175 fields require direct data entry.
- Currently working on data validation – in-person meetings with vendor November 8-9

Refresh and Retreat Stroke Camp

STACIE STEVENS

Virginia Stroke Coordinators Consortium

Laurie Mayer

October 20, 2023

VHHA, Glen Allen, VA

WELCOME!! NEW VSCC Co-Chair

ELIZABETH HART

LewisGale Hospital

Stroke Conferences

REGISTER NOW!

Earn 4 CE contact hours

- October 25th AANN Amplify, Virtual Stroke Conference
  - https://aann.org/meetings/aann-amplify
- Nov 2-3 Inova Stroke Conference, Fairfax VA
  - https://www.eventbrite.com/e/fourth-annual-inova-neuroscience-nursing-conference-tickets-656652724977
- Nov 4 Novant Health Stroke Symposium
  - https://events.novanthealth.org/StrokeSymposium2023
- Nov 11-12 ANVC (Association of Neurovascular Clinicians) Annual Conference, Las Vegas
  - https://www.anvc.org/i4a/pages/index.cfm?pageid=3511

ANVC
Association of Neurovascular Clinicians
Because Stroke Patients Deserve Nothing Less

October VDH Stroke Coffee Hour
Tuesday, October 24 at 2:00 pm
Crystal Glodek of AHA/ASA GWTG

GWTG DEMONSTRATION and REPORTS

1. Difference in various GWTG layers including difference in GWTG-Stroke vs TJC layers
2. Reporting functionality
3. Filtering reports
4. Data Download Reports
5. Plans for DNV layer
6. Custom fields

Please email Crystal at Crystal.Glodek@heart.org to submit requests and questions

VDH VIRGINIA DEPARTMENT OF HEALTH

Guest Speaker
Sean Riley

Stroke Patient Perspective

Sean Riley
cerebellar ischemic
12/19/22

October 20, 2023

About Me

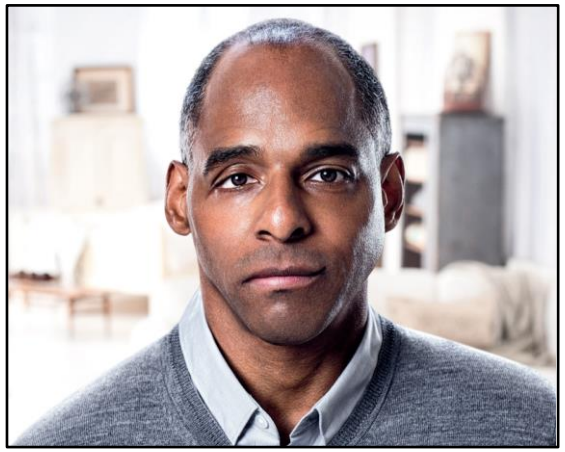
- 53 years old
- Lifelong good health; well-managed BP/cholesterol
- No family history of chronic conditions
- Married 26 years; 2 grown daughters
- Live in Midlothian
- Work in post-acute healthcare services

Disclaimer

Every stroke is different & I was very lucky. I'm here because the healthcare system as a whole both propelled & inhibited my recovery process; I believe there are addressable gaps that could improve outcomes for many people

About My Stroke

- 12/19/22: bolted upright in bed 1:30am
  - Mostly extreme dizziness
  - Had no "airport guy" symptoms
- Initial CT/CTA negative; 1st PT asked to speed up MRI, which confirmed stroke
- Testing confirmed undiagnosed PFO
- 60 hours in hospital regarded for strokes
  - Wife listened to 14 hrs of Christmas carols
  - "Annoyed my way out" early via self-PT
- Last contact w/hospital was wheeling to my car with discharge packet
- **My goal**: help improve stroke outcomes via better-coordinated post-acute care



How Life is Different Post-Stroke

- **Very lucky in my recovery**: 90% back to normal; expecting long/healthy/normal life with limited impairment
- **First experience with visible disability**: people treated me differently & I found it frustrating. Know what paralysis feels like.
- **First experience with <u>invisible</u> disability:** opposite issue…people treat me as "normal" when I'm not. Deficiencies blur w/life in my 50's.
- **Work**: changed jobs…was very open about stroke w/former company, but hide it from current company. Learning how to work around fatigue.

Recovery Process Highlights

Q1	Q2	Q3
• Initial shock	• Temporary adjustments	• Permanent adjustments
• Rapid progress	• Progress plateau	• "Daily life is my PT"
• Overly-ambitious	• Worries emerge	• Renewed determination

12+ Post-Acute Providers*…What Would Have Improved the Process?

- **Like an "Unrehearsed Symphony"**: each provider great at their own instrument, but clearly never play together. *On our own to connect dots.*
- **No preparation**: most providers seemed semi-surprised about my stroke after walking into exam room. *Those appts are a big deal!*
- **Check-box feel**: *Neuro*: checklist approach to first Neuro appt…couldn't ask questions. *Ophtho*: had to ask for my prognosis after 3 hour exam.
- **Appointment headwinds**: Neuro office tried to schedule first post-acute appointment in 4 months. *Who could help fast-track?*
- **No involvement from PCP**: very hands-off at a pivotal life moment. Was my primary for 15 years; shopping for new PCP. *Who quarterbacks?*

* Neuro (3), Cardio (4), PT/OT (3), PCP (1), Ophtho (1+)

How Was Spouse Critical?

- **Pushed through constant headwinds:** getting appts set
- **Follow-Up:** ensured all instructions followed for meds, PT, etc.
- **Nutrition:** good/regular meals I would never have prepared for myself

Wish We Would Have Known?

- **Less common stroke symptoms:** Googling during & after episode wasn't helpful
- **Aspirin is a no-no:** 911 instructed taking; EMTs administered on arrival

What Gives Me Purpose?

- **Gratitude:** stroke was a "dodged bullet" that fundamentally changed trajectory of our lives; adjusted life plan to now retire at 60
- **Purpose:** got my life back; plan to live well, but help people who didn't

What Would I Recommend to Stroke Coordinators?

- **Assess patient's ability to project manage & problem-solve throughout a prolonged recovery process**: everyone's accountable for their own care, but most would likely shortcut and/or give up without assistance
- **Pre-schedule a 30-day check-in**: help catch problems & dysfunction while there's still time to course-correct
- **Intervene w/providers**: at least within your own health system!
- **Seek clinical "ratings"**: only satisfaction survey I received was for food service. Spoiler alert…it was horrible!
- **Offer guidance re: mobility aids**: other than the walker, had to figure everything out on my own (e.g. DME/shower chair, cane, etc)

Thank You!